The experience, meaning and value of social and community participation following acquired spinal cord injury.

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B.App.Sc(O.T.), M.O.T.

A thesis submitted for the degree of Doctor of Philosophy (Thesis by Publications)

at Monash University in 2017

Department of Occupational Therapy

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Abstract

Background

Limited information currently exists regarding the experience and meaning of social and community participation from the perspective of people with traumatic spinal cord injuries (TSCI), and almost no information exists regarding the experience and meaning of social and community participation from the perspective of people with non-traumatic spinal cord injuries (NTSCI). It is known that satisfactory social and community participation influences quality of life and therefore is considered an important outcome of rehabilitation following a spinal cord injury. This thesis contributes important information to inform occupational therapy practice, rehabilitation approaches, and disability and aged care policy, by exploring the experience, meaning and value of social and community participation for adults living with an acquired spinal cord injury (SCI).

Methods

A qualitative inquiry approach was taken to investigate this topic. Purposive sampling as part of an emergent design process, resulted in two samples, one of 19 people with TSCI and one of 17 people with NTSCI. In-depth semi-structured interviews were conducted, and transcribed verbatim. Thematic analysis involving inductive identification of categories and themes from the data was completed (Braun & Clarke, 2006; 2013). The study consisted of three phases, each phase addressing different research questions. The thesis includes four manuscripts, of these two articles have been published, and two are currently under review for publication.

Findings and discussion

Social and community participation was identified as being important to the participants with SCI in this study, and contributed to their self-worth. A journey with four identified stages of adjustment was described. Barriers to participation included ageing, fatigue, incontinence, negative societal attitudes, inaccessible environments, issues with transport, poor access to appropriate assistive equipment and lack of client-centred paid care. Support from family and friends facilitated participants' social and community participation, particularly in the absence of sufficient paid personal care. Inconsistencies and inequities were found between the services available to people with SCI depending on where they lived, the age at which they were injured, and whether or not they were eligible for compensation. It was identified that there are multiple and complex policies, services and systems that impact the social and community participation of people with SCI in Australia.

The meaning of social and community participation that emerged from the study highlights four key facets of social and community participation not reflected in the ICF definition of participation. These are: giving back to the community and society, participating in meaningful roles, feeling as though one is part of the community, and contributing to self-worth. A definition of social and community participation representing the experience of people with SCI emerged from the findings.

Conclusions

Social and community participation is seen as valuable and important by the people with SCI in this study, however, their experiences indicate that current policies, systems and services in Australia that impact on people with SCI are inequitable,

complex, and not well coordinated. Occupational therapists working with clients with SCI should facilitate their involvement in meaningful social and community based activities, in addition to advocating at a policy and service delivery level, in order to maximise the wellbeing and quality of life of their SCI clients.

Publications during enrolment

Thesis including published works general declaration

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes two original papers published in peer reviewed journals, and two submitted publications. The core theme of the thesis is an exploration of social and community participation following acquired spinal cord injury. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, Linda Barclay, working within the Department of Occupational Therapy under the supervision of Dr Primrose Lentin, Assoc Prof. Rachael McDonald and Assoc Prof. Helen Bourke-Taylor. The inclusion of co-authors reflects the fact that the work came from active collaboration between researchers and acknowledges input into team-based research.

In the case of chapters 2, 4, 5, and 6 my contribution to the work involved the following:

Table 1 *Publications during candidature*

Thesis Chapter	Publication Title	Publication Status	Nature and % extent of candidate's contribution	Co-author names, nature and % of co-author's contribution
2	Social and community participation following spinal cord injury: a critical review. (Appendix A)	Published	80% - concept development, literature review, evaluation of literature, writing and submission of manuscript, amendments to manuscript post peer review.	Rachael McDonald 10% Primrose Lentin 10%
4	Facilitators and barriers to social and community participation following spinal cord injury. (Appendix B)	Published	70% - concept development, literature review, ethics application, data collection, data analysis, writing and submission of manuscript, amendments to manuscript post peer review.	Rachael McDonald 10% Primrose Lentin 10% Helen Bourke-Taylor 10%
5	Understanding the factors that influence social and community participation as perceived by people with non-traumatic spinal cord injury.	Submitted	70% - concept development, literature review, ethics application, data collection, data analysis, writing and submission of manuscript, amendments to manuscript post peer review.	Rachael McDonald 10% Primrose Lentin 10% Helen Bourke-Taylor 10%
6	A qualitative study on how social and community participation following spinal cord injury influences self-worth.	Submitted	70% - concept development, literature review, ethics application, data collection, data analysis, writing and submission of manuscript, amendments to manuscript post peer review.	Rachael McDonald 10% Primrose Lentin 10% Helen Bourke-Taylor 10%

I have renumbered and reformatted sections of submitted or published papers in order to generate a consistent presentation within the thesis.

Student Signature: [redacted]

Date: 4/5/2017

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the student's and co-authors' contributions to this work. In instances where I am not the responsible author I have consulted with the responsible author to agree on the respective contributions of the authors.

Main Supervisor Signature: [redacted]

Date: 4/5/2017

Table 2 *Related publications*

Appendix	Publication Title	Publication Status	Nature and extent of candidate's contribution
Appendix C	Time use following spinal cord injury: an examination of the literature.	Published	80% - concept development, literature review, evaluation of literature, writing submission of manuscript, and amendments post peer review.
Appendix D	Secondary health conditions experienced by people with spinal cord injury within community living: Implications for a National Disability Insurance Scheme.	Published	30% - concept development, literature review, writing, amendments to manuscript.

Conference presentations during candidature

Barclay, L., McDonald, R., and Lentin, P. (2014). Social and Community Participation Following Spinal Cord Injury: A Critical Review. Oral paper presented at: *16th International Congress of the World Federation of Occupational Therapists (WFOT). 18-21 June 2014. Yokohama, Japan.*

Barclay, L., McDonald, R., and Lentin, P. (2015). Social and Community Participation Following Spinal Cord Injury: A Critical Review. Poster presentation at: *International Spinal Cord Society (WHO & ISCOS) & American Spinal Injuries Association (ASIA) 4th Joint Scientific Meeting, Montreal, 14-16 May 2015.*

Barclay, L., McDonald, R., and Lentin, P., and Bourke-Taylor, H. (2015). Facilitators and Barriers to Social and Community Participation Following Spinal Cord Injury. Oral paper presented at: *Occupational Therapy Australian National Conference, Melbourne, July 2015.*

Barclay, L., McDonald, R., and Lentin, P., and Bourke-Taylor, H. (2016). A qualitative study on how social and community participation following spinal cord injury influences self-worth. Oral paper presented at: *Annual Scientific Meeting of the Australian and New Zealand Spinal Cord Society held in Adelaide, November 16-18, 2016.*

Barclay, L., McDonald, R., and Lentin, P., and Bourke-Taylor, H. (2016). Barriers and facilitators to social and community participation as perceived by people with non-traumatic spinal cord injury. Poster presentation at: *Annual Scientific Meeting of the Australian and New Zealand Spinal Cord Society held in Adelaide, November 16-18, 2016.*

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Chapter One

Introduction

1.1 Researcher's Background and Reasons for Research

The motivation for this thesis arose as a result of my clinical experience as an occupational therapist working with people with spinal cord injuries (SCI) in the Australian community for over twenty years. Following establishment of a private practice in which I primarily worked with people following acquired SCI living in the community, I observed the significant impact that the injury had on the social and community participation of some people. Sometimes people were socially isolated and ceased to participate in social activities in the community, and I wanted to find out more about why this was the case, with the aim of assisting people with SCI to lead more satisfying lives.

The aim of the study was to explore whether social and community participation is important to people living with SCI, how people with SCI experience social and community participation, and what influences their participation. In order to explore this topic from the perspective of people with SCI a qualitative design was used. In-depth semi-structured interviews conducted with 36 people with SCI living in the Victorian community were analysed thematically. The findings inform understanding of how people with SCI participate in their communities once they return home from hospital, including the person and environmental impacts on their participation. Important implications for occupational therapy practice are identified as a result of this study, and the fragmented, complex service systems that currently influence the social and community participation of people with SCI are highlighted.

1.2 Structure of Thesis

This thesis consists of a series of traditional chapters plus papers that have been published, or submitted for publication in peer reviewed journals, or in draft form, thus forming a thesis by publication.

Chapter One defines and explains the mechanisms of acquired spinal injuries, both traumatic and non-traumatic, and reviews current literature regarding the consequences of SCI. Two theoretical models that underpin this thesis – the International Classification of Functioning, Disability and Health (ICF) and the Canadian Model of Occupational Performance and Engagement (CMOP-E) are compared and analysed. The ways that the terms participation, social participation, and community participation have been conceptualised in the literature, and the link between social and community participation and quality of life (QOL) of people with SCI is discussed. Approaches to investigating social and community participation are also outlined. To provide context for the thesis, a summary of relevant Australian policies is provided.

Chapter Two is a critical literature review published in the International Journal of Rehabilitation *(*Barclay, McDonald, & Lentin, 2015) (Appendix A). This paper presents a critical review of the available evidence regarding social and community participation following SCI, and the factors that influence that participation. In addition, the quality of the evidence is examined, and recommendations for further research provided.

Chapter Three describes the methodology used for the study, including the research aim and associated research questions. The rationale for the selection of the methodology, sampling approach, ethical considerations and data collection processes are outlined. As a result of the emergent design process followed, there were three phases of data analysis, which are described in this chapter. Strategies utilised to ensure trustworthiness and rigour are described.

Chapter Four is a published paper that presents the findings of the first phase of the study. The views of 17 adults with traumatically acquired SCI (TSCI) regarding their experiences of the facilitators and barriers to social and community participation are presented (Barclay, McDonald, Lentin, & Bourke-Taylor, 2016) (Appendix B). The main findings are discussed in relation to existing literature, and issues of relevance to occupational therapists, other health professionals, and policy makers are raised including recommendations for future practice.

Chapter Five is a manuscript that presents the findings of the second phase of the study. The views of 17 people with non-traumatic SCI (NTSCI) regarding their experiences of social and community participation and the barriers and facilitators to their participation are presented. The findings are discussed in the relation to occupational therapy practice. The manuscript has been submitted for publication to the British Journal of Occupational Therapy.

Chapter Six is a manuscript that presents the findings of the third phase of the study. The experience, meaning and value of social and community participation for people living with an acquired SCI (both traumatically and non-traumatically

acquired) (*n* = 36) are presented and discussed. The findings have important implications for the rehabilitation process and the transition home from hospital, particularly in relation to how occupational therapists can facilitate people to participate in their communities in ways that they find meaningful. This manuscript has been submitted for publication to the journal OTJR: Occupation, Participation and Health.

Chapter Seven is the first of the two discussion chapters. Further analysis of the findings from phases one and two, including comparison of the experiences of the two samples in relation to research questions: one, four, five and six, raised important issues that intersect with legislation, policy and service delivery. These issues and their implications are outlined in this chapter.

Chapter Eight is the second discussion chapter. The overall findings of all three phases of the study are applied to the CMOP-E, and implications for SCI rehabilitation, and occupational therapy practice at a person and environment level are outlined. Finally, the original contribution that this thesis makes to understanding the social and community participation of people with SCI is outlined.

Chapter Nine is a concluding chapter which provides a summary of the original contribution that this thesis makes to the field of SCI rehabilitation and occupational therapy practice. A definition of social and community participation for people with SCI is provided. Strengths and limitations of the study are outlined. Conclusions and final recommendations for occupational therapy practice, SCI rehabilitation and further research are summarised.

1.3 Overview of the Literature

This thesis focuses on the social and community participation of people who have acquired a spinal cord injury in adult life either by traumatic or non-traumatic causes, as opposed to spinal cord damage that has resulted from congenital causes such as spina bifida. The following literature review provides the background to the development of the overall research aim and research questions that guided the study.

1.3.1 Aetiology of Acquired SCI.

Acquired SCI is a serious life event whereby an individual experiences permanent spinal cord damage, resulting in major physical and sensory disabilities (van Leeuwen, Post, Westers, van der Woude, & de Groot, 2012). Traditionally, SCI type has been classified according to the mechanism of injury. The term traumatic spinal cord injury (TSCI) is used when the cause has been an external event such as a motor vehicle accident, fall or violence. Damage to the spinal cord from pathology such as spinal cord myelopathy, or transverse myelitis has been referred to as non-traumatic SCI (NTSCI) (Guilcher, Parsons, Craven, Jaglal, & Verrier, 2016). Classification of causes and types of SCI are reflected in the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) (2016). TSCI is classified in Chapter XIX – Injury from external causes. However, there is a lack of standardized International Classification Diagnostic (ICD) codes for people with NSTCI (Guilcher et al., 2016). For example, abdominal aortic aneurysm – ruptured (a common cause of NTSCI) is classified in Chapter IX – Diseases of the Circulatory System, while transverse myelitis is classified in Chapter VI - Diseases of the Nervous System (ICD-10, 2016).

1.3.2 Incidence of acquired SCI.

Internationally incidence rates for TSCI are estimated to range from 16 - 40 people with TSCI per million of population (Lee, Cripps, Fitzharris & Wing, 2014). New, Baxter, Farris and Noonan (2015) used a cohort survival model to derive estimates of TSCI incidence in Australia for people who survived hospitalization in 2011. Their estimates ranged from a lower figure of 21 incidence per million population per year, to an upper figure of to 32.3 per million. The incidence was highest in males aged 46 – 60 years (New et al.). The Australian Institute of Health and Welfare Research (AIHW) Series published in 2010, identified 362 new hospital admissions of people with SCI in Australia, as reported to the National Injury Surveillance Unit (NISU) during the period 1 July 2007 to 30 June 2008. Of these, 285 were reported as TSCI and the other 77 were NTSCI due to other causes (Norton, 2010). However, these figures are not recent and are likely to underestimate the total number of people in Australia with SCI (New et al, 2015; New & Sundararajan, 2008; Norton, 2010). The figures were obtained through the Australian Spinal Cord Injury Register (ASCIR), which only represents people admitted to specialist spinal units, and therefore underestimates the numbers of people with NTSCI who are often not admitted to specialist spinal units (New et al; New & Sundararajan; Norton).

Incidence of NTSCI in Australia and other countries such as Canada and USA has been difficult to ascertain due to lack of a specialist rehabilitation and recording system for people with NTSCI, and the absence of standardized International Classification Diagnostic (ICD) codes as outlined in 1.3.1 (Guilcher et al., 2016). To determine incidence of new NTSCI admissions in Victoria, New and Sundararajan (2008) conducted a study using data extraction from a state-wide, population-based,

health-administration database of new hospital admissions between 2000 and 2006. They estimated that there were 26.3 new NTSCI admissions to hospital per million per year in Victoria, Australia (New & Sundararajan, 2008). More recently New, Simmonds, and Stevemuer (2011) conducted a population-based study of newly injured SCI inpatient admissions in Australia. They found that 62.1% of new admissions were for people with NTSCI (New, Simmonds, & Stevemuer, 2011).

The difficulty estimating incidence of NTSCI highlights one of health service issues relating to people with NTSCI in Australia. That is, that people with NTSCI tend not to be admitted to dedicated specialist spinal units as people with TSCI are. As a result the care of people with NTSCI tends to be fragmented and uncoordinated (New, 2006), and their long term health and well-being outcomes are not well researched.

Despite the lack of up to date Australian incidence rates, and inaccuracy of reporting, it is becoming increasingly recognised that the incidence of people with NTSCI is increasing in developed countries (Noreau, Noonan, Cobb, Leblond, & Dumont, 2014). Guilcher, Parsons, Craven, Jaglal and Verrier (2016) conducted a retrospective cohort study between April 2006 and March 2012 in Ontario, Canada. They found that of the 7,693 people admitted to hospital with SCI in Ontario, Canada, 1,537 (20.0%) were categorized as having TSCI and 6,156 (80.0%) as having NTSCI (Guilcher et al., 2016). There are emerging estimates that people with NTSCI currently represent more than 50% of all those living with acquired SCI (Guilcher et al.). This highlights the imperative to ensure that this group is recognised and the challenges specific to this group are explored.

1.3.3 Classification of SCI.

An injury to the spinal cord causes disruption to the motor and sensory pathways at the site of the lesion (Atkins, 2008). Classification of SCI is complex and involves a number of steps. The International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) is the internationally accepted format for classifying type and severity of SCI (American Spinal Injury Association, 2016). It is a multi-dimensional approach to categorizing motor and sensory impairment in individuals with SCI, and is currently in its 6th edition. The first step of classification is to apply the ASIA Impairment Scale (AIS) (American Spinal Injury Association, 2016). This consists of a 5 point ordinal scale, based on the Frankel scale, and classifies individuals from “A” (complete SCI) to “E” (normal sensory and motor function), with optional clinical syndromes.

The second step in classification is to determine the neurological level of the injury through sensory and motor assessment. The person is determined as having tetraplegia if they have damage to the cervical segments of the spinal cord, causing functional impairment in the arms, trunk, legs and pelvic organs. The person is determined as having paraplegia if they have damage to the thoracic, lumbar or sacral segments of the spinal cord, resulting in various combinations of motor and sensory impairment to the trunk, lower limbs, bladder and bowel function (American Spinal Injury Association, 2016; Atkins, 2008). Thus each person’s injury is a unique combination of sensory and motor loss.

1.3.4 Consequences of acquired SCI.

SCI is complex and multifaceted, and results in significant consequences for the person with SCI, their family and society in general (WHO & ISCOS, 2013). Understanding these consequences is important as they have implications for the social and community participation of people with SCI.

1.3.4.1 Physical consequences of SCI for the injured person.

In addition to impaired motor and sensory function, other physical consequences of SCI can include impaired bladder and bowel function, and hypotension (resulting in light headedness and fainting) and thermoregulation problems. In addition people living with SCI are susceptible to a range of secondary health conditions (SHC) and complications (Dorsett & Geraghty, 2008; Savic, Short, Weitzenkamp, Charlifue, & Gardner, 2000). Such SHC include bladder and bowel complications such as urinary tract infections, intermittent muscle spasm and spasticity, chronic pain, fractures, pressure ulcers, and respiratory, renal, cardiac and circulatory problems. Such conditions can results in poor health outcomes and may further exacerbate the degree of disability for some people with SCI, impacting on quality of life, and productivity (Dorsett & Geraghty). A recent mixed methods study found that people living with SCI experience a range of significant secondary health conditions that impact on their occupational performance and participation, including important productivity and family roles (Callaway, Barclay, McDonald, Farnworth, & Casey, 2015) (Appendix C). Pain and pressure sores are the two most frequently reported health conditions following SCI, and have been found to significantly impact on people's ability to reintegrate in to the community (Donnelly & Eng, 2005; Dorsett & Geraghty, 2008; Hammell, 2010).

1.3.4.2 Mental health consequences of SCI for the injured person.

There are mixed findings in relation to the mental health of people who have sustained a SCI, however, the majority of evidence demonstrates higher rates of depression than in the non-injured population. A longitudinal study conducted in 2011 in the United States found that major depression was prevalent in 21% of participants at year 1, and 18% at 5 years post SCI (Hoffman, Bombardier, Graves, Kalpakjian, & Krause, 2011). A two year longitudinal study of 233 people with SCI from four countries utilised the Hospital Anxiety and Depression Scale to examine depression and anxiety symptoms. They found that there were ongoing symptoms of chronic high depression but not chronic high anxiety (Bombardier, Richards, Krause, Tulsky, & Tate, 2004). In a cross-sectional, self-report survey conducted with 443 Australian adults with SCI, approximately 50% reported experiencing emotional disorders (depression and anxiety), with a 56% increase in the likelihood of people experiencing two or more emotional disorders than the general population (Migliorini, Tonge, & Taleporos, 2008). None of the above studies investigated the possible correlation between mental health issues and social and community participation, an area that warrants further investigation.

1.3.4.3 Quality of life of the person with SCI.

Quality of life (QOL) has been widely used as an outcome of rehabilitation for people with SCI (Van Leeuwen, Kraaijeveld, Lindeman, & Post, 2012). QOL is generally reported by people with SCI to be lower than the general population (Tonack et al., 2008). However, evidence relating to changes to quality of life (QOL) following SCI is variable and contradictory. This is partly due to disagreement as to what constitutes QOL, and partly due to how it has been measured in studies (Tonack et

al., 2008). It has been noted that QOL is a multidimensional concept that can only be defined subjectively, as it is a person's own sense of well-being that stems from satisfaction or dissatisfaction in areas of their life that are important to them (Kreuter, Siosteen, Erkholm, Bystrom, & Brown, 2005).

Barker, Kendall, Amsters, Perhouse and Haines (2009) conducted a cross-sectional analysis of data from a prospective and longitudinal study of 270 individuals with TSCI in Australia, and compared them with the general population. The instrument they used to measure QOL was the World Health Organisation Quality of Life Assessment Instrument-Bref, and the Community Integration Measure (CIM) was used to measure community participation. They found that on average the SCI participants reported a significantly lower QOL than the Australian norm across all domains (physical, psychological, social relationships and environment). The single most important predictor of QOL was the presence of secondary conditions, while the second most important predictor was the extent of societal participation as measured by the CIM (Barker et al).

Duggan and Dijkers (2001) conducted a qualitative study in which they interviewed 20 people with TSCI aiming to understand their life stories and what QOL meant to them. Their study participants found it difficult to define QOL, and also how to rate it. However, contributors to QOL identified by at least half the group were: satisfying social relationships and available support; financial independence; meaningful social roles; and opportunities and freedom to pursue hobbies, sports, travel and community service (Duggan & Dijkers, 2001).

1.3.4.4 Change to activities, roles and occupations for people following SCI.

Due to motor and sensory impairment following acquired SCI, people may become less able to complete self-care tasks (for example, dressing, showering, and eating) independently and have reduced mobility (Atkins, 2008). Consequently people with SCI may have reduced ability to participate in meaningful roles and activities outside the home (for example leisure, and work) (Brown, Gordon, Spielman, & Haddad, 2002; Whiteneck et al., 2004). Schonherr, Groothoff, Mulder and Schoppen (2005) conducted a survey of 57 people with SCI in the Netherlands and found that the total level of participation in vocational and leisure activities reduced by 40% following SCI (Schönherr et al., 2005). While a study by Tasiemski, Bergstrom, Savic, and Gardner (2005), in which 45 newly spinal cord injured people in the United Kingdom were surveyed, showed the frequency of involvement in sporting activities fell from 42% before the accident to 9% at the time they conducted their survey. While these studies report changes to the extent of participation in activities outside the home, there is no information reported regarding the reasons for these changes and how people with SCI can be assisted to re-engage in such activities.

1.3.4.5 Time use after SCI.

The importance of personally meaningful time use, and its influence on health and wellbeing, is a core focus for occupational therapists (Harvey & Pentland, 2010). Comparisons of the time use of a disabled population to that of the population as a whole can suggest where participation is restricted or strained (Farnworth, 2003). A variety of techniques and methods have been implemented to investigate time use, including use of time diaries, observation, and activity frequency and duration

surveys (Pentland & Harvey, 1999). A review of the literature regarding the time use of people following SCI conducted by this author (Appendix D), found that people with SCI were less likely to spend their time participating in paid employment and more likely to spend time in home-based sedentary activities (Barclay et al., 2011).

1.3.4.6 Consequences for family members of people with SCI.

When someone experiences a SCI, there are impacts on the injured person's family members. Family members may be called on to provide care and support across the injured person's lifespan. Informal care can involve tasks such as organising appointments, advocacy for care, assistance with meal preparation, shopping, cleaning, household maintenance, mobility, community participation, assistance with daily care such as grooming, advice and emotional support (Guilcher et al., 2012). Spouses in particular are the key support providers for many people with SCI, providing physical as well as emotional support (Post, Bloemen, & De Witte, 2005).

Length of inpatient admission for people with SCI has decreased, and people are often discharged into the community before their condition has stabilised, resulting in increasing responsibility being shifted to individuals and their informal care networks, who typically do not have the skills, knowledge or support that they need (De Jonge et al., 2011; Guilcher, 2012). As the number of people with long term health conditions such as SCI increase and live for longer, health care and welfare systems struggle to accommodate the additional servcie requirements placed on the system, leading to more care responsibilities falling to family members.

Increasing family carer responsibilites can impact on the informal carers' quality of life, and change the nature of the relationships between the family member and the injured person. Dickson, O'Brien, Ward, Allen, and O'Carroll (2010) conducted in-depth individual interviews with eleven spouses who were primary care givers to people with SCI. A distinct change in role from spouse and lover to care provider was reported and this ultimately contributed to relationship change (Dickson, O'Brien, Ward, Allan, & O'Carroll, 2010). Dickson et al concluded that caregivers seldom receive the necessary preparation for their caregiver role, or the support needed to maintain the level of care required. They recommended that caregivers be more meaningfully integrated into the rehabilitation process, and the development of more effective screening tools for detecting caregiver stress be implemented (Dickson et al.). No studies located specifically examined the experience of being an informal carer of someone with NTSCI, therefore it is not known if their experience is similar or different.

1.3.4.7 Economic consequences of SCI.

The reduced participation of people with SCI and the need for the community to provide medical and personal care, results in financial costs to society. In 2008, healthcare costs in Australia associated with paraplegia were $52.5 million and for tetraplegia $76.5 million (Access Economics Pty Ltd, 2009). In developed countries improvements in first-aid, rapid transport to specialist units, and advances in medical and surgical techniques and rehabilitation, have resulted in reductions in mortality, and increased life expectancy for people with TSCI (Frankel et al., 1998; Krause, DeVivo, & Jackson, 2004; Krause, Carter, Pickelsimer, & Wilson, 2008; WHO & ISCOS, 2013; Yeo et al., 1998). However, increased life expectancy requires that

extra care and medical assistance is provided across the life span. As people age with an SCI, their co-moribities have been shown to increase and the effects of ageing amplified (Savic et al., 2009). No studies were located that report on the costs to the person with an SCI. This is an area that warrants further invesitgation.

In summary, SCI can result in a variety of consequences for the injured person, their family and society. These may include changes to the person's physical and mental health, QOL, time use, and participation in activities, roles and occupations both at home and in the community. Often there are increased informal care responsibilities required of family members which can impact the QOL of the carer, and change the nature of the relationship between the injured person and the carer. There is an economic impact on society associated with caring for the injured person, and there is likely to be a financial impact on the injured person and their family.

1.4 Theoretical Models and the Concept of Participation

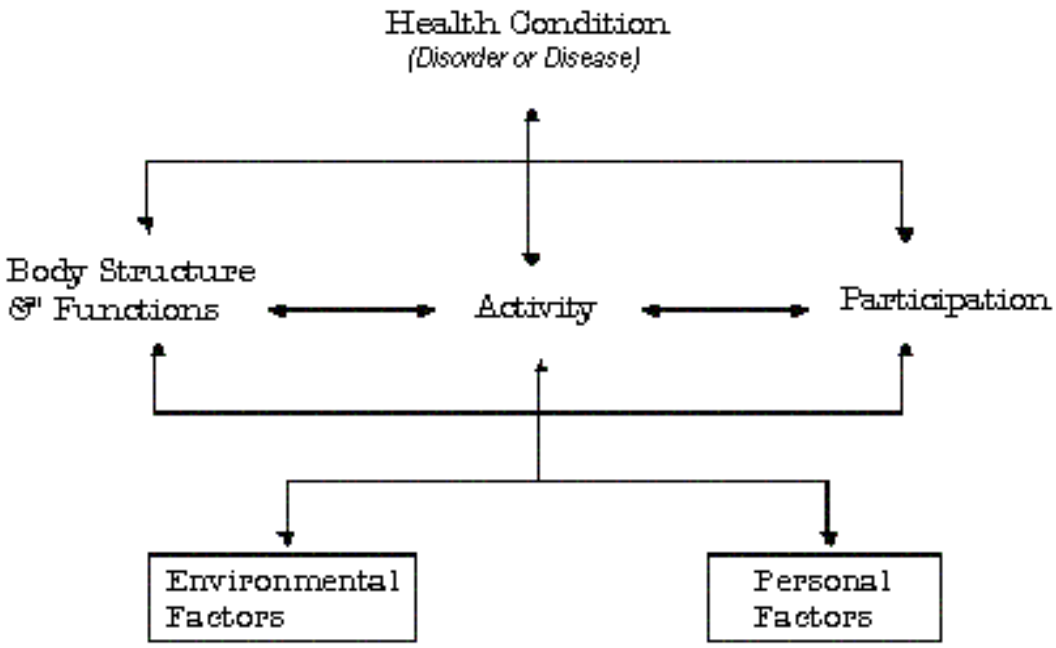
Two theoretical models that have informed the current thinking regarding health, disability, and functioning – the International Classification of Functioning Disability and Health (ICF) and the Canadian Model of Occupational Performance and Engagement (CMOP-E) will be discussed and compared, including how the concepts of participation, social participation, and community participation are conceptualized in each of these models.

1.4.1 International Classification of Functioning, Disability and Health.

In May 2001, the World Health Organisation formally endorsed The International Classification of Functioning, Disability and Health (ICF) (Bornman, 2004) (Figure 1).

The ICF is a framework that was developed to create a consistent language between health professionals (World Health Organisation, 2001).

Figure 1 *International Classification of Functioning, Disability and Health (WHO, 2001)*



The ICF describes the impact of health conditions on people's lives, by highlighting the relationship between the health condition (for example TSCI or NTSCI) and body structure and functions and activity and participation in daily life, within a context which includes both environmental (for example policies and funding structures) and personal factors (for example age, pain) (Townsend & Polatajko, 2007). Disability is therefore viewed as the result of the interaction between the health condition and its consequences (for example incontinence), with the contextual factors of that person (environmental factors and personal factors) (Bornman, 2004; WHO, 2001). Environmental factors in the ICF refer to the physical, social and attitudinal

environments in which people live and conduct their lives, while personal factors refer to features that the individual may have that impact on the experience of disability, for example old age (WHO, 2001).

In the diagrammatic representation of the ICF, *activity* and *participation* are defined and depicted as two separate constructs. However, they are combined in the nine domains, which are: D1 Learning and applying knowledge; D2 General tasks and demands; D3 Communication; D4 Mobility; D5 Self-care; D6 Domestic life; D7 Interpersonal interactions and relationships; D8 Major life areas (e.g. work or school); D9 Community, social and civic life (WHO, 2001).

The WHO has not differentiated which of these are *activity* domains or which are *participation* domains. Although the ICF defines *participation* as "involvement in life situations" and *activity* as "the execution of a task or action by an individual" (WHO, 2001, p.10), the lack of clear conceptual distinction between the definitions has led to confusion regarding the potential differences in their meaning (Noreau, Fougeyrollas, & Vincent, 2002a; Whiteneck & Dijkers, 2009). The nine domains encompass all life activities from self-care through to work and spiritual activities, and are coded with two qualifiers – capacity and performance. However, it has been argued that activities such as dressing, showering and toileting, communication, mobility, and domestic skills align more closely with the concept of activities rather than participation as they need to be performed for survival (Noreau et al. 2002a). "Involvement in life situations" has not been clearly defined by the WHO, leading to speculation as to what the concept of participation really refers to, for example, life situations could relate to social, and/or productivity roles. *Participation* is more likely

to refer to active engagement at the community level, and as a means to experience social connectedness with other people (Hammel, Magasi, Heinemann, Whiteneck, Bogner,& Rodriguez, 2008). In addition, *participation* can also be considered to include the extent to which social roles are fulfilled (Whiteneck & Dijkers, 2009), and include a person's ability to be an active and contributing member of society (Magasi, Heinemann, & Whiteneck, 2008). At the present time the concept of *participation* is still being examined and conceptualized (Martin Ginis, Evans, Mortenson, & Noreau, 2016).

When considering TSCI and NTSCI through the lens of the ICF, differences can be identified in relation to person factors and environmental factors. In relation to person factors, people who sustain a NTSCI tend to be older and are as equally likely to be female as male (Guilcher et al, 2010). Whereas people with TSCI are more likely to be male, aged 46-60 years, have tetraplegia and have a complete injury (New, Baxter, Farry, & Noonan, 2015). In relation to environmental factors, people with NTSCI do not usually get admitted to specialist spinal centres, but rather to general slow stream rehabilitation facilities, not specifically designed for people with spinal injuries. In addition, in Australia people with TSCI are more likely to be in receipt of compensation (eg. motor vehicle insurance or work insurance) than people with NTSCI, which currently provides them with access to the equipment and care support that they need (Access Economics Pty Ltd, 2009).

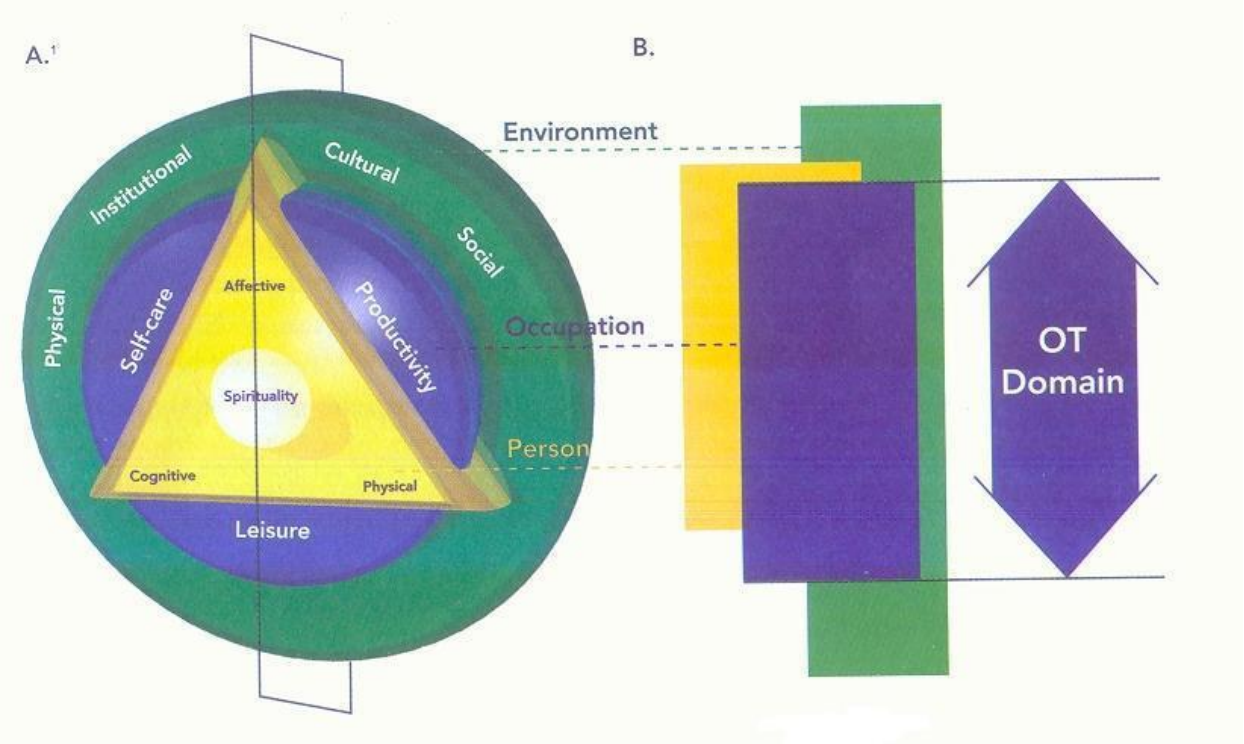
In addition to the ambiguity regarding the concept of participation, an additional criticism of the ICF is the exclusion of the meaning and experience of participation to the person with the health condition. In the ICF participation is measured by

observation of the person's performance, and does not include the person's subjective experience (Hemmingson & Jonsson, 2005). These issues will be discussed further in relation to an occupational therapy model – the Canadian Model of Occupational Performance and Engagement.

1.4.2 Comparison of the ICF with the Canadian Model of Occupational Performance and Engagement.

The Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko et al., 2007) conceptualises occupational performance as the dynamic interaction between the person, the occupation and the environment. The person is depicted as the triangle at the centre of the model, and is portrayed as having three performance components – the cognitive, affective and physical, with spirituality at the core. The person is embedded in the environment, (cultural, institutional, physical and social), and occupation is depicted as the bridge that connects the person and the environment. Although not central to the model, Townsend and Polatajko define participation as "involvement in a life situation through occupation" (p. 26). The CMOP-E is depicted in Figure 2.

Figure 2 *Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko et al., 2007)*



When comparing the ICF to the CMOP-E there are a number of differences and similarities. The ICF does not recognise the importance of the satisfaction of the person with their participation in occupations (Hemmingson & Jonsson, 2005; Piskur et al., 2013). One of the core values of the occupational therapy profession is the importance of client-centred practice which emphasises recognising the clients' knowledge and experience, strengths, capacity for choice and overall autonomy (Kielhofner, 2009). Occupational therapy models include the subjective experience of participation in occupations by the person with the disability (Desrosiers, 2005), and include person or client-centred input when assessing occupational performance (Townsend & Polatajko, 2007). From a CMOP-E perspective it would not be sufficient to only observe a person's performance in participation of an occupation such as work or leisure as the ICF suggests, but also to assess its importance and the person's satisfaction with it. A tool such as the Canadian Occupational

Performance Measure (COPM) can be used to do this (Townsend & Polatajko, 2007). The COPM includes a scale where the person rates the importance and satisfaction with their occupational performance. Therefore, one of the main differences between The CMOP-E and the ICF is the inclusion of the subjective experience of participation in occupation (Hemmingson & Jonsson, 2005; Kielhofner, 2009; Townsend & Polatajko, 2007).

Although there are differences between the ICF and the CMOP-E, there are also similarities. The ICF concept of *body function and structure*, has similarities to the CMOP-E person components of cognitive and physical, but does not include the affective and spiritual components (Townsend & Polatajko, 2007). The ICF includes the variable *personal factors*, which are similar to the CMOP-E concept of person. Both models include the concept of activities or occupations occurring within an *environmental* context. The four environmental variables within the CMOP-E are physical, cultural, social and institutional, while the environmental factors of the ICF include the physical, social and attitudinal environment within which people conduct their lives (Townsend & Polatajko, 2007), and are compared in Table 3.

In the ICF activities are tasks and actions that are performed without personally constructed meaning or a social role, while in the CMOP-E activities (composed of tasks) are a subset of occupational performance (Townsend & Polatajko, 2007). The ICF refers to participation while the CMOP-E uses the term occupational performance. While these terms are related they do not have the same meaning. Participation may be an outcome of occupational performance or a context for occupational performance, whereas occupation may have value and meaning, but

not involve participation in the community or society (Townsend & Polatajko). Table 3 provides a comparison of these two models, utilising some characteristics of a person with SCI as an illustration.

Table 3 *Comparison of ICF and CMOP-E applied to SCI*

ICF	CMOP-E
Personal factors - Background of individual (gender, age, psychological characteristics)	**Person** - Cognitive (eg. problem solving capacity) - Affective (eg. depression)
Body functions & structures - Level of SCI - Associated health conditions (spasticity, pain, depression) - Does not include all aspects of cognitive or affective	- Physical ((level of SCI; spasticity; pain) - Spiritual - (although not specifically stated in model, background information is implied e.g. gender, age)
Activity & Participation - Nine domains (learning & applying knowledge; general tasks & demands; communication; mobility; self-care; domestic life; interpersonal interactions; major life areas; community, social & civic life) - Activity and participation not clearly differentiated - Does not include meaning or subjective experience	**Occupational performance & engagement** - Three occupational groupings (self-care; productivity & leisure) - Includes meaning and engagement in occupation - Includes subjective experience - Participation is “involvement in a life situation through occupation”
Environmental factors - Physical (buildings, transport) - Social (compensation structures, disability supports), possibly includes cultural) - Attitudinal environment (employer’s attitudes)	**Environment** - Physical (buildings, transport) - Social (community & employer’s attitudes) - Cultural - Institutional (compensation structures, disability supports, policy)

1.5 Social and Community Participation

Due to the ambiguity of the conceptualisation of *participation* as used in the ICF, researchers and clinicians have called for a clearer definition (Noreau, Fougeyrollas, Post, Asano, 2005; Whiteneck & Dijkers, 2009). The lack of consensus regarding a definition has consequences in terms of communication between professions and clinicians, for the development and selection of instruments to measure it, for policies aimed at addressing it, and for individual interventions to facilitate it (Levasseur, Richard, Gauvin, & Raymond, 2010). Other terms including social participation and community participation have been raised as possible alternatives that could provide more clarity and will be discussed.

In an opinion piece, Piskur et al. (2014) observed that authors often use the terms participation and social participation interchangeably. They also identify that authors may discuss social participation in terms of social integration, social inclusion or social activity, hence contributing further to the ambiguity. Levassuer, Richard, Gauvin and Raymond (2010) conducted an inventory and content analysis regarding use of definitions of social participation with older adults by systematically reviewing publications between 1980 and 2009. They discuss the fact that many similar concepts such as participation, social engagement, social connectedness, social capital, social support, social network, social integration and community involvement have been used interchangeably with social participation. As a result of the review, they propose a taxonomy of social activities and finally a definition of social participation, as "a person's *involvement* in activities that provide interaction with others in society or the community" (Levasseur et al., 2010, p.2147).

The term community participation is often used to refer to activities undertaken outside the home environment, therefore features of the community environment become an important consideration. It is argued that measuring outcomes following rehabilitation, needs to include returning to community life as this reflects the return to the "real world" (Cott, Wiles, & Devitt, 2007; Hammell, 2010). Chang, Coster and Helfrich (2013) conducted a systematic review of instruments designed to measure community participation for people with disabilities, to evaluate which domains of the ICF they addressed and to what extent. They concluded that none of the instruments addressed all of the ICF participation domains. They assert that participating in activities outside the household requires different capabilities, including mobility in the community and socializing with people. Therefore, they argue, the concept of

community participation should be distinguished from domestic life by including engagement in vocational, social (outside the household), and other community roles such as neighbour or volunteer (Chang, Coster, & Helfrich, 2013). Chang et al define community participation as “active involvement in activities that are intrinsically social and either occur outside the home or are part of a nondomestic role” (p.1).

People with disabilities consistently state that “Lack of social inclusion and the multiple barriers to meaningful participation in the community” are one of the major issues they face (National People with Disabilities and Carer Council, 2009, p.12). Referring back to my clinical observation that sometimes people with SCI were socially isolated and ceased to participate in social activities in the community, I assert that **involvement** in activities that provide **social** interaction **outside the home** are important aspects of participation. Therefore for the purpose of this thesis, to encompass aspects of both social and community participation the term *social and community participation* will be used. Due to the continuing discussions and ambiguity relating to the meaning of the terms participation, social participation and community participation, one of the aims of this thesis is to gain further understanding of these concepts from the perspective of those living with SCI.

1.6 Social and Community Participation and its Influence on Quality of Life (QOL)

As discussed in 1.3.4.3, there is disagreement as to what constitutes QOL, and how it can be measured. This, in combination with the ambiguity and interchange of participation definitions, makes it difficult to draw conclusions regarding the influence of social and community participation on QOL. However, if, as Hammell asserts,

QOL is the ultimate goal of rehabilitation following SCI, and a determinant of rehabilitation success, this is an area that requires further examination (Hammell, 2007).

Hammell (2007) conducted a meta-synthesis of qualitative studies published between 1990 and 2006 regarding QOL following SCI. The aim of the meta-synthesis was to identify factors that people living with SCI in the community identify as contributing to or detracting from their experience of a life worth living (Hammell). She refers to the lack of a clear definition of QOL in the medical literature, a lack of consensus on what QOL means, who should measure it and whether it is realistic to measure it (Hammell, 2007). For the purpose of the meta-synthesis, she used a working definition of QOL as the “experience of a life worth living” (p.124). Among the findings was the importance of being able to participate and be involved in meaningful occupations and roles, both inside and outside the home. The findings of the meta-synthesis support the link between engagement in valued occupations (using time in personally meaningful ways) and perceptions of self-worth (of perceiving oneself to be able, competent, capable and valuable) (Hammell, 2007).

Levassuer, Desrosiers and Noreau (2004) conducted a cross-sectional study on QOL of 46 people aged 60 – 90 living in the community with a physical disability. They used the Quality of Life Index to measure QOL, and the Assessment of Life Habits (Roy-Bouthot et al., 2014) to measure social participation. They found that interpersonal relationships, responsibilities, fitness and recreation were the categories of social participation most associated with improved QOL (Levasseur, Desrosiers, & Noreau, 2004).

The aim of a study by Hammell (2004a) was to explore how people with high SCI reconstruct lives worth living and identify the factors that contributed to or constrained the quality of their lives. She conducted semi-structured interviews with 15 people with high spinal cord injury living in the community. As in the meta-synthesis described earlier she conceptualised QOL as the experience of a “life worth living” (Hammell, 2004a). She found that QOL was associated with the opportunity to be engaged in meaningful activities, which provided a sense of competence, value and self-worth. Also noted in Hammell’s findings was that engagement in social activities and social interaction were positively associated with QOL, lending further evidence to the important role that social participation has in maximising QOL after SCI.

While taking into account the definitional limitations and the varying instruments used in these studies, there is an apparent link between social and community participation and QOL, making this a critical area to further investigate. Gaining increased understanding of the barriers and facilitators to the social and community participation of people with SCI will assist in developing appropriate policies, and effective interventions and programs to address the identified barriers.

1.7 Investigating Social and Community Participation following SCI

Due to the lack of a standard definition of participation, attempts have been made to operationalise it and assess it through instrument development (Dijker, 2010), resulting in the creation of multiple instruments (Bogner et al., 2011; Eyssen, Steultjens, Dekker, & Terwee, 2011). Some instruments utilise an objective approach (society-perceived participation, based on a societal perspective of participation

accomplishment), while others take a subjective approach (based on the individual's perspective, and their level of satisfaction (Bogner; Eyssen et al.). Appendix E provides a table of the most commonly used quantitative instruments aiming to assess participation, social participation and community participation in the SCI and rehabilitation literature. The instruments are summarised regarding their purpose, the domains they assess, the rating scale used, the number of items, the population the instrument was designed to be used with, the psychometric properties, whether a satisfaction measure has been included and the advantages and limitations of the instrument. Review of this table highlights the differences in the type of participation they purport to assess, the domains they aim to assess and the way the domains are assessed.

Chang, Coster and Helfrich (2013) conducted a content analysis of 17 quantitative instruments purported to measure the construct of community participation, describing the features and limitations of the instruments. They found that very few instruments simply assess community participation with most measuring a mixture of concepts, including activities, functioning, symptoms and participation, and most did not consider community participation as a distinct construct (Chang et al., 2013).

In relation to measuring participation, Brown (2010) discusses the insider-outsider distinction, and the limitations associated with developing participation instruments based on the "outsider's" perspective, in this case, people who are not disabled. Current instruments, including those listed in Appendix E, assess the degree to which participation is difficult and in some cases, how satisfied people with disabilities are with their participation, but they do not determine what is important to

the person with the disability (Brown, 2010) Brown recommends that insider generated instruments are developed, with dimensions or qualifiers that are important to those with disabilities included. Furthermore, Rochette Korner-Bitensky and Levasseur (2006) recommend caution when interpreting scores of instruments designed to quantify participation (Rochette, Korner-Bitesnsky, & Levasseur, 2006). According to Rochette et al, optimal participation can only exist when there is a perfect fit between the reality of how roles are performed and the expectations of how roles should be performed by the person with the disability or condition.

Development and utilisation of measurement tools designed to quantify participation, without the involvement of the insiders (people with SCI) from the beginning, can result in the complexity of issues regarding participation following SCI not being fully explored. Increasingly it is being recognized that use of standardized quantitative measures alone, do not capture the **experience** of participation from the client's viewpoint (Brown, 2010). Quantitative approaches do not take into consideration the **quality** of participation (Noreau, Fougeyrollas, Post, & Asano, 2005) or what is **important** to the person living with SCI (Brown, 2010). Quantitative studies are therefore at risk of failing to measure variables that have not been identified, leaving results to be a display of investigated relationships but not necessarily highlighting the range of issues that are important to people with SCI. This issue is of particular interest to the occupational therapy profession that supports clients as citizens who are entitled to participate in making decisions about occupational therapy and other services (Townsend & Polatajko, 2007).

There is limited understanding of what participation, social participation and community participation means to people with SCI, and whether it is important to them. However, there have been some studies conducted in this area, from the perspective of people with lived experience of disability. Hammel, Magasi, Heinemann, Whiteneck, Bogner, and Rodriguez (2008) completed a qualitative study that included the perspective of people living with a variety of disabilities. They conducted focus groups with 63 people with disabilities to gain an insider perspective regarding what participation means to them. Participants wanted participation in community life through meaningful engagement, with access to a full range of opportunities, unrestricted by bodily impairments or disability, social and political environments (Hammel et al., 2008). From their findings it can be concluded that participation not only includes active engagement at the community level, but it also includes personal **meaning** and **satisfaction** resulting from that engagement.

Ripat and Woodgate (2012) conducted a grounded theory study with 19 people living with SCI to gain an understanding of how adults with SCI participate in their daily life and within their communities. Participants engaged in individual in-depth interviews, and took photographs of aspects of their environment that promoted and restricted participation. Participants described participation as an experience, explaining what it meant “to participate” rather than discussing ability to complete specific activities or roles. They spoke of: “feeling a part of something”, “feeling welcome” and a “sense of belonging”. In addition, the social component was highlighted, and included the sense of **meaningful involvement** in activities (Ripat & Woodgate).

These studies highlight the differences in findings between quantitative and qualitative approaches to this topic, and reinforce that there is limited understanding as to of what social and community participation **means** to people living with SCI, and whether it is **important** to them.

1.8 Legislation, Policy and Service delivery in Australia

Policy influences the delivery of services as well as the social, political and institutional environment of people living with SCI, and as such is relevant to this study. There are a number of changes currently being implemented relating to the delivery of aged care and disability services and supports in Australia, which impact on the participants included in this study. It is therefore important to consider legislation and policy in relation to the social and community participation of this group, and how services to support participation are delivered in a changing legislative and policy environment. A brief introduction and summary of the reforms are outlined below.

1.8.1 National Disability Strategy (Strategy).

The National Disability Strategy 2010-2020 (Strategy) was endorsed by the Council of Australian Governments (COAG) in February 2011 (Department of Social Services, 2010). The Strategy outlines a ten year national policy framework to improve the lives of people with disability, promote participation and create a more inclusive society. It guides public policy across all levels of government and drives changes in mainstream and specialist programs and services, in addition to community infrastructure – to better meet the needs of people with disability, their families and carers (Department of Social Services, 2010). The strategy is

aspirational so that all Australians, including those with living with a disability, should have fair and equal access to the full range of mainstream services and programs available, including employment, healthcare, education, transport or public facilities and infrastructure (Department of Social Services, 2010). As part of the Strategy the Productivity Commission (PC) undertook a public inquiry into a long term disability care and support scheme for people with disability. The Council of Australian Governments subsequently agreed to the need for major reform of disability services through a National Disability Insurance Scheme (NDIS). While the NDIS represents a major step forward for many people with disability, the Strategy remains the key to achieving improvements in access to mainstream services and support for people with disability (Department of Social Services, 2010).

1.8.2 National Disability Insurance Scheme (NDIS).

Following the Productivity Commission (PC) report, a period of negotiation occurred to enshrine the NDIS into Australian law, which occurred on 28 March 2013 (National Disability Insurance Scheme Act, 2013). The NDIS is based on an insurance model, where expenditure is factored in over the lifetime of an individual. The PC identified that without reforms in the disability sector, government expenditure on disability would increase, causing strain on the other universal access systems – such as health, education, transport, social services, accommodation etc. The former disability system was ad hoc, state based with a lack of availability, inconsistency of quality and systemic failures. The key components written into the scheme are firstly to increase funds into the sector, and secondly, to give choice and control to the person with disability rather than a service provider or government agency. The introduction of the NDIS marks a shift away from the block funding of disability

services to individualised funding for people eligible for the scheme (Hallahan, 2015). The emphasis is on supporting social and economic participation rather than addressing an individual's impairment. The first stage of the roll-out of the NDIS began in 2013, and will continue across the country until 2019-2020. It is anticipated that by 2019, about 460,000 people under the age of 65 with a permanent and significant disability, will have access to the reasonable and necessary supports they need to live an ordinary life (NDIS, 2016).

Participants of the NDIS will have more choice and control over how, when and where supports are provided (NDIS, 2016). It is about making sure people with a disability and their families get the support, care, therapy, equipment, early intervention and training they need to participate in the community in the way they want to do (NDIS, 2016). The underlying principle of the Scheme is that a change to the environment will lead to a cultural shift across all parts of society. Implementation will be through the local area coordinators (LAC).

1.8.3 National Injury Insurance Scheme (NIIS).

In August 2011, in addition to recommending the NDIS, the Productivity Commission (PC) recommended a separate National Injury Insurance Scheme (NIIS). Their reasons for this recommendation were:

- to reduce the cost of the NDIS through a fully funded insurance accident scheme
- to make use of existing expertise and institutions of accident compensation schemes to use incentives to deter risky behaviour and reduce local risks that can contribute to accidents

- to cover a broader range of health costs associated with catastrophic injuries, such as acute care and rehabilitation services.

The PC recommended that a NIIS be developed for catastrophic injuries caused by four types of accidents: motor vehicle accidents, workplace accidents, medical accidents and general accidents (occurring in the home or community) (Australian Government, 2016). At this stage the Australian Government is still considering this scheme as there are a number of complexities that make it challenging to implement (PC, 2011). The Australian Government is currently working with States and Territories to develop the NIIS as a federated model of separate, state-based no-fault schemes that provide lifetime care and support for people who have sustained a catastrophic injury. The NIIS will build on existing State and Territory accident compensation schemes (for example, for motor vehicle and workplace accidents) to complement the NDIS (Australian Government, The Treasury, 2016). At present, in Victoria, existing state based insurance and compensation schemes, for example the Transport Accident Commission and Worksafe (WSV) remain, as does the right to challenge common law.

1.8.4 My Aged Care – Living Longer Living Better reforms.

Australia's population is ageing. Life expectancy is increasing at both birth and over the course of the person's lifetime, as Australians enjoy higher standards of living and greater access to quality healthcare (AIHW, 2016). Based on population projections by the Australian Bureau of Statistics, there will be 9.6 million people aged 65 and over and 1.9 million people aged 85 and over by 2064 (AIHW, 2016). This means there will be a greater demand on the limited resources available to support the health and quality of life of older Australians, requiring reforms to best

meet these demands. The Australian Government recognised the need for reforms, and for the last ten years has been working to implement reforms to the National Aged Care system, culminating in the introduction of the Aged Care (Living Longer Living Better) Act on 1 August 2013 (Aged Care, 2013). The overall purpose of the reforms is to ensure that aged care funding (that is funding for people over aged 65 years) is sustainable and affordable. One of the main aims is to keep people living in their own home for as long as possible, and prevent premature admission to residential aged care which is costly to the government and society. Therefore more funding has been put into community based services, in addition to changing the way services will be delivered, thereby offering more choice and flexibility for consumers (Department of Social Services, 2016). This involves a shift towards consumer-directed care, the essence of which is to provide recipients of home based care packages with more choice and control over how their package is spent, what services are delivered and who will deliver them. This approach focusses on people's strengths, rather than their deficits, and assumes that everyone has some capacity to improve their own health and wellbeing (Department of Social Services, 2016; Victorian Government, 2016).

The findings of this study and how they intersect with the reforms outlined above are discussed in Chapters Seven. However, it is important to note that people with SCI are also living longer, and, as with the rest of the population, age related changes will mean increased service use.

1.9 Chapter Summary

SCI is a serious life event, which has implications for the injured person's physical and mental health, and can result in changes to time use, roles and occupations, and the person's social and community participation. In addition, there is often a significant impact on family members, and costs to the community in providing assistance to someone with SCI. Currently there are a number of reforms occurring in the disability and aged care sectors, which will influence the social and community participation of people with SCI in the future, particularly as people with SCI are living longer. There is a link between satisfactory social and community participation and QOL, and various attempts have been made to measure participation, social participation and community participation using quantitative approaches. However, quantitative approaches do not take into consideration the complexities of social and community participation, and do not necessarily include the **meaning** and **importance o**f that participation to the person living with SCI. Only a few qualitative studies have explored the meaning and importance of social and community participation from the perspective of someone with living an SCI. In order to fully review all the available evidence regarding the social and community following SCI, and to assess the quality of that evidence, a critical literature review was conducted. This review is presented in the next chapter.

Chapter Two

Social and Community Participation Following Spinal Cord Injury: A Critical Review (published article)

Chapter One provided the background to the thesis and the reason for the author's interest in this area of research. To rigorously identify the current evidence regarding social and community participation following SCI, a critical literature review was conducted. This chapter presents this review, which was published in January 2015.

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2.1 Introduction

Participation in meaningful occupations has been shown to have a positive influence on health and well-being, and is a vital part of the human condition and experience (Law, 2002). It is internationally recognized that all people, including those with disabilities have a right to be able to fully participate in society (Whiteneck et al., 2004). Participation has been shown to more strongly relate to quality of life than either impairment or functional ability (Djikers, 1997) and is therefore a highly valued rehabilitation outcome for people with disabilities (Magasi et al., 2008).

In the 1980s the “International classification of impairment, disability and handicap” (ICIDH) was developed by the World Health Organization (Bornman, 2004). Although the ICIDH was generally well-received, disability rights groups and others were critical that the ICIDH was based on the medical model placing the problem of disability within the individual rather than within the context of society (Hemmingson & Jonsson, 2005). Revisions started in the 1990s which ultimately resulted in the “International classification of functioning, disability and health” (ICF), which was formally endorsed by the WHO in May 2001 (World Health Organisation, 2001). The ICF describes the impact of health conditions on people’s lives and places functioning and disability in a context which includes both environmental and personal factors (Polatajko et al., 2007).

Since the introduction of the ICF over 12 years ago, there has been scrutiny of its strengths and limitations. The ICF defines Participation as “a person’s involvement in a life situation” and Activity is defined as “the execution of a task or action by an individual” (WHO, p.213). In the diagrammatic representation of the ICF, Activity and Participation are depicted as two separate constructs, but these have not been differentiated between in the nine Activity and

Participation domains listed (WHO & ISCOS). The lack of specificity or clear conceptual distinction between the terms Activity and Participation by the WHO, has led to considerable debate among researchers and scholars about the difference in meaning between these two terms (Noreau et al., 2005; Whiteneck & Dijkers, 2009). The nine Activity and Participation domains encompass all life activities from self-care through to work and spiritual activities. However, tasks such as dressing, showering and toileting, mobility, communication, and domestic skills can be considered activities of daily living, and more closely align with the concept of activities (Noreau, Fougeyrollas, & Vincent, 2002b). Participation can be seen as including active engagement at the community level, and a means to experience social connectedness with other people and communities (Hammel et al., 2008). It has been recommended that the distinction between the terms be made clearer (Whiteneck & Djikers).

There has been considerable discussion in the health literature, both prior to and after the introduction of the ICF, regarding the definition of social participation. In the Disability Creation Process model (DCP) developed by Fougeyrollas and colleagues in the 1990s, social participation was conceptualized as “life habits”. However, both daily activities (nutrition, fitness, personal care, communication, residence/housing, mobility) and social roles (responsibilities, interpersonal relationships, community life, education, employment, and leisure/recreation) were included (Desrosiers, 2005; Fougeyrollas et al., 1998). More recently the question has been raised as to whether participation as defined by the ICF and social participation are in fact distinct concepts (Piskur et al., 2013). Piskur and colleagues found that authors often use the terms participation and social participation interchangeably (Piskur). Levasseur, Richard, Gauvin and Raymond (2010) conducted a systematic review of the literature on aging, to identify the meaning and definition of social participation. They

defined social participation as “a person’s involvement in activities that provide interaction with others in society or the community” (Levasseur et al., 2010). More recently Chang and colleagues defined community participation as “active involvement in activities that are intrinsically social and occur outside the home or are part of a nondomestic role” (Chang et al., 2013, p772). The common features of these definitions are that the person is involved in social roles and activities outside the home that provide interaction with others. The ICF domains of Activity and Participation considered to most closely reflect these definitions of social and community participation are: Interpersonal Interactions and Relationships; Major Life Areas; Community, Social and Civic Life. These domains will be used to structure this critical review.

Rehabilitation professionals working with people with an acquired SCI need evidence to guide their practice to ensure it is client-centered and that it meets the needs of those living with SCI. To assist with this, a critical review of the literature regarding the barriers and facilitators to social and community participation of people following SCI is needed.

2.2 Objectives

The objectives of this critical literature review are to examine the available evidence regarding social and community participation following SCI, as conceptualized above, and to examine the factors that influence that participation. The barriers and facilitators will be identified and described in terms of the contextual factors - personal or environmental, as outlined by the ICF. An additional objective is to appraise the quality of the evidence examined.

2.3 Methods

2.3.1 Search strategy.

The following databases were searched electronically: OVID MEDLINE; AMED; CINAHL PLUS; PSYCHINFO. These databases were selected as they were considered most likely to provide the types of studies required for this review. The following search terms were used: spinal cord injur* OR tetrapleg* OR parapleg*, AND community participation OR participat* OR life roles OR participation in activities OR social participation OR community role* OR role*, OR occupational engagement. Reference lists from retrieved articles and other related articles were also reviewed.

2.3.2 Inclusion criteria.

- English language
- Studies published from 2001 (to reflect the introduction of the ICF) to 2013
- Participants have an acquired spinal cord injury
- Participants were adults over 18 years (no upper age limits applied)
- Studies were conducted in developed countries (USA, Canada, Australia, United Kingdom, Europe) to enable direct comparisons and meaningful discussion
- The article was an original research study, the primary purpose of which was to provide information regarding social and community participation following SCI
- Qualitative, quantitative and mixed method studies were included.

2.3.3 Exclusion criteria.

As the aim of this paper is to examine and appraise the current evidence relating to social and community participation following SCI, papers that were not original research studies were not included. Literature reviews, theoretical papers, opinion pieces, and studies that

validated an instrument or tool were therefore excluded. Additionally, in order to examine as many factors involved in social and community participation as possible, studies that provided information regarding only **one** specific aspect of social or community participation (for example work only, or leisure only), or regarding only one specific influence (for example the built environment) were excluded. Figure 1 provides a detailed flowchart of the process used to select the included studies.

2.3.4 Appraisal of studies.

In order to examine all evidence relating to this topic, qualitative, quantitative and mixed methods studies were included for review. The studies were appraised for quality utilising the Critical Review Form – Quantitative Studies (Law et al., 1998) and the Critical Review Form: Qualitative Studies Version 2 (Letts et al., 2007). Both of these tools were developed by the McMaster University Occupational Therapy Evidence-Based Practice Research Group. The decision to use these tools was taken following review of a number of other quality appraisal tools (Classon et al., 2008; Downs & Black, 1998; Katrak, Bialocerkowski, Massy-Westropp, Saravana Kumar, & Grimmer, 2004). Katrak and colleagues conducted a systematic review of critical appraisal tools, and found that there is no gold standard critical appraisal tool for any type of study design (Katrak et al.). The McMaster tools have been used in previous allied health studies (Massy-Westropp & Masters, 2003; O'Brien, 2010), are easy to use and comprehensive. Each study was assessed as to whether it met the requirements listed under each criterion. If the requirement was met it was rated a "yes" and received a score of one point. If the requirement was not met or was inadequately addressed, it received a "no" or "n/a" and received no points. Headings used in the two forms are outlined in Table 4 and Table 5. The total possible score for the quantitative studies was 15, and for the qualitative studies was 24. The first and second named authors

completed the quantitative reviews, while the first and third named authors completed the qualitative reviews. The authors completed the reviews independently and were blinded to the others' results. Discussion then occurred between the reviewers and a final score was determined for each article. The final scores given are included in Table 4.

Figure 3 *Flowchart of process for including studies.*

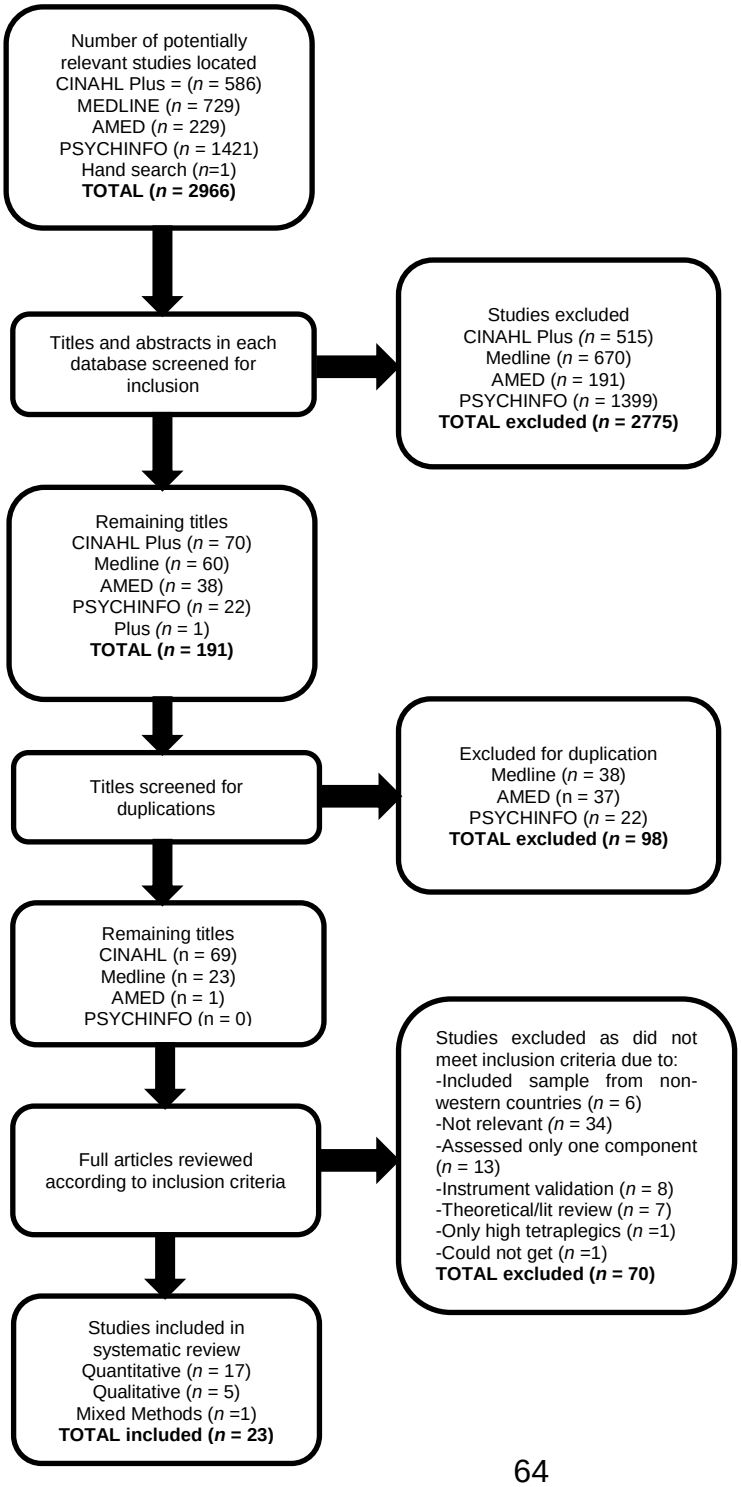


Table 4 *Results McMaster Critical Review Form - Quantitative (Law et al., 1998)*

Criterion	Score
Study Purpose	1
Literature	1
Design	1
Sample	2
Outcomes	2
Interventions	3
Results	4
Conclusions	1
Total	15

Table 5 *Results McMaster Critical Review Form: Qualitative Studies Version 2 (Letts et al., 2007)*

Criterion	Score
Study Purpose	1
Literature	1
Design	2
Method	1
Sampling	3
Data Collection	5
Data Analysis	4
Theoretical Connections	1
Overall Rigour	4
Conclusions & Implications	2
Total	24

2.3.5 Data synthesis.

Due to the heterogeneity of the studies (variation in the instruments and methods utilized) it was not possible to undertake a meta-analysis of the findings. Therefore, a descriptive or qualitative review was completed (Polgar & Thomas, 2008). Relevant data were extracted and presented according to the Activity and Participation domains: Interpersonal Interactions and Relationships; Major Life Areas; Community, Social and Civic Life. In addition the personal factors and environmental factors that influenced participation were also extracted and are presented.

2.4 Results

A total of 2966 publications were located for possible inclusion. Following review of the titles and abstracts the number reduced to 191 articles. Of those, there were 98 duplicates, which left 93. Full review of these articles according to the inclusion and exclusion criteria, resulted in seventeen quantitative studies (Brown et al., 2002; Bushnik, 2002; Carpenter, Forwell, Jongbloed, & Backman, 2007; Charlifue & Gerhart, 2004; Johnston, Nissim, Wood, Hwang, & Tulsky, 2002; Kennedy, Lude, & Taylor, 2006; Kennedy et al., 2010; Krause, Saladin, & Adkins, 2009; Lund, Nordlund, Nygård, Lexell, & Bernspång, 2005; Lund, Nordlund, Bernspång, & Lexell, 2007; Lysack, Komanecky, Kabel, Cross, & Neufeld, 2007; Noreau, Fougeyrollas, & Boschen, 2002b; Perhouse et al., 2012; Roach, 2002; Schönherr, Groothoff, Mulder, & Eisma, 2005; Schopp et al., 2007; Whiteneck et al., 2004), five qualitative studies (Isaksson, Lexell, & Skar, 2007; Kuipers, Kendall, Amsters, Pershouse, & Schuurs, 2011; Price, Stephenson, Krantz, & Ward, 2011; Ripat & Woodgate, 2012; Van de Velde, Bracke, Van, Josephsson, & Vanderstraeten, 2010), and one mixed method study (Boschen, Tonack, & Gargaro, 2003).

Of the 23 studies included, 9 were undertaken in the USA, 4 in Canada, 3 in Sweden, 3 in the United Kingdom, 2 in Australia, one in the Netherlands and one in Belgium. There are differences between these countries in government health systems and policies, and aspects of the built and natural environment, but all of the studies included were from developed countries. Table 4 provides a summary of all the studies included in the review.

2.4.1 Methodological quality of quantitative studies.

The overall mean rating of the quantitative studies using the Critical Review Form – Quantitative Studies was 9.3 out of a possible 15. Individual study scores are provided in

Table 4. None of the studies reviewed were intervention studies or randomized control trials, but were cross-sectional surveys or questionnaires. In general the older articles received lower scores, due to lack of breadth in the literature review and discussion sections, and use of instruments developed prior to the ICF. Due to the convenience sampling methods used in most of the studies, those people who agreed to participate were likely to be a biased group. Issues such as literacy levels and whether or not potential participants were working would have likely influenced whether or not people agreed to participate in postal or telephone surveys. There were also differences in time since injury, and the gender mix of samples. The sample size ranged from 57 participants (Schonherr et al., 2005), to 2726 participants (Whiteneck et al., 2004).

Table 6 outlines the variety of instruments used to attempt to quantify social and community participation. Only one study utilized a participation measure specifically based on the participation domains as outlined by the ICF (Schopp et al., 2007), while three studies developed their own measures (Boschen et al., 2003; Kennedy et al., 2006; Carpenter et al., 2007).

Table 6 *Participation instruments used in quantitative studies*

Participation measure used	Number of studies measure was used in
Researcher designed	3
CHART	6
IPAQ	3
CHART-SF	1
CIQ	2
CIM	2
LIFE-H	2
Parts of CHART	2
PARTS/M	1
HQQ	1

Note: some studies used more than one measure
CHART: Craig Handicap Assessment and Reporting Technique
CIQ: Community Integration Questionnaire
IPA: Impact on Participation and Autonomy Questionnaire
CIM: Community Integration Measure
LIFE-H: Assessment of Life Habits
PARTS-M: Participation Survey/Mobility
CHART-SF: Craig Handicap Assessment and Reporting Technique-Short Form
HQQ: High Quadriplegia Questionnaire

2.4.2 Methodological quality of qualitative studies.

The overall mean rating of the qualitative studies using the Critical Review Form - Qualitative Studies Version 2 was 16.7 out of a possible 24. Individual study scores are provided in Table 5. There was lack of detail regarding the process of sample selection in some studies (Kuipers et al., 2011; Price et al., 2011) and limitations in procedural rigour in most of the studies. There was insufficient information regarding the methods of data analysis and audibility in two of the four studies (Kuipers; Price). The study by Ripat and Woodgate (2012) was the most methodologically sound. Method, data collection techniques and analysis were described in detail, and multiple methods were incorporated to maximise the overall rigour of the study.

2.4.3 Mixed method study.

One mixed method study was included (Boschen et al., 2003). This study was not rated using either of the above quality appraisal forms. Because the paper reported on a multi-phase study, there was limited detail regarding both the quantitative or qualitative aspects of the study. The reader was referred to another publication for detail regarding the qualitative methodology, but this publication was not available.

Table 7 *Summary of studies included in critical review*

Study	Mean Quality Score	Sample	Study design	Participation measures/questions used	Conceptual Model or Definition of Participation used in study	Overall participation findings for ICF Domains (*Interpersonal Interactions and Relationships; Major Life Areas; Community, Social and Civic life)*	Environmental factors of ICF as influences	Personal factors of ICF as influences
Boschen *et al.,* 2003. Long-term adjustment and community reintegration following spinal cord injury. Canada	Mixed methods - No score	*n* = 100 for quant phase of study *n* = 34 from first quantitative phase of study participated in focus groups. Male and female adults between 1 – 5 years post-discharge.	Mixed methods. Phase 1 – cross-sectional Phase 2 - Grounded theory.	Quantitative phase : LIFE-H (pre-ICF) MQE (pre ICF) Qualitative phase: Focus group discussions.	Community integration = individuals involved in community activities and social roles to the extent that they desire.	Sharp decline in number of people employed after SCI (36% post-injury compared to 90% employed pre-injury).	*Facilitator s* -Key support provider (could be family or friends or peer mentor) -Accessible housing -Personal transportation *Barriers* -Built environment -Low income and high cost of services -Winter conditions -Poor attitude of health professionals	Locus of control is crucial to subjective quality of life, productivity, status, satisfaction with performance of daily activities & satisfaction with community integration. Frustration with choice and control over important matters in their life. Chronic pain impeded daily activities.
Brown *et al.,* 2002 Participation by individuals with spinal cord injury in social and recreational activity outside the home. USA	8/15	*n* = 62 (Utilised data from a previous study of individuals with disabilities between 1993-1998. This study utilised data from the people with SCI, aged 18-65 years, and who were at least one year post injury. Matched with 219 non-disabled participants *n*= 219	Design : cross-sectional – interview	CIQ (pre-ICF) CHART (pre-ICF)	Discusses social and recreational activities outside the home. Does not offer a definition of social participation. Uses a combination of CHART and CIQ.	There was a statistical significance in the difference between the non-disabled group and SCI group in two areas. The non-disabled group were more active than the SCI sample in recreation and out-of-home leisure activity, but not in pure social activities such as visiting, socialising and opportunities to meet more people. Some individuals with SCI were relatively socially isolated, overall the differences between activity levels were relatively small across the groups.	Transportation was essential for the SCI group.	
Bushnik, 2002 Access to equipment, participation, and quality of life in aging individuals with high tetraplegia (C1-C4) USA	4/15	*n = 58* Total sample consisted of adults with high tetraplegia (C1-C4 injury levels), 49 males, 9 females.	Design: Longitudinal study, data collected at three phases- (1984-1985; 1992-1994; 1997-1999). Telephone or in-person interviews conducted.	HQQ (pre-ICF) Level of Free Time Activities Scale	Refers to Participation as used in ICIDH-2 – the effect of disability on the capacity of the individual to interact with the environment	Participation in leisure activities in the community was highest in the first time period at just over 17 times per month.	Hypothesis that increased access to equipment would increase participation was not supported. In phase 3 individuals with access to a modified van spent statistically significantly more hours out of the house compared to those who did not have a van (4.1 +/- 2.0 hours compared to 3.4 +/-2.0 hours per week).	Older individuals tended to participate in activities inside and outside the home, less than younger people.
Carpenter *et al.,* 2007.	9/15	*n* = 357 Participants were	Cross-sectional, Self-report, mail	Survey designed by researchers after completion of previous	Utilises ICF definition of participation, but focuses on community participation as	No limitations to participation experienced by 18.5%	Factors that supported participation in chosen activities were: help and support from	17% stated that pain limited their participation in physical activity

Community participation after spinal cord injury. Canada		aged between 17 – 98 years. 26% complete tetraplegia, 40% complete paraplegia; 30% incomplete lesions. Gender not identified.	survey	qualitative study. Combination of open ended and closed questions. Questions related to: employment; social activities; computer use, transportation; community access; physical activity; accessing information; home support services; relationships with others; access to professional services; life satisfaction.	including: social involvement; physical activity; relationship with others; influence of transportation on community access; facilitators and constraints to community participation.	56% used a gym or community facility for at least one physical activity	family members and friends (35%); transportation (22%); adapted and special equipment (20%). Activities and socialising with family and friends were cited nearly twice as much by the high life satisfaction groups.
Charlifue and Gerhart, 2004 Community integration in spinal cord injury of long duration. UK	11.5/15	*n* = 178 Participants were individuals ageing with an SCI who had been injured a minimum of 20 years, injured between the ages of 15 and 55 years and had undergone rehabilitation. 84.8% male; 33.1% complete tetraplegia, 46.1% complete paraplegia, 20.8% all other incomplete.	Design: longitudinal study. Participants were evaluated at three year intervals from 1990 – 1999. These results are from the fourth phase – data collected in 1999.	CHART (pre-ICF)	Utilises concept of community reintegration – defined as "extends beyond the person: it promotes his/her fullest inclusion and participation within the physical and psychosocial environment. However, uses CHART which is a measure of handicap.	There was a statistically significant decline in Physical Independence, Mobility, Occupation and total CHART scores over time There was an increase in Economic Self-Sufficiency scores CHART scores over time The change in Social Integration was not significant. In this study, the most compelling relationships were between the CHART scores on the Life Satisfaction Index, both as predictors and outcomes.	
Isaksson *et al.,* 2007 Social support provides motivation and ability to participate in occupation. Sweden	19.5/24	*n* = 13 (women) Purposive sampling, selection criteria, continued until saturation of data achieved.	Grounded theory analysis approach	Utilized in-depth interviews & fieldnotes. Three interviews performed by 1st author, in-depth interviews and fieldnotes written at end of each interview. Each of the 3 interviews had a different focus, which is described.	Participation in occupation, where occupation = everything people do to occupy themselves (self-care, leisure, productivity).		Social support is an important factor after sudden and major injury because it motivates the person to participate in occupation. Two types of social support needed – practical & emotional The importance of social support for a person's motivation & ability to participate expands our knowledge of the relationship between individuals, their social environments and their occupational participation.
Johnston *et al.,* 2002. Objective and	10.5/15	*n* = 126 Participants had	Design: Prospective longitudinal correlational study	CHART (pre-ICF) CIQ (pre-ICF)	Discusses in detail the concept of handicap used in the ICIDH and the newer term participation used in	The greatest increase in handicap scores occurred in occupation (CHART) and productivity (CIQ).	Ethnicity and marital status did not have statistically significant relationships to handicap.

subjective handicap following spinal cord injury: interrelationships and predictors. USA		suffered a traumatic SCI, aged between 14 – 83 years, and enrolled in the SCI Model System. Sample had over-representation of African-Americans and more severe neurologic injuries.			the ICF, however, they state that the terms “handicap” and “participation” denote very similar constructs. Notes that both handicap and participation assess broad activities or interactions between the person and environment, but do not assess the person’s feelings about those interactions.	Home integration (CIQ) was next followed by mobility/transport (CHART) and social integration (CIQ). Mean hours of work for pay per week pre-injury were 27.44, compared to one-year post-injury at 2.29. Days of the week out of home decreased from a Mean of 6.72 hours per week to 3.95 hours per week. Respondents were most typically most satisfied with their cognitive abilities and social integration. Economic self-sufficiency and employment were the lowest rated domains. Problems with love life and sexuality were repeatedly mentioned.		
Kennedy *et al.,* 2006. Quality of life, social participation, appraisals and coping post spinal cord injury: a review of four community samples. UK, Austria, Germany, Switzerland	8/15	Germany *n* = 171 UK *n* = 108 Austria *n* = 44 Switzerland *n* = 27 People with SCI identified from a database. Ratio of males to females 4:1. 48% had complete paraplegia, 9% incomplete paraplegia, 25% complete tetraplegia, 18% incomplete tetraplegia.	Design: cross-sectional with questionnaire.	CHART (pre-ICF) Researcher designed questionnaire to identify current needs in a variety of areas.	Social participation definition not made explicit, but refers to major components of social participation as: home and family roles and activities; other productive roles (work, school and volunteering); social networks; leisure activities; mobility; and economic self-sufficiency. Discusses use of CHART as most commonly used objective measure of handicap.	Across the whole sample, sexual activity had the lowest mean score (4.01, SD= 3.66), followed by employment (5.58, SD = 3.77) and pain relief (5.94, SD = 3.17) Participants from the UK indicated significantly less physical independence and social interaction but significantly greater economic self-sufficiency Generally participants were well integrated into the community, although less so in occupation and economic self-sufficiency	A residential SCI training centre with psychological support & psychotherapeutic care was seen as the treatment most likely to meet participants’ needs in 23% of responses, closely followed by a general health spa (22%) and home-based treatment & rehabilitation closely behind (20%).	
Kennedy *et al.,* 2010 A multi-centre study of the community needs of people with spinal cord injuries: the first 18 months	8/15	*n* = 80 or 81 – unclear from article, no where do they state exact sample size. Participants were recruited 3-18 months following discharge from one of the three	Design: Multi-centre, single cohort. Cross-sectional. Postal questionnaire.	CHART (pre-ICF) CHIEF-SF (pre-ICF) Open-ended questions	Uses terms societal participation, community participation, community integration and community needs interchangeably. However, uses CHART as an objective measure of participation.	Community needs were generally well-addressed Main areas of dissatisfaction were sexual, vocational, leisure and financial	Lack of resources that made transition to home most difficult were: adaptations (35%); equipment (27%); and poor access (19%) Overall impact of environmental barriers was low, with highest barriers reported to be physical environment and transportation.	Women had higher anxiety scores than men but overall the sample was generally well-adjusted 17.3% of sample identified pain as a significant disruption

UK		centres, aged 18 years or above.						
Krause *et al.,* 2009 Disparities in subjective well-being, participation, and health after spinal cord injury: A 6-year longitudinal study USA	11.5/15	*n* = 475 at baseline, *n* = 250 at follow-up Participants were adults with traumatic SCI of at least one year duration from three different Model SCI centres in USA. Stratified sampling procedure used – resulted in 24.8 % Caucasians; 24.4% African-Americans; 28.4% Hispanics and 22.4% American-Indians. Overall 43.1% were women.	Design: Longitudinal study (one at baseline, then sent another questionnaire six years later). Stratified sampling was used to maximise inclusion of women and racial-ethnic minorities. First interview conducted at the SCI centre, six years later recontacted and sent materials and interviewed.	Three items from the CHART (a) daily hours out of bed (b)times leaving home per week (c)number of nights spent away from home during previous year	Does not specifically define participation, but uses sections of the CHART as outcome measure for participation.			Caucasians and African-Americans reported significantly higher engagement scores than either the Hispanics or American-Indians. Caucasians reported significantly higher career development scores than either the Hispanics or American-Indians. African-Americans reported significantly higher career development scores than Hispanics. Caucasians reported significantly more hours out of bed per day (13.6) than either African-American (11.5) or Hispanic (11.3) participants. There were no differences in gender outcomes. There was no tendency for disparities too increase overtime as a function of either race-ethnicity or gender.
Kuipers *et al.,* 2011 Descriptions of community by people with spinal cord injuries: concepts to infroma community integration and community rehabilitation. Australia	11/24	*n* =269 (people with traumatic SCI aged between 15-55 years at the time of injury) Part of larger study	Telephone interview of participants taking part in a prospective, longitudinal study examining the outcomes across the lifespan for people with SCI	Participants were asked to describe the community in which they live with a view to identifying patterns across those qualitative responses	Investigation of concept of community integration following SCI. Concluded there were differing perspectives of what a “community” is.	Diversity of responses suggested participation in community at all sorts of levels. Three dimensions identified: social integration; occupation; independent living. Concludes that participation in the community is a more suitable term than community integration. Authors acknowledge that they have presented qualitative data in a quantitative way and identify the limitations of the question they asked participants.	Importance of family & friendships, peer support & self-help groups. Importance of advocacy & policy change to address environmental, transport, & independence issues.	Those who described their community in terms of physical space and access expressed a relatively greater proportion of negative views than those who described it in terms of social and relational descriptors
Lund *et al.,* 2005 Perceptions of participation and predictors of perceived problems with participation in	10/15	*n*=161 People with SCI admitted to a specialized SCI rehabilitation centre in Southern	Design : cross-sectional, postal questionnaire	IPAQ (pre-ICF)	Uses ICF definition of participation.	57% reported one or several severe problems in different aspects of participation. Areas rated as having greatest problems with participation: work; family role; going on holidays;	Access to social support was the most important variable predicting perceived severe problems with participation.	Persons with tetraplegia had a greater risk to perceive severe problems with participation compared to those with paraplegia except for problems with social relations.

persons with spinal cord injury. Sweden		Sweden between1993 - 2001				intimate relationships.		Single persons had a greater risk to perceive severe problems with participation than married or cohabiting persons, except for problems with education.
Lund *et al.,* 2007 Perceived participation and problems in participation are determinants of life satisfaction in people with spinal cord injury. Sweden	10.5/15	*n* = 157 People with SCI admitted to a specialized SCI rehabilitation centre in Southern Sweden between1993 – 2001. Same cohort as above.	Design : cross-sectional, postal questionnaires.	IPAQ (pre-ICF)	Stated purpose of study to determine relationship between perceived participation and problem with participation in people with SCI, but use a measure developed prior to the ICF.	ADL and sexual life were the areas that were reported to have the lowest levels of satisfaction. 43% of respondents reported no severe problems with participation; 26% reported 1-2 severe problems with participation; 19% reported 3-4 severe problems with participation; 12% reported 5-8 problems with participation. Perceived participation and problems with participation considered to be strong determinants of life satisfaction.		
Lysack *et al.,* 2007 Environmental factors and their role in community integration after spinal cord injury. USA	9/15	*n* = 136 Medical diagnosis of traumatic SCI; African American or white male or female; aged 18-70 years; self-reported current wheelchair use. 38% of sample were women, and 41% were African-American.	Design: cross-sectional using standardized instruments and in-depth qualitative interviews	CHIEF-SF (pre-ICF) CIM (pre-ICF)	Discusses ICF concept of participation and limitations of the CHART in relation to it. Utilises perceived community integration as a proxy for participation.	The sample rated their community integration quite highly. The CIM items with the lowest mean scores were: there are fun things I can do in my free time", "I have something useful to do" and "I like where I am living now". Perception of fewer barriers was associated with greater integration (statistically significant). Qualitative data not reported here.	The top five environmental factors in descending order were: the natural environment, government policies, transportation, availability of health care services, and attitudes at home.	None of the socio-demographic variables (age, gender, ethnicity, marital status, current work status or residential locale) or injury variables (injury type, time since injury, injury cause) were significantly associated with the CHIEF-SF in this sample.
Noreau *et al.,* 2002b Perceived influence of the environment on social participation among individuals with spinal cord injury. Canada	9.5/15	*n* = 482 Participants were adults with a traumatic SCI who returned a mailed survey. Ages ranged from 30 – 55 years. 81.1% males, and 18.9% females.	Design: cross-sectional, mailed survey.	LIFE-H (pre-ICF) MQE (pre-ICF)	Definition not specifically outlined, but refers to Social Participation as conceptualised in the Disability Creation process Model and the LIFE-H (daily activities and social roles)		*Facilitators* Attitudes and support from family, friends or colleagues were reported as the main facilitators (reported by 60 – 73% of sample) Use of assistive devices, electronic technologies, access to community health services, disability insurance programs were all seen as important contributors to social participation *Barriers* Physical environment, winter climate, poor availability of jobs, inaccessibility of friends' houses, and time taken to complete tasks	Assistive devices as facilitators different for women than men. As time since injury increases the perceived influence of most environmental factors remained largely unchanged.

							Barriers varied in the degree and conflicted with some who saw these aspects as positive.	
Perhouse *et al.,* 2012. Investigating changes in quality of life and function along the lifespan for people with spinal cord injury. Australia	10.5/15	*n* = 270 Participants had sustained a traumatic SCI over the previous 60 years, between the ages of 15 and 55 years.	A wave panel design in which data were collected annually over five years (2004 – 2008) across 6 strata that represented different periods post injury (less than 5 years since injury; 5-9 years; 10-14 years; 15-19 years; 20 – 24 years, over 25 years since injury). Telephone interviews were conducted in people's homes.	CIM (pre-ICF) IPAQ (pre-ICF)	Utilises ICF definition of participation. Uses measures based on handicap (IPAQ) and community integration (CIM).	The participation component as measured by the CIM showed an increase with time since injury, but not when adjusted for ASIAIS (American Spinal Injury Association Impairment Scale), income, and social situation (living alone). No time-since injury trend for the IPAQ. There was no time-since-injury trend for the IPAQ.		
Price *et al.,* 2011. Beyond my front door: the occupational and social participation of adults with spinal cord injury. USA	12.5/24	*n* = 11 Individuals living in the community 1 to 5 years after spinal cord injury	Longitudinal study using qualitative methods Open-ended semi-structured interviews Inductive thematic and narrative data analysis methods	Questions were: How satisfied are you with your daily life? What is your definition of a good life, and where do you think your life falls on a continuum of this? How important is it to you to be able to participate in meaningful activities? What social activities do you participate in, and what roles and responsibilities do you have in the group? What aspects of your therapy were most useful in helping you resume your life? What are you looking forward to in the future?	Occupational and social participation = "the ability to choose and move freely in one's environment and do what one wants and needs to do"	Overarching theme of adaptation Challenging and shocking for participants when leave the supportive environment of the rehabilitation centre Had to deal with stigma of notions of disability	*Barriers* Inaccessibility to others' homes Managing social attitudes *Facilitators* OTs as social partners facilitated social participation Peer mentoring helped see a future Involving family and friends was important Social and occupational participation significantly related to life satisfaction	Tension between wanting to hide and wanting to rejoin the social world.
Roach, 2002 Community social structure as an indicator of social integration and its effect on quality of life for persons with a spinal cord injury.	8.5/15	*n* = 139 Participants had suffered a traumatic SCI between June 1995 – Sept 2000, and were at least 2 years post-injury. 75% males, 25% females.	Design: cross-sectional. Data collected via structured face-to-face and telephone interviews, either at outpatient clinic or over the phone.	Three measures of community participation were constructed relating to different layers of human relationships (outer, middle and inner). Each measure was created using two items from the CHART.	Uses a sociological approach to the definition of community integration. Community structure is defined in terms of participation in community organisations, that is, involvement in social networks, and involvement in intimate relationships.	More participation in the community resulted in higher levels of satisfaction with life. These aspects of community structure explained 23% of the variance in satisfaction with life.	Not known from this analysis how community-level characteristics affect community participation, but authors suggest this is a major area for future research.	

USA Ripat and Woodgate, 2012 Self-perceived participation among adults with spinal cord injury: a grounded theory study. Canada	/24	*n = 19* Participants were adults with SCI. 13 males, 6 females, age range between 20 – 60+ years.	Design: Constructivist grounded theory study. Individual in-depth interviews, photovoice, focus groups.	Three methods of data collection: 1.in-depth individual interviews 2.photovoice to capture insider perspective on meaning and influences on participation 3.focus groups	Purpose of study was to develop theory related to participation experiences of adults with SCI	Participation was described in four ways: Inclusion; opportunity for reciprocity; accomplishment; autonomy. Participants did not define participation by type, or amount of engagement in activities, but sought ways to satisfy their participation needs of accomplishment, autonomy, opportunity for reciprocity, and inclusion through the use of strategies.	Assistive technology and adaptions were used to negotiate the body-environment interface. Assistive technology for leisure was emphasised. Having a vehicle allowed for independence and convenience. The importance of family for emotional and physical support. Accessible environments supported engagement. Individuals actively interacted within their environment to develop a sense of identity, establish meaning & engage in a process of participation.	Strategies used: Use of assertiveness with other people. Gathering information required for decision making.
Schonner *et al.,* 2005. Participation and satisfaction after spinal cord injury: results of a vocational and leisure outcome study. Netherlands	8/15	*n*=57 People who had suffered traumatic SCI (aged 18-60 years) between 1990-1998, and living in the community. Divided the participants into four sub-groups for analysis: A:full-time workers B: part-time workers C:non-workers with high participation D: non-workers with poor participation	Design : survey – descriptive analysis of a questionnaire	Dutch version of the CHART (pre-ICF) Parts of a questionnaire developed by the Netherlands Organisation for Applied Scientific Research as part of the Vocational Handicap research Programme.	Defines participation as reintegration into vocational and leisure activities.	Hours spent in paid work decreased more than 20 hours per week Total vocational & leisure participation of the group was reduced by 40%. Significantly more time was spent on self-care activities (from 30 minutes per day to a mean of 70 minutes per day) At time of injury 86% had a job, of this group 67% were successful in in returning to paid work. 72% reported loss of hobbies. About half found new hobbies. 21% were currently in active sports compared with 60% pre-injury People in sub-group C compensated for their lost working hours with one or more specific other activities, e.g. involvement in housekeeping, leisure or voluntary work. People in sub-group D lost participation in all activities and were active for 16 hours per week compared to 60 hours pre-injury.	25% of respondents reported wanting more contact with reintegration professionals, and half of them wanted more support from the rehabilitation team	

Schopp *et al.,* 2007. Life activities among individuals with spinal cord injury living in the community: Perceived choice and perceived barriers. USA	10.5/15	*n* = 255 Multiple and purposive sampling methods Archival data were examined from three databases maintained by SCI Model System Programs (USA) between November 1999 – August 2003	Design: exploratory & inferential Survey data were collected from one Model System through telephone interviews (n=75), & the other two sites conducted mail surveys & in-person interviews	PARTS/M (post-ICF)	Uses ICF definition of participation.	Choice – participants reported little or no choice with meeting needs related to: employment (53%); working inside the home (44%); bladder care (40%); leaving the home (33%). Satisfaction – 60% of respondents were dissatisfied or only somewhat satisfied with their level of choice in participating in employment.	Participants reported needing a "moderate" or "a great deal" of assistance for working inside the home (62%). 37% reported needing at least moderate amount of help to leave home. Poor transportation, limited physical accessibility were among barriers to employment.	Pain was identified as a barrier to employment (21%), working inside the home (18%) and leaving the home (17%). Fatigue was reported as a barrier to employment (15%), working inside the home (11%), and leaving the home (11%).
Van de Velde *et al.,* 2010. Perceived participation, experiences from persons with spinal cord injury in their transition period from hospital to home Belgium – not entirely clear	21.5/24	*n*=11 Theoretical sampling method used. Participants were recently discharged from rehabilitation & transitioning home	Grounded theory using individual in-depth interviews	Questions were: i) what maximizes your level of involvement in your actual life and how do you experience this involvement? (ii) What exactly determines whether this involvement is perceived as important and/or satisfactory? (iii) What is the impact of your Injury? (iv) how can your personal objectives maximize involvement in your life situation?	Aim is to add to the existing body of knowledge of participation as described in the ICF.	Three categories of participation found – occupational participation, social participation & socio-occupational participation. Participation is not experienced as an objective of performing activities within a societal context, or as frequencies of activities performed Concept of autonomy is central. Participation can be seen as the dyad between individual's social interactions and specific activities performed		
Whiteneck *et al*., 2004 Environmental factors and their role in participation and life satisfaction after spinal cord injury. USA	11.5/15	*n*= 2726 Follow up of people between 2000-2002 from 16 Model Spinal Cord Injury Systems	Design: Cross-sectional, follow-up survey.	*Environmental factors (CHIEF-SF) (pre-ICF) *Societal participation (CHART-SF) (pre-ICF)	Discusses societal participation and that environmental factors will influence disability outcomes. Uses measures based on handicap.		The top 5 environmental barriers were in descending order of importance: natural environment; transportation; need for help in the home; availability of healthcare; governmental policies	People with higher level injuries were more likely to report lower participation. People injured by violence or falls also had higher probabilities of having lower participation. The groups that reported more environmental barriers were middle-aged participants, women, minorities and those not married at the time of the injury, those injured more recently, those with higher levels of injury and those with greater activity limitations.

Key – Participation and Environmental Measures Used
LIFE-H: Assessment of Life Habits
MQE: Measure of the Quality of the Environment
PARTS-M: Participation Survey/Mobility
CHART-SF: Craig Handicap Assessment and Reporting Technique-Short Form
HQQ: High Quadriplegia Questionnaire
CIM: Community Integration Measure
CHIEF: Craig Hospital Inventory of Environmental Factors
CHIEF-SF: Craig Hospital Inventory of Environmental Factors-Short Form
CHART: Craig Handicap Assessment and Reporting Technique
CIQ: Community Integration Questionnaire
IPAQ: Impact on Participation and Autonomy Questionnaire

2.5 Discussion

2.5.1 Overall findings regarding social and community participation.

There was a large variation in how the terms participation, social participation and community participation were conceptualized in the quantitative studies. Although most authors referred to participation as outlined in the ICF, most of the instruments selected for use were developed based on the previous model, the ICIDH, which utilized the concept of handicap (Lund et al., 2005; Kennedy et al., 2006; Krause et al., 2009; Perhouse et al., 2012). While one author acknowledged this limitation (Lysack et al., 2007), others used terminology interchangeably without clarification of the differences between the terms (Johnston et al., 2002; Kennedy et al., 2010). Community integration was also used to describe participation (Roach, 2002; Charlifue and Gerhart, 2004; Lysack, et al., 2007). However, community integration is a term more commonly used in the brain injury literature and, it could be argued, that it has a broader meaning which includes issues relating to deinstitutionalization and independent living (Minnes et al., 2003).

The Craig Handicap Assessment and Reporting Technique (CHART) was the most frequently used instrument in the quantitative studies. The CHART attempts to quantify handicap by measuring hours of care provided per day, or by hours spent in certain activities (Whiteneck, Charlifue, Gerhart, Overholster, & Richardson, 1992). The CHART was developed based on the ICIDH, and therefore does not have good fit with the ICF concept of participation, or with social and community participation as defined for this review. The variation in, and inappropriateness of the instruments in relation to more recent concepts of social participation, makes it difficult to compare the studies to one another, and highlights the need for new ways of investigating

social and community participation. In the studies that attempted to quantify participation, it was found that there was a less than optimal level of participation (Lund et al., 2005; Schönherr, Groothoff, Mulder, & Eisma, 2005). In one study 57% of respondents reported one or several severe problems in different aspects of participation (Lund), while changes in the type of activities and roles were found, including significantly more time being spent on self-care and less time on work or study (Charlifue et al., 2004; Schonherr et al., 2005).

The importance of understanding participation through the lens of the person with SCI rather than that of society was highlighted in the qualitative studies (Van de Velde et al., 2010; Kuipers et al., 2011; Ripat and Woodgate, 2012). In the study by Van de Velde and colleagues (2010), participants described three different types of participation – occupational participation, social participation and socio occupational participation. In addition, participation was not described by the type, or amount of engagement in activities, but rather as a process to develop a sense of identity and establish meaning (Ripat and Woodgate). The qualitative studies highlighted that hours per day spent in an activity does not reflect the meaning, quality of participation or level of engagement in the activity.

2.5.2 ICF Participation Domains.

Interpersonal Interactions and Relationships (family relationships; intimate relationships; sexual relationships)

The importance of family relationships was highlighted in four qualitative studies (Isaksson et al., 2007; Kuipers et al., 2011; Price et al., 2011; Ripat and Woodgate, 2012) and in one quantitative study that explored this aspect (Noreau et al., 2002b).

Social support was identified as an important factor after sudden and major injury because it motivated the person to participate in occupation (Isaksson et al., 2007), while both emotional and practical support were seen as important (Ripat and Woodgate). In the quantitative studies, respondents gave a high rating of satisfaction with their social relationships (Johnston et al., 2002; Schönherr, Groothoff, Mulder, & Eisma, 2005). Consistently problems with participation in satisfactory sexual activity were reported (Johnston et al., 2002; Kennedy et al., 2006; Krause et al., 2009). Sexual activity was the most reported unmet need in one European sample (Kennedy et al), while problems with love life and sexuality were repeatedly mentioned by participants in another study, even though this study did not specifically aim to evaluate or quantify this particular area of function (Johnston et al).

Major Life Areas (school education; higher education; remunerative employment; economic self-sufficiency).

Lack of ability to engage in a satisfactory level of employment was a consistent finding in all the studies that investigated this component (Johnston et al., 2002; Noreau et al., 2002; Kennedy et al., 2010; Schönherr, Groothoff, Mulder, & Eisma, 2005; Schopp et al., 2007). One study found “I have something useful to do” was one of the lowest scoring items on the CIM (Lysack et al., 2007), while in another work and education was one of the highest rated problem areas, in particular difficulty getting a job and doing work the way one wants (Lund et al., 2005).

Community, Social and Civic Life (recreation and leisure - physical fitness activities included in this domain; religion and spirituality; human rights).

Most studies found that participation in the areas of community, social and civic life altered following the SCI. Although some participants were able to replace previous hobbies with new ones (Schönherr, Groothoff, Mulder, & Eisma, 2005), many people with SCI were socially isolated (Brown et al., 2002). “There are fun things to do in my free time” was one of the two lowest scoring items on the CIM in one study (Lysack et al., 2007). The ability to go on trips and holidays, and the ability to participate in sports or games and attend recreational events were significantly disrupted (Lund et al., 2005). The tension between wanting to hide and wanting to rejoin the social world, and the need to manage social attitudes towards disability, was reflected on by some participants (Price et al., 2011).

2.5.3 Factors that influence social and community participation.

Factors were considered as either barriers or facilitators to participation depending on which instruments were utilized (Whiteneck et al., 2004), what questions the participants were asked (Noreau et al., 2002b), and how people described their community (Kuipers et al., 2011). How people with SCI perceive participation and what aspects of social and community participation are important to them will influence how they answer questions regarding their level of satisfaction with it (Isaksson et al., 2007). In general, it was hypothesized that researcher perceived barriers such as lack of transport, or inaccessible built environments would decrease community participation but this was not always found to be the case. A statistically significant relationship was found between fewer barriers and increased community

integration in one study (Lysack et al., 2007), but in another, environmental factors were more strongly related to life satisfaction than to societal participation (Whiteneck et al).

Environmental factors as defined by ICF (products and technology; natural environment; built environment; support and relationships; attitudes; services, systems and policies).

Transport.

Problems with transport was consistently cited by people with SCI as a major impediment to their ability to fully participate in community life (Brown et al., 2002; Bushnik, 2002; Boschen et al., 2003; Whiteneck et al., 2004; Carpenter et al., 2007; Lysack et al., 2007; Schopp et al., 2007; Kennedy et al., 2010). Being able to access appropriate transport is necessary if people with limited mobility are to get to work or other social and recreational activities. While one study found a positive relationship between owning a modified van and getting out of the house more often (Bushnik, 2002), none of the studies that used only a published instrument were able to outline specifically which aspects of transport cause people with SCI difficulties, due to lack of detail in the design of the questionnaires or instruments. Use of open-ended questions identified that appropriate public transport and the ability of people to drive their own car, were facilitators to participation in the community (Carpenter et al.). If the person with an SCI had a car, access was facilitated by available disabled parking spaces, and fully serviced petrol stations (Carpenter et al.).

Natural and built environment.

The findings in relation to the built and natural environment, varied depending on the country and region that the study was conducted in, due to differences in weather conditions, and social policy regarding accessible buildings. One study found that the built environment was in the top five barriers to participation (Carpenter et al., 2007), while two other studies found that inability to access other people's homes was a barrier to social participation (Boschen et al., 2003; Price et al., 2011). Three studies found that the natural environment was a barrier to participation (Whiteneck et al., 2004; Price et al., 2011; Perhouse et al., 2012). Two of these studies utilised the Craig Hospital Inventory of Environmental Factors (CHIEF) as their measure of environmental barriers. Conversely, accessible environments were reported to support engagement in important and meaningful activities (Ripat and Woodgate, 2012).

Help in the home.

Findings in this area were difficult to interpret in those studies that used the CHIEF as a measure of environmental influences. The CHIEF does not differentiate between the type of help the person is lacking, that is, whether they lack paid help (e.g. personal carers) or family help. There was only one study to specifically include paid carers (PAS) as part of their investigation (Schopp et al., 2007). This study found that persons with SCI, who were dependent on a wheelchair or other mobility device, reported needing substantial personal assistance to have adequate participation in major life activities, particularly working inside the home and employment. Another study that utilized the CHIEF, found that "attitudes at home" was in the top five barriers to participation reported (Lysack et al., 2007). How

“attitudes at home” is understood by the participants is not known. Attitudes at home may refer to family members’ attitudes, or it could refer to personal care assistants’ attitudes. The difference between these two interpretations has implications in terms of healthcare service planning.

Social support.

It was clearly identified in the qualitative studies that social support was an important facilitator to assist people to re-engage in social and community based activities. Emotional support could be provided through a key support person such as a family member, friend or peer mentor (Boschen et al., 2003; Carpenter et al., 2007; Isaksson et al., 2007; Price et al., 2011). Practical support was particularly critical for community participation (Ripat and Woodgate, 2012), and the timing of both emotional and practical support was important (Isaksson et al). Most support was needed early on after discharge, while a more reciprocal relationship was needed later in the community integration process (Isaksson et al). Husbands/partners and children were the most important providers of support (Isaksson et al). Few outcomes were reported in the quantitative studies in the area of social support, although it was found that the more contact people had with family and friends, the higher the level of life satisfaction (Roach, 2002). A pet or service animal was also reported to be a great support (Carpenter et al.).

Healthcare services.

Availability of healthcare and government policies were both placed in the top five barriers to participation in two studies (Whiteneck et al., 2004; Lysack et al., 2007). Overall there was a general lack of satisfaction with health professionals and the

rehabilitation process. Respondents felt unprepared for discharge, that poor attitude of health professionals could limit choice and control (Boschen et al., 2003), and that there was insufficient support from reintegration professionals (Schonner et al., 2005). There were positives however, as identified in one study that found that occupational therapists used strategies to counteract social isolation and encourage community participation. These strategies included therapists acting as social partners, doing tasks in the community “with” the participants prior to discharge, and solving problems with the client to help remove barriers to participation (Price et al., 2011).

Products and technology.

Technology, adaptations and equipment were found to serve as both barriers and facilitators. Adapted or special equipment for access was an important facilitator for 20% of respondents in one study (Carpenter et al., 2007), while in another study adaptations (35%) and equipment (27%) were the highest reported barriers to transitioning home (Kennedy et al., 2010).

Personal factors as defined by the ICF (gender, age, psychological characteristics).

Factors such as gender, age, cultural background, injury type and secondary health conditions were found to impact on the type and quality of participation in those studies that investigated these components (Bushnik, 2002; Noreau et al., 2002b; Whiteneck et al., 2004; Krause et al., 2009). This is consistent with the ICF (World Health Organization, 2001), which highlights how the interaction between person factors and the environment influence participation. People with higher level injuries

were more likely to report lower participation, while people injured by violence or falls also reported lower participation (Whiteneck et al). In one study Caucasians reported significantly higher participation engagement scores than either Hispanics or American-Indians (Krause et al., 2009), while another found that minorities reported more barriers (Whiteneck et al). There were mixed findings with regard to gender differences, in relation to identification of barriers to community participation (Noreau et al; Whiteneck et al). While there were significant changes to secondary conditions over time, participation and quality of life remained stable (Perhouse et al., 2012). Personal characteristics such as locus of control were found to influence participation (Boschen et al., 2003), while having a feeling of being back in control was important in experiencing participation (Van de Velde et al., 2010). The most significant finding relating to person factors was pain (Boschen et al., 2003; Kennedy et al., 2006; Carpenter et al., 2007; Schopp et al., 2007; Kennedy et al., 2010). Problems with pain was the third most highly reported unmet need in one European sample (Kennedy et al., 2006), while it was reported as a barrier to employment and to leaving the home in a number of studies (Boschen et al; Carpenter et al; Schopp et al).

2.6 Conclusions

The quantitative studies included in this review were cross-sectional surveys or questionnaires with no intervention studies or randomized control trials located. There was lack of breadth in the literature review and discussion sections of some papers, and most of the samples were relatively small. In addition sample bias was noted as a limitation in many of the studies. The use of instruments that were developed before the ICF contributed to confusion regarding the terms participation,

social participation and community participation, which were often used interchangeably, with no clarification of the meaning. These limitations resulted in the studies receiving low quality scores, and impacts on the ability to apply the findings to clinical settings.

The overall quality of the qualitative studies was also low. This was due to limited detail regarding the process of sample selection, limitations in procedural rigour, and insufficient information regarding the methods of data analysis and audibility used. However, taking these limitations into account, the inclusion of qualitative studies in this review has highlighted some important differences between the perspectives of those living with SCI and the findings of studies using predetermined factors attempting to “measure” participation. In particular participation was not described by people living with SCI by the type, or amount of engagement in activities, but rather as a process to develop a sense of identity and establish meaning.

Factors that were identified in the studies as facilitating participation included having adequate personal care assistance, having appropriate social support – particularly a key support provider, having adequate specialized equipment and appropriate occupational therapy input. Among the barriers identified were problems with transport, inaccessibility of the natural and built environment, issues with healthcare services and rehabilitation providers, and pain. While this information provides preliminary valuable information to clinicians and policy makers, more evidence from the perspective of those living with SCI is needed.

It is recommended that further research into social and community participation following SCI utilizing in-depth exploratory approaches is conducted. In particular, more detailed information regarding environmental barriers and facilitators, and personal characteristics such as coping strategies is needed. Further investigation into what aspects of social and community participation are important to those living with SCI is also necessary. This will enable client focussed and community based solutions and interventions to be identified and developed, which are aimed at promoting and creating opportunities for social and community participation.

2.7 Impact of the Study

Journal metrics:

Journal Impact Factor:	1.25
Journal rank:	40 of 65 Rehabilitation (Science)
	31 of 71 Rehabilitation (Social Sciences)

2.8 Chapter Summary

The conclusion of the published critical review was that the quantitative and qualitative studies conducted in the field of social and communication participation following SCI were of low methodological quality. The results of the published quantitative studies and the findings of the qualitative studies differ, highlighting the need to gain more evidence from the perspective of those living with SCI to inform understanding in this complex area. Utilising in-depth exploratory approaches will enable potential interventions to be identified that address barriers to social and community participation.

Chapter Three

Methodology

Chapter One provided the background to the study and described how the thesis is structured. It was established that following an SCI people's physical and mental health can be affected, with a resulting impact on their activities, roles, social and community participation. A link between social and community participation and QOL was identified, and it was highlighted that people with disabilities want to be able to participate equally in society. Chapter Two presented a published critical literature review of the available evidence on social and community participation following SCI, and the factors that influence satisfactory participation. The conclusion from this critical review was that the existing literature is of low methodological quality, and that quantitative studies do not provide understanding of the complexity of what influences social and community participation, or what is of importance to people with SCI.

3.1 Rationale for Selection of Research Design

People with SCI have expressed frustration that the current focus of research is predominantly on impairments and activity limitations, such as self-care and mobility, and causes of secondary health problems such as pressure sores (Barker et al., 2009; Hammell, 2010). In order for research efforts to inform better care and enhance the QOL of those living with SCI, it is critical that their perspectives are explored and taken into account (Hammell). Exploration of the value and meaning of social and community participation and further understanding of the barriers and facilitators to participation for people living with SCI will provide critical information to clinicians who work with people with SCI, will inform the design of quantitative

studies, and will inform the policy that influences the environment in which people with SCI participate. Qualitative methodology was considered the most appropriate way to address the research aim and questions.

3.2 Aim

The aim of the study was to explore the experience, influences, meaning and importance of social and community participation for adults living with an acquired spinal cord injury (SCI) in Victoria.

3.3 Research Questions

3.3.1 Overarching research question.

How do people living with acquired spinal cord injury (SCI) experience social and community participation, and what are the meanings of and influences on that participation?

3.3.2 Subsidiary research questions.

1. What is the experience of social and community participation for people living with an acquired SCI?
2. How important is social and community participation from the perspective of people living with an acquired SCI?
3. What are the meanings associated with social and community participation for people living with an acquired SCI?
4. What are the facilitators and barriers to social and community participation following traumatic SCI?

5. What are the facilitators and barriers to social and community participation following non-traumatic SCI?
6. Are there differences in the social and community participation of those with non-traumatically acquired SCI compared to those with traumatically acquired SCI?

3.4 Research Design

In 1982, as part of the postpositivist movement, Guba and Lincoln published a seminal article proposing a new paradigm that opposes rationalism (positivism), that is, naturalistic inquiry (Guba & Lincoln, 1982). In this article they described the advantages of naturalistic inquiry over other paradigms. One advantage was the inclusion of a contextual relevance and richness unmatched by other paradigms. There is sensitivity to the process, and theory is grounded in the data (not searching for data to fit a theory). Finally, they argued, research results using methods that align with this paradigm, will yield findings that can be more readily translated into practice. In later writings, Guba and Lincoln replace the term naturalistic inquiry with constructivism (Guba & Lincoln, 1994; Lincoln, Lynham & Guba, 2011).

In constructivism, realities are understood in the form of multiple, intangible mental constructions, socially and experientially based, and local and specific in nature (Creswell, 2013; Guba & Lincoln, 1994). In terms of epistemology, the researcher and the researched are assumed to be interactively linked, so that knowledge is created by interaction between the researcher and the participants. Methodology consists of techniques to elicit individual constructions through interaction between the researcher and the participants, for example the qualitative methods of

interviews and focus groups (Braun & Clarke, 2013; Creswell; Guba & Lincoln, 1994).

Qualitative research is appropriate to use when a problem or issue needs to be explored (Creswell, 2013). Rationales for conducting research have led to different emphases when engaged in qualitative inquiry (Patton, 2015). Various qualitative methodologies were considered for this study. A grounded theory approach is taken if the primary aim is theory development. If the question relates to the culture of a group of people, then an ethnographic approach would be used (Patton). However, if practical and useful answers to solving concrete problems are sought (as was the case for this study) then a pragmatic approach may be appropriate (Patton). Pragmatism informs qualitative inquiry by investigating practical questions in search of useful and actionable answers, and secondly by making pragmatic decisions while conducting the inquiry based on real-world constraints of limited time and resources (Patton). A pragmatic approach can be used to address practical and concrete questions without the need to strictly adhere to any single epistemological perspective. As the aim of the study was to explore the realities of social and community participation that are constructed by those living with a SCI, a pragmatic qualitative design, underpinned by the constructivist paradigm was selected. A generic qualitative inquiry approach was considered appropriate and the most practical (Patton). Smith, Bekker and Cheater (2008) argue that a generic qualitative approach is suitable for understanding the perspectives of health users, which can inform policy.

In designing this study, specific characteristics of qualitative research as outlined by Creswell (2013) were incorporated. The research was conducted in the participants' natural setting, which in this case were the participants' homes and workplaces. The researcher was the key instrument, as data were primarily collected by interviewing participants using semi-structured, open-ended questioning. Development of the semi-structured interview guide resulted from review of the literature, and identification of gaps in understanding in this area. In particular, more detailed information from those living with SCI regarding their experience of social and community participation, and what aspects were important to them was sought (see Interview Guide – Appendix F).

Patterns, categories and themes were built from the "bottom up", which involved an inductive process, working back and forth between themes and the data until a comprehensive set of themes was developed. This is also known as the constant comparative method (Creswell, 2013), and will be elaborated on in 3.8.

Multiple forms of data are typically collected by researchers in qualitative studies (Creswell, 2013). In this study in addition to semi-structured in-depth interviewing, field notes were kept. This is also known as triangulation of data resources (Curtin Fossey, 2007) and is expanded on in 3.9.2.

An important design component outlined by Creswell (2013) utilised in this study was the use of emergent or evolving design. Emergent design occurs when the initial plan for the research changes or shifts after data collection begins, questions may change, or the people studied may be modified during the process of conducting the

research, as occurred in this study. After 17 people with traumatic SCI had been interviewed, and their data analysed, data saturation was occurring within that group. However, a different group, those with non-traumatically acquired SCI were also responding to advertisements. Initial data analysis of their interviews indicated some differing issues being raised from the participants with TCSI. Simultaneously, further review of the literature identified very little research regarding the outcomes of people with NSTCI, and no research about their social and community participation. Therefore, after discussion with supervisors the decision was made to recruit and interview people with NTSCI. The research questions were altered and added to accordingly (addition of Research Questions five and six). Further information regarding the purposive sampling approach taken is included in 3.6.

In a qualitative study, researchers convey their background and how it informs their interpretation of the information in the study (Creswell, 2013). As an experienced clinician, I came to the research with considerable awareness of the inadequacies of the current rehabilitation, and disability service systems. In addition, as an occupational therapist, I was influenced by the theoretical models, and associated values that underpin my profession, that is, that there is an underlying link between participation in meaningful occupation (in this case social and community based occupations) and health and well-being (Law, 2002). In Chapter One, two theoretical models, the ICF and the CMOP-E, were outlined. These models provided a theoretical foundation for guiding the research questions that have been proposed. In these models, participation in occupations in society is seen as the result of the interaction between the person's characteristics and his or her environment (Noreau, Fougeyrollas, & Boschen, 2002a; Townsend & Polatajko, 2007). In addition, the core

value of client-centredness which is integral to the CMOP-E and occupational therapy practice, informed this research (Kielhofner, 2009).

One of the ways I addressed the biases and assumptions that I bought to the research, was by keeping a reflective journal during data collection and analysis. The journal was used to report and reflect on the process and progress of the research (Braun & Clarke, 2013). Analytic insights that occurred during data collection were recorded, in addition to emotional aspects of the research journey, for example frustrations and successes, and emotional responses to client interviews (Braun & Clarke). In addition, during peer debriefing sessions, my supervisors often challenged my assumptions, and encouraged me to consider alternative ways of viewing and interpreting the findings. In particular, debriefing occurred with Dr Lentin during data analysis. Discussion occurred regarding meanings and interpretations, and provided a forum for me to talk about my feelings and thoughts regarding the data (Creswell, 2013).

Finally Creswell (2013) discusses the importance of reporting the multiple perspectives and complex interactions that occur in any situation. In this study, four manuscripts have been generated from the data analysed. The findings are outlined in detail in these manuscripts providing comprehensive descriptions of the multiple realities of the participants, and discussing these in relation to the complex environmental contexts in which they occur.

3.5 Ethical Considerations and Procedures

According to the National Statement on Ethical Conduct in Human Research 2007 (Updated 2014) Section 2, page 13, this study was considered low risk (The National Health and Medical Research Council [NHMRC], 2014). The only foreseeable risk was one of discomfort. Therefore low risk ethics applications were completed for: Monash University and Alfred Health (Appendices I, J and K). The possible risks and how these risks were mitigated in the design and implementation of this study follows.

3.5.1 Risks/Beneficence.

Given that participants had sustained a SCI, and the aims of the study were to explore their social and community participation, issues raised were potentially sensitive for some of the participants. There was the possible risk of inconvenience due to the time commitment required to participate in a potentially lengthy interview. There was also the potential to cause psychological distress either in the short or long term as people reflected on their experiences. Given the nature of the disability of the population, there was a potential risk of physical or mental fatigue being experienced by individual participants. Strategies that were outlined in the ethics applications to address these risks were:

1. If at any time during the interview the participant showed signs of fatigue or reduced concentration, the interview was to cease and the following choices given to the participant, the remainder of the interview could be rescheduled for another day of convenience to the participant. The participant could have a rest break (of a duration determined by them) and then the interview recommenced. The participant could have a rest break (of a duration

determined by them) and then, if the participant and/or the researcher still felt that fatigue would impact on the interview process, the interview could be rescheduled for another day convenient to the participant. The participant could choose to stop and no longer continue with the interview. No participants required a rest break or needed to discontinue the interview.

2. In the event that the research participant became distressed at any time during the interviews data gathering was to cease immediately. In order to manage the risks to participants, I was to assess the situation and, based on my clinical skills and judgment, was to arrange debriefing and/or counselling for the participant as required. As an experienced clinician with counselling skills and over 25 years of experience, primarily working with people with an SCI, I had an understanding of potential issues this group of participants may face. If the participant demonstrated distress after the interview, and had given consent, I was to refer them to an appropriate counselling service. These services were outlined in the Explanatory Statement (Appendix F). Three participants did become slightly emotional during the interview process, but no participants became sufficiently distressed for counselling services to be required.

3.5.2. Consent

People with a cognitive impairment, an intellectual disability, or mental illness.

As stated in Section 4.5, National Statement on Ethical Conduct in Human Research 2007 (Updated 2014) it is important for those with a cognitive impairment or mental illness to have their voices heard, and they are entitled to participate in research

(NHMRC, 2014). However, due to the nature of the data collection used for this project, that is in-depth semi-structured interviewing, participants needed to have the capacity to not only consent to participate but also to be able to provide in-depth answers to sometimes complex questions. For these reasons, and to minimise the risk of harm, participants were to be excluded from the study if they had a pre-existing or acquired intellectual disability or mental impairment that impacted upon their ability to provide informed consent and/or complete such interviews. One participant had some mental health issues, but during discussion over the telephone he was definite that he wanted the opportunity to participate in the research.

Informed consent.

In addition to the person being competent to consent, in order to give informed consent, the person needed to understand the information given and the consent to participate must have been voluntary (NHMRC, 2014). The Explanatory Statement (Appendix G) and Consent Form (Appendix H) used in this project, clearly documented that participation in this study was completely voluntary, that the participant was under no obligation to consent to participate, they could withdraw at any stage during data collection, and could avoid answering questions that they felt were too personal or intrusive. After the potential participant was provided with the Explanatory Statement and Consent Form, the researcher contacted the potential participant a week later to provide them with the opportunity to ask for more information and to determine if they wished to participate. They were also provided with the opportunity to discuss the information with others if they wished to do so. If, after being contacted they decided to participate, and were able to sign their name, they signed the Consent Form and returned it to the researcher either by mail using

a stamped, self-addressed envelope, or provided it at interview. If the person was unable to sign their name (as was the case for some people with high tetraplegia), they provided oral consent (as outlined in 2.2.5 of the National Statement on Ethical Conduct in Human Research (2007) (Updated 2014) either over the telephone or at interview.

3.5.3 Unequal relationships.

There was no inherent unequal relationship in this project, however given that the participants would have had extensive experience with health care professionals in the past, they may have perceived an unequal relationship. This needed to be taken into consideration during data collection. No person directly involved in the participant's care or rehabilitation participated in this research project, thus withdrawal from the project in no way affected the person's ongoing care or rehabilitation.

3.5.4 Privacy/confidentiality.

Information provided by the participants was potentially sensitive in nature. Additionally the spinal cord community is a small one. For these reasons it was of particular importance to protect the identities of the participants. Following provision of consent to participate in the project, an identification code was assigned to each individual participant. Only this identification code was used during data analysis. When reports and manuscripts were prepared, participants' names were replaced by a pseudonym to enable reports to be more easily read. The participant names associated with each identification code are kept in a separate locked filing cabinet in the Department of Occupational Therapy at Monash University. No identifiable information has been used or will be used in any reports, publications or

presentations arising from this project. In publications pseudonyms have been used in place of peoples' actual names.

Data will be retained within locked filing cabinets and on a password-secure computer in the Department of Occupational Therapy at Monash University for five years following collection. At the end of this period, hard copy data will be shredded and computer-based data will be permanently deleted from the hard drive of the password-secure computer upon which it has been stored.

3.5.5 Risks to the researcher.

I conducted the interviews alone in people's homes, therefore there was a low risk associated with being in an unknown person's house. However, to minimize the risk I informed someone of where I was going, the address and expected time the interview was to take place, and ensured that I had a mobile telephone with me at all times should I need assistance. I am a clinician with over 25 years of experience conducting home visits and as such was well qualified to be able to identify potentially threatening situations. It is common practice for clinicians to enter client homes, and the knowledge of strategies to maximise personal safety in such environments was drawn on for this project. A Monash University Occupational Health and Safety Risk Assessment was completed and submitted as part of the Monash University ethics application.

There was also a possibility that some information disclosed by participants would be distressing for me. There was a plan put in place, that if such distress did occur, I would debrief with the supervisors either by telephone or in supervision sessions. All

the supervisors are experienced health clinicians and able to provide appropriate support. Fortunately, there was no such distress, however, discussing interviews with the supervisors did provide the opportunity to review how interviews went, and make any changes to the interview process as needed.

3.6 Sampling and Recruitment

3.6.1 Inclusion and exclusion criteria

Inclusion criteria

Adults aged between 18 – 85 years, living in the Australian community with acquired spinal cord injury or damage.

Exclusion criteria

- The person was under 18 years of age or over 85 years
- The person was diagnosed with a brain injury or intellectual disability and was unable to provide informed consent
- The person was able to provide informed consent but had an intellectual disability or mental impairment that affected their capacity to comprehend and answer in-depth interview questions
- The person was currently completing an inpatient rehabilitation stay–this project aimed to explore participation of those living in the community
- The person could not understand written or spoken plain English–participants received written and verbal information regarding the project

3.6.2 Recruitment and purposeful sampling approach.

The concept of purposeful sampling is used in qualitative research (Creswell, 2013). The researcher selects participants that can purposefully inform understanding of the

research question and the central phenomenon in the study (Creswell; Patton, 2015). Creswell states that sampling can change during the study and researchers need to be flexible. In qualitative research sampling is interrelated with data collection, and ongoing sampling decisions evolve from data analysis and developing understanding, and sampling continues until saturation occurs (Minichiello et al. (2004).

The initial recruitment approach in this study was to access people aged over 18 years living in the Australian community. Approval was granted by the Monash University Human Research Ethics Committee on 21 June 2013 (CF13/1107-2013000540) to advertise for people to contact the student researcher (Appendix I). Peak bodies representing people with SCI in Australia (Independence Australia, formally known as ParaQuad Victoria, The Australian Quadriplegic Association [AQA Victoria], Disability Sports Victoria; and Spinal Cord Injury Network) were contacted and asked to place advertisements in their organisational newsletters to invite people to participate. In addition on-line sites and forums commonly used by people with SCI were also contacted to advertise the study on their websites. These included The Australian Quadriplegic Association (AQA Victoria) Spinal Hub website; Spinal Cord Injury Network and Monash Memo. The advertisements requested potential participants to contact the researcher either by telephone or email to find out more about the research project.

Once potential participants contacted the researcher, they were sent an Explanatory Statement (Appendix G) and Consent Form (Appendix H) to read. The potential participants were then contacted a week later to determine if they wished to

participate and if so, were asked to sign the Consent Form and return it to the researcher either by mail or at interview.

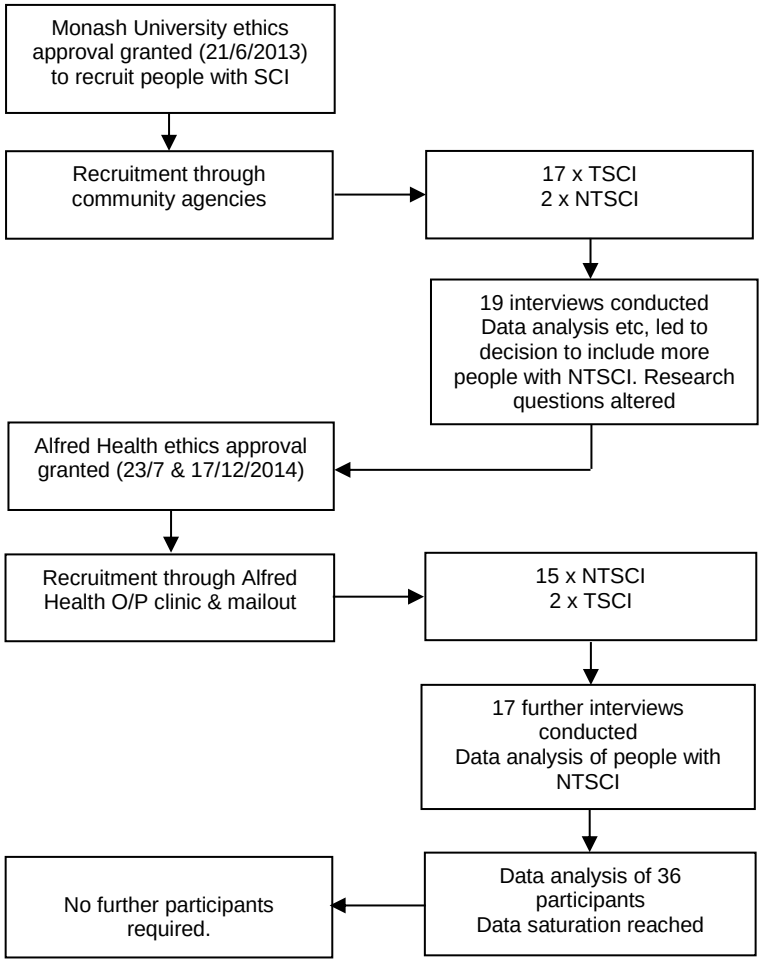
As interviews were conducted data analysis occurred. That is, 1-2 interviews were transcribed and then thematically analysed in relation to the research questions (more detail regarding this is outlined in Section 3.8 Data Analysis), before the next 1-2 interviews were conducted. Initial respondents were typically middle-class males in the 40 – 50 year age bracket. After 5-6 interviews had been conducted it was apparent that in order to gain a more comprehensive and representative understanding of this area, a more diverse sample consisting of people from different backgrounds was needed. For example, people who were younger, or were not employed, or who were from lower socio-economic backgrounds were purposefully sought to gain a broader range of views and experiences. Towards the end of recruitment, when potential participants contacted me, if they were of similar background to those already interviewed they were not followed up. It should be noted, however, that it was particularly challenging to recruit people who were under 25 years, or were from lower socio-economic backgrounds. This initial strategy resulted in 17 people with TSCI and two people with NTSCI being recruited and interviewed.

Consistent with the emergent design and the concept of purposeful sampling, as data analysis of the first 17 people with TSCI and two with NTSCI occurred, it became apparent that the views and experiences of the people with NTSCI were somewhat different to those with TSCI. In addition, data saturation was beginning to occur with the TSCI data, that is new themes or sub-themes were not being

identified from the data (Braun & Clarke, 2013). Further examination of the literature revealed that there was almost no published evidence regarding the social and community participation of people with NTSCI. After discussion with supervisors, the decision was taken to actively recruit those with NTSCI, and revise the research questions. Consequently additional ethics applications were submitted to the two main health networks that rehabilitate people with SCI in Victoria - Alfred Health and Austin Health. Ethics approval was granted by Alfred Health on 23/7/2014 to enable people to be approached through the spinal rehabilitation outpatient clinic (Appendix J). An amendment was applied for and approved on 17/12/2014 to conduct a mail out to people on the SCI outpatient list with NTSCI (Appendix K).

These two recruitment strategies resulted in a number of potential participants expressing interest in being interviewed. A further 15 people with NTSCI and two more people with TSCI were interviewed, after which time no new themes or sub-themes were emerging from either group, therefore recruitment ceased (Braun & Clark, 2013). The final samples consisted of 19 people with TSCI and 17 people with NTSCI. More detail about data analysis is provided in 3.8. Tables 8 and 9 outline the characteristics of the final two samples of participants once codes were applied (TSCI and NTSCI). The recruitment and sampling process is depicted in Figure 4.

Figure 4 *Recruitment and sampling process*



3.6.3 Traumatic spinal cord Injury (TSCI) sample.

The aim of the sampling strategy was to purposefully select information rich cases with a variety of characteristics. Gender, cause of injury and time since injury, are characteristics which may influence people's experience of social and community participation. A range of these characteristics were sought in order to contribute to the depth of data collected. Table 8 *Participants with TSCI with code applied*outlines the details of the TSCI sample once codes had been applied to de-identify participants. The TSCI sample (*n*=19) consisted of five females (26%), and 14 males (74%). These proportions are representative of the general population of people with TSCI (females: 28.4%, males: 71.6%) as identified in the most recent study available

on the characteristics of people with TSCI and NTSCI in Australia (New et al., 2011). In the TSCI sample of this study the median age at which the injury occurred was 30 years. This is similar to the median age identified in the literature. For example, Cripps (2009) identified the 15-24 year age group as having the highest incidence of injury. In this study, 63% of participants experienced tetraplegia[1]. This is a slight over representation of people with tetraplegia in comparison to the figures reported by Cripps (2009), who found 50% of those with TSCI had tetraplegia, with the remaining 50% having paraplegia[2] In the 2006-07 period (Cripps, 2009).

3.6.4 Non-traumatic spinal cord injury (NTSCI) sample.

Table 9 *Participants with NTSCI with code applied*outlines the details of the NTSCI sample once codes had been applied to de-identify participants. In the NTSCI sample, there were eight females (46%), and nine males (53%). This is similar to the gender mix of NTSCI identified by New et al. (2011) of 45% females, and 55% males. The median age that the injury or damage to the spinal cord occurred for the NTSCI sample was 54.5 years, which is somewhat younger than the median age identified by New, Rawicki, & Bailey (2002) of 61 years. 82% of the NTSCI sample had incomplete paraplegia (82%), which reflects the most common type of injury experienced by this group as reported by Guilcher et al., 2010. Figures 5 and 6 consist of pie charts showing the range of different injury types of each of the two samples.

[1] Tetraplegia = damage to the cervical segments of the spinal cord, causing functional impairment in the arms, trunk, legs and pelvic organs

[2] Paraplegia = damage to the thoracic, lumbar or sacral segments of the spinal cord, resulting in various combinations of and sensory impairment to the trunk, lower limbs, bladder and bowel function

Table 8 *Participants with TSCI with code applied*

Code	Age at interview & gender	Age at time of injury	Time since injury	Cause of injury	Injury type/level	Funding	Living situation (including State lives in)	Social & community participation
(T1)	37 year old male	20 years	17 years	Sport	Incomplete tetraplegia	Public funding	Lives with partner and off-spring. (Victoria)	Runs own business; coaches & participates in sport; very active socially
(T2)	42 year old male	26 years	16 years	Fall	Complete paraplegia	Work insurance	Lives alone. (Victoria)	Volunteers one day per week. Minimal other social.
(T3)	40 year old male	26 years	14 years	Fall	Complete paraplegia with other injuries	Work insurance	Lives with partner and parent. (Victoria)	Paid work one day per week; voluntary work one day per week. Socially active – camping, fishing, dog training, socialising
(T4)	44 year old male	30 years	14 years	Motor vehicle accident	High tetraplegia	Motor vehicle insurance	Lives with partner and off-spring. (Victoria)	Three days paid work. Involved in interest based club.
(T5)	43 year old male	20 years	23 years	Swimming	Complete tetraplegia	Public funding	Lives with parents and sibling. (Victoria)	Works full-time. Plays high level sport. Very involved with family.
(T6)	50 year old male	45 years	5 years	Motor vehicle accident	Complete paraplegia	Third Party Insurance	Lives partner and two off-spring. (Canberra)	Recently finished voluntary work. Sporting interests.
(T7)	46 year old male	18 years	29 years	Fall	Complete tetraplegia	Public funding	Lives alone. (NSW)	Four days paid work per week. Involved in advocacy work.
(T8)	57 year old male	40 years	17 years	Work accident	Complete paraplegia	Work insurance	Lives with long-term partner. (Victoria)	Works full-time. Volunteers in community club. Busy with family and friends.
(T9)	28 year male	18 years	10 years	Motor vehicle accident	Complete tetraplegia	Motor vehicle insurance	Lives with parent.(Victoria)	Looking for work. Involved in sports.
(T10)	51 year old male	34 years	17 years	Unknown	Incomplete tetraplegia	Public funding	Lives with parent. (NSW)	Paid work 3 days per week. Goes to movies and shops.
(T11)	35 year old female	30 years	4 years	Motor vehicle accident	Complete tetraplegia	Third party insurance	Lives with partner. (QLD)	Very involved in art and music.
(T12)	67 year old female	39 years	28 years	Motor vehicle accident	Complete tetraplegia	Motor vehicle insurance	Lives alone. (Victoria)	Studying at TAFE. Paid work part-time work. Sees friends and family. Other leisure interests.
(T13)	50 year old male	45 years	5 years	Swimming	Complete tetraplegia	Public funding - support through superannuation	Lives with parent and two off-spring. (NSW)	Occasional voluntary work. No other specific leisure interests mentioned.
(T14)	19 year old male	15 years	4 years	Motor vehicle accident	Incomplete tetraplegia	Motor insurance scheme	Lives with parents and three siblings. (Victoria)	Full-time university student. Goes to personal trainer regularly, and physiotherapist.
(T15)	43 year old female	30 years	14 years	Medical incident	Incomplete paraplegia	Public funding	Lives with parents and off-spring.(Victoria)	Paid part-time work. Sees friends regularly, part of community groups. Some voluntary work.
(T16)	53 year old male	37 years	16 years	Work accident	Complete tetraplegia	Work insurance	Lives with parent.(NSW)	Casual paid employment. Family activities. Exercise.
(T17)	50 year old female	45 years	5 years	Motor vehicle accident	Complete tetraplegia	Motor vehicle insurance.	Lives with partner. (QLD)	Paid work 3 days per week. Volunteers as sports coach.
(T18)	59 year old female	59 years	Less than 12 months	Fall	Incomplete paraplegia	Public funding	Lives alone in supported accommodation. (Victoria)	Minimal, rarely goes out.
(T19)	70 year old male	18 years	51 years	Motor vehicle accident	Complete paraplegia with complications	Public funding	Lives alone.	Minimal – goes to physiotherapist. Rarely sees anyone socially.

Table 9 *Participants with NTSCI with code applied*

Code	Age at interview & gender	Age at time of damage	Time since damage	Cause of injury/ damage	Level of damage & mobility status	Funding	Living situation (including State lives in)	Social & community participation
(NT1)	59 year old female	51 years	8 years	Transverse myelitis	Incomplete paraplegia – walks with walking frame	Public funding	Lives alone.(Victoria)	Has many friends and very involved socially in community. Currently not working.
(NT2)	69 year old male	59 years	10 years	Triple A	Complete paraplegia - wheelchair dependent	Public funding	Lives with spouse. (Victoria)	Retired trade union official. Gardening, cooking. Goes out 2-3 time per week only with wife.
(NT3)	33 year old male	33 years	8 months	Epidural abscess	Incomplete paraplegia. Full mobility.	Public funding	Lives with flat mate. (Victoria)	On sick leave from work. Socialises with friends.
(NT4)	75 year old female	72 years	3 years	Spinal canal stenosis	Incomplete paraplegia – walks with walking frame	Public with limited private health insurance	Lives alone in flat. (Victoria)	Retired. Very active in community – attends music concerts, shows, films, friends.
(NT5)	68 year old male	67 years	1 year	Triple A	Incomplete paraplegia – wheelchair dependent	Public funding. Private health insurance.	Lives with spouse. (Victoria)	Very limited. Rarely sees friends since injury. Mostly family. Occasional movie or park with grandchildren.
(NT6)	70 year old male	68 years	20 months ago	Triple A	Incomplete paraplegia- Wheelchair dependent.	Public funding.	Lives with spouse. (Victoria)	Only goes out to shops or medical appointments. Not interested in other activities.
(NT7)	67 year old male	6 years	61 years	Transverse myelitis	Complete paraplegia- wheelchair dependent.	Public funding.	Lives with spouse. (NSW)	Very active advocate in community. On multiple committees.
(NT8)	78 year old male	75 years	2 ½ years	Triple A	Incomplete paraplegia- wheelchair dependent	Public funding	Lives with spouse. (Victoria)	Forced retirement when SCI. Minimal community based activities.
(NT9)	52 year old female	46 years	6 years	Spinal inflammation	Incomplete paraplegia - wheelchair dependent.	Public funding	Lives with spouse. (Victoria)	Full-time mother. Goes to gym and physiotherapist. Sees friends.
(NT10)	53 year old female	52 years	10 months	Blood clot	Incomplete tetraplegia - walks with SPS	Public funding.	Lives with spouse. (Victoria)	Was running own business. Wants to work in future. Enjoys travel. Sees friends but not a lot.
(NT11)	66 year old male	Unclear	6 years	Neurofibromatosis	Incomplete paraplegia – walks with SPS	Public funding.	Lives with spouse & grandchild.(Victoria)	Runs own business. Some volunteering about once per month. Minimal other interests.
(NT12)	67 year old female	65 years	2 ½ years	Infection in spinal cord	Incomplete paraplegia. Walks with walking frame.	Public funding.	Lives alone. (Victoria)	Has a partner she sees regularly but doesn't live with. Volunteers regularly; sees friends & family socially; travels with partner.
(NT13)	43 year old female	36 years	7 years	Viral infection in cervical region	Incomplete tetraplegia – walks with SPS inside, crutch outside	Public funding.	Lives with husband and 3 children. (Victoria)	Religious activities. Attends physiotherapy. Few other outings.
(NT14)	65 year old male	63 years	2 years	Spinal myelopathy	Incomplete tetraplegia. Walks with 2 x single point sticks	Public funding	Lives with spouse. (Victoria)	Socially isolated. Just joined community group.
(NT15)	75 year old female	71 years	4 years	Bleeding fistula.	Incomplete paraplegia. Wheelchair dependent.	Public funding	Lives alone. (Victoria)	Goes down to local shops daily. Otherwise very few social outlets – no regular friends or social groups.
(NT16)	83 year old female	76 years	7 years	Blood clot	Incomplete paraplegia. Walking frame.	Public funding	Lives alone. (Victoria)	Very active. Regular volunteer work. Goes out nearly every day.
(NT17)	59 year old male	48 years	11 years	Infection	Incomplete paraplegia. Wheelchair dependent.	Compensation	Lives alone. (Victoria)	Does shopping, sees friends. Minimal organised social groups.

Figure 5 *Types of injuries of TSCI participants*

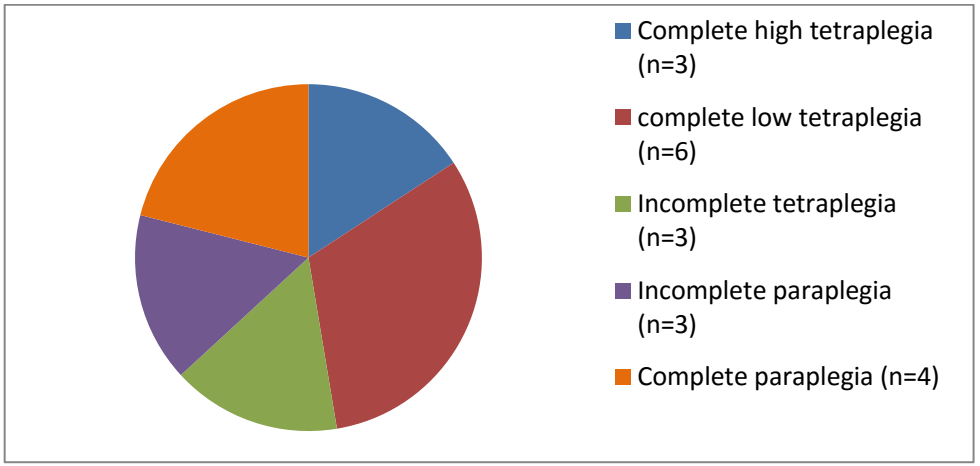
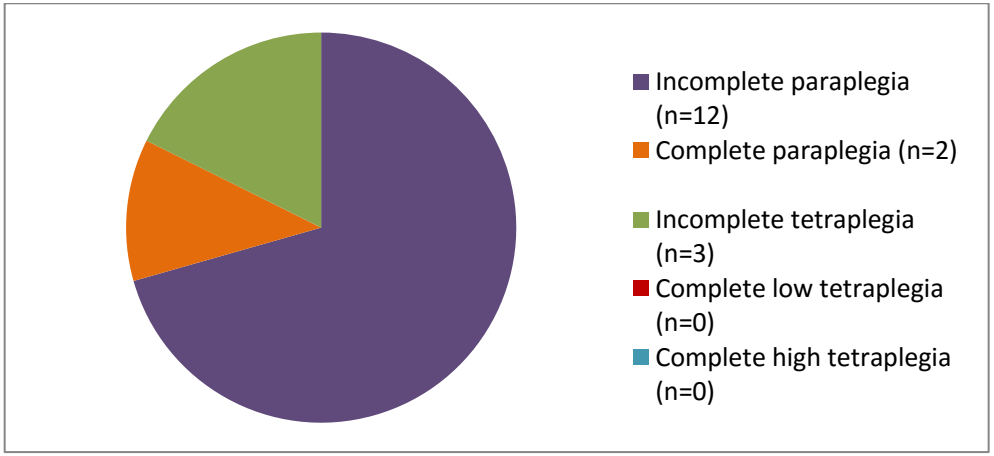


Figure 6 *Types of injuries NTSCI participants*



3.7 Data Collection.

3.7.1 Interviewing.

In-depth interviewing which was semi-focussed or semi-structured was the primary method of data collection used for this study. Minichiello, Aroni, Timewell and Alexander (1992) state that in-depth interviewing is appropriate to use when the purpose of the interview is to gain an understanding of activities and events that cannot be directly observed by the researcher. Minichiello, Aroni, Timewell, and Alexander argue that in-depth interviewing can be unstructured or semi-structured. For semi-structured interviewing a guide or schedule is developed around a list of topics, without fixed wording or fixed ordering of questions (Minichiello). This type of questioning, while maintaining focus on the main research issue(s), enables greater flexibility than survey style or structured interviewing.

Creswell (2013) outlines steps to follow for interviewing in qualitative studies. Applied to this study, the following steps were informed by Creswell.

1. Decide on the research questions that will be answered by interviews (see 3.4 Research Design).
2. Identify interviewees who can best answer these questions (see 3.6 Sampling and Recruitment) (return to Step 1 as design evolved to include people with NTSCI)
3. Determine what type of interview is practical. Where possible face-to-face interviews were conducted at the participant's home, otherwise Skype or telephone interviews were conducted. Of the 36 interviews completed, 22 were face-to-face interviews in the participants' homes, ten were completed over the telephone, and three via Skype. The advantage of the face to face interview is that the researcher can see the informal and/or non-verbal communication and

the interviewer can also gather information from the person's environment to inform analysis (Creswell, 2013). For this study, these observations were recorded as field notes, and included in analysis.

4. Use adequate recording procedures. A digital recorder was used, and the recorded interviews downloaded onto computer as soon as practical.
5. Design and use an interview protocol. The semi-structured interview guide used in this study resulted from review of the literature, and identification of gaps in understanding in this area, and based on the research questions (3.3 Research Questions). The guide served a structure but allowed for flexibility and the opportunity to seek more in-depth information from the participant as appropriate (Minichiello et al., 1992).
6. Refine the interview questions through pilot testing (including keeping field notes). A pilot interview was conducted with a person with SCI known to the researcher. Based on feedback from this person, some of the questions were rephrased. Part of piloting the interview was to determine if questions demonstrated any unintentional biases or assumptions held by the researcher. As interviews progressed, the questions were regularly and constantly reviewed and refined. The final interview guide is outlined in Appendix F, but flexibility was maintained, and when interesting points were raised by the participants, these were further pursued by the researcher, and prompts or further questions used to gain more information or enhance clarity.
7. Determine the place – quiet, private. In all but three instances the participants were in their own homes, allowing the participant to feel comfortable, and have privacy. Televisions, radios and music were turned off. Three interviews were completed in the participants' work place in a quiet, private room.
8. Consent was obtained using a consent form (see 3.4.2. and Appendix H)

9. Good interview procedures (be a good listener, don't offer advice) were used. Funnelling is the process whereby the interviewer starts the interview asking general questions to encourage the participant to start thinking about the issue in general terms (Minichiello et al., 1992). Then as the interview progresses, the questions become more focussed and specific. This technique was used during the interviews, which allowed the participants to feel comfortable and less threatened, and had a more conversational feel. In addition, probing or secondary questions were used to elicit more detailed information, and to clarify the meanings intended by the participant (Minichiello).

3.7.2 Field notes.

Field notes contain the description of what has occurred. They contain everything that the observer thinks is worth noting (Patton, 2015). In this study, dated field notes were made immediately after the interview, and stored together with the transcribed interview and demographic information of each participant. Details about the participant's environment, their appearance, demeanour, and non-verbal language were recorded. In addition, the researcher's reaction to the interview, meanings and significance of observations were noted (Patton). Field notes were referred to during data analysis and assisted in compiling a thick description of the context of the interview.

3.8 Data Analysis.

Qualitative methods are orientated towards exploration, discovery and inductive logic (Patton, 2015). Inductive analysis involves discovering patterns, themes and categories from the data. Findings emerge from the data, through the analyst's interactions with the data (Patton). This is consistent with the constructivist paradigm, where the

researcher seeks to understand the multiple realities and inter-relationships that emerge from the data (Lincoln, Lynham & Guba, 2011; Patton, 2015).

Thematic analysis was used in this study, and involved inductive identification of codes, categories and themes from the data (Braun & Clarke, 2013). Coding is the process of examining data, and identifying and noting aspects that relate to the research question(s). Similar codes were then grouped into categories, which were potential themes. A theme is a patterned meaning across data that captures something important in relation to the research question (Braun & Clarke, 2006; Braun & Clarke, 2013). Codes, categories and themes were developed using a constant comparative approach, that is going back and forth from the data and comparing it to the emerging codes and categories until final themes and sub-themes were decided (Creswell, 2013).

The participants' interviews were transcribed verbatim. The transcripts were laid out with a column of space on the right hand side to allow room for note taking. Line numbers were also applied to enable quick and easy reference to different parts of the transcripts as reading, re-reading and note-taking occurred. Familiarisation with the data occurred by reading and re-reading the individual transcripts. Field notes were also reviewed and included in this familiarisation process.

Initial codes were systematically generated by including everything and anything of interest or relevance to answering the research questions (Braun & Clarke, 2013). Codes were then collated into groups containing similar ideas or categories and given a name. Categories were then reviewed and identified as a potential theme. The themes were rechecked to see if they worked in relation to the coded extracts, resulting in a thematic map. Further comparison between the themes and the data was undertaken

until definitions and names for each theme were generated. A reflective journal was kept during the analysis process, and discussion occurred with Dr Lentin, which also informed the development of some of the potential themes and sub-themes. Dr Lentin and I completed coding, independently, and then came together to compare and discuss codes, categories and potential themes. Table 10 provides examples of data extracts from interviews, with codes applied related to some of the research questions.

Table 10 *Data with code applied*

Data extract	Research question	Initial codes
"It's good to meet people and people that have done it before and who are similar so you can sort of know where you're going". (T3)	What are the facilitators and barriers to social and community participation following traumatic SCI?	Peer mentors help to see where you're heading
"I rely on someone to be with me all the time. Because of needing help to get the wheelchair in the back of the car, and all that business." (NT6)	What are the facilitators and barriers to social and community participation following non-traumatic SCI?	Need assistance to help to access community Cannot drive – needs help with transport
"In those roles [swimming coach] you feel like you are contributing to society, which is really wonderful". (T17)	What are the meanings associated with social and community participation for people living with an acquired SCI?	Being in roles that involve contributing to society

Data analysis was a constant process as described above, but as analysis and then discussion with supervisors occurred, the research questions were refined and altered (consistent with emergent design). Further recruitment was then undertaken and the next phase of interviewing and data analysis was completed (refer also to 3.4 and 3.6). This process resulted in three phases of the study. For each phase data analysis continued until data saturation was reached for the relevant research question(s), that is when no new themes or sub-themes were evident (Braun & Clarke, 2006; 2013).

Phase One

Recruitment, data collection and analysis in relation to subsidiary research questions: *1.What is the experience of social and community participation for people living with an acquired TSCI? 4. What are the facilitators and barriers to social and community participation following traumatic SCI?* The findings resulted in the published article as Chapter Four.

Phase Two

Recruitment, data collection and analysis in relation to subsidiary research questions: *1.What is the experience of social and community participation for people living with an acquired NTSCI? 5. What are the facilitators and barriers to social and community participation following non-traumatic SCI?* The findings resulted in the manuscript provided in Chapter Five.

Phase Three

Data from all participants (TSCI and NTSCI) analysed in relation to subsidiary research questions: *1.What is the experience of social and community participation for people living with an acquired SCI? 2. How important is social and community participation from the perspective of people living with an acquired SCI? 3. What are the meanings associated with social and community participation for people living with an acquired SCI?* The findings resulted in the manuscript provided in Chapter Six.

3.9 Strategies to Ensure Trustworthiness

Consistent with the aim of the study and the constructivist paradigm underpinning it, strategies were incorporated into the research design to maximise the trustworthiness of the study (Lincoln and Guba, 1985). That is, strategies were employed to ensure that

the findings of the study had credibility, transferability, dependability and confirmability (Lincoln and Guba, 1985). These strategies are outlined below.

3.9.1. Credibility.

Lincoln and Guba (1985) outline a number of techniques that can be employed in the research design to maximise the credibility of the findings (that is, the “truth” of the findings). Triangulation, peer debriefing and member checking were used in this study.

Data triangulation refers to a strategy of using two or more data sources in the one study (Patton, 2015; Curtin & Fossey, 2007). It refers to cross-checking and comparing the consistency of information derived at different times and by different means (Patton). Interviewing was the primary method of data collection. In addition, field notes were taken during and immediately after the interviews (3.7.2). These notes were then reviewed. The notes made from observations added to the context of the interview data and in some cases assisted the researcher to make sense of what the participant discussed.

Researcher triangulation occurs when two or more researchers are involved in analysis of the data in order to try and compensate for single-researcher bias (Curtin & Fossey, 2007). In this project, I was primarily responsible for data analysis, however, Dr Lentin also analysed transcripts and completed coding. Discussions about codes and categories, and later themes occurred with Dr Lentin on a regular basis. In addition, during supervision sessions, there was further discussion of the findings, themes and sub-themes with Assoc. Prof. McDonald and Assoc Prof. Bourke-Taylor, providing opportunities to examine the context and therefore application of the findings.

Peer debriefing is the process whereby the researcher's biases are questioned and probed, meanings explored and the basis of interpretations challenged (Creswell, 2013; Lincoln and Guba, 1985). Regular peer debriefing with supervisors occurred throughout the research process. My supervisors often challenged my assumptions and encouraged me to consider alternative ways of viewing and interpreting findings. Debriefing also served a critical role in developing the next steps in the emerging methodological design, resulting in the inclusion of people with NTSCI in the research.

Member checking is when data, analytic categories, interpretations and conclusions are tested with those people from whom the data was originally collected, and is a critical technique for establishing credibility (Lincoln and Guba, 1985). Two member checking strategies were employed in the research. Interviews were digitally recorded, transcribed verbatim, and later sent back to participants for verification and to seek feedback regarding their accuracy. Some feedback was obtained from two participants, resulting in minor changes to their transcripts. In addition, newsletters were prepared and sent to participants to inform them of the progress of the research, and to ask for feedback on the content of the findings (Appendix L). The findings were also published on relevant organisational websites, with an invitation for people to comment or add their own perspectives. Minimal feedback was received but one participant noted that it helped to feel included in the research process, while another took the opportunity to restate some information previously provided.

3.9.2 Transferability.

Transferability refers to whether or not findings have applicability to other contexts. The main strategy to maximise transferability described by Lincoln and Guba (1985) is thick description. A thick description of the context and circumstances surrounding the

phenomenon being studied is required so that the meaning of the information obtained can be fully understood (Curtin & Fossey, 2007). The main context of this study was the Victorian and Australian disability and aged care service systems described in Chapter One. My background as an experienced clinician has been described, together with the biases I brought to the study, which informs understanding of the findings. Another aspect of thick description is understanding where the participants were recruited from, and information about their circumstances and characteristics. This information is provided in Tables 8 and 9.

3.9.3 Dependability

Dependability refers to the findings being consistent and able to be repeated. One technique employed in this research to maximise dependability was maintaining an audit trail (Lincoln & Guba, 1985; Patton, 2015). All raw data (interviews, field notes and journal) have been carefully recorded and stored and can be produced if required. In addition, summary notes, records of discussions at meetings, process notes regarding design decisions, and notes relating to analysis (e.g. how categories and themes were arrived at) have been maintained in a series of journals. Earlier in this chapter, a description of the design process, data collection decisions, recruitment and sampling decisions and processes, and data analysis procedures were described.

3.9.4 Confirmability.

Confirmability is the extent to which the findings of a study are shaped by the respondents and not by researcher bias, motivation or interest (Lincoln and Guba, 1985; Patton, 2015). Techniques employed to assist with confirmability in this research were maintaining an audit trail (already described in 3.9.3), triangulation (already described in 3.9.1) and reflexivity (Lincoln and Guba, 1985; Patton, 2015). Strategies

employed to foster reflexivity in the research were to keep a reflective journal (3.4) and to have regular discussions with supervisors. Discussions with supervisors assisted in viewing findings in different ways, and sometimes challenged my beliefs, values, perspectives and assumptions (Creswell, 2013).

Chapter Summary

The aim of the study was to explore the experience, meaning and importance of social and community participation for adults living with an acquired spinal cord injury (SCI) in Victoria. The chapter outlined the rationale for using qualitative research methods to conduct the study. An emergent research design was employed as the initial plan for the research was modified after data collection began, and it was decided to include people with NTSCI in the study. This resulted in a staged recruitment and sampling strategy, starting with recruitment of people with acquired SCI, and then refining this to finish with two samples – one consisting of 19 people with acquired TSCI and one consisting of 17 people with acquired NTSCI. Specific techniques were included to maximise the trustworthiness of the study. Three phases of data analysis occurred, resulting in the production of three manuscripts suitable for publication. The following three chapters present these manuscripts.

Chapter Four

Facilitators and Barriers to Social and Community Participation Following Spinal Cord Injury (published article)

As a result of the literature reviews conducted in Chapters One and Two it was identified that there was limited high quality evidence from the perspective of people living with SCI regarding their experience of social and community participation. This study utilised a pragmatic qualitative design to explore the experience (including the facilitators and barriers), meanings and value of social and community participation for people with SCI. As described in Chapter Three, an emergent research design was employed, resulting in three phases to the study. This chapter presents the findings of the first phase of the study. The data from seventeen people with TSCI were analysed in relation to the research questions: *What is the experience of social and community participation for people with SCI? What are the facilitators and barriers to social and community participation following SCI?*

Barclay, L., McDonald, R., Lentin, P, & Bourke-Taylor, H. (2016). Facilitators and barriers to social and community participation following spinal cord injury. *Australian Occupational Therapy Journal, 63(1). Doi:10*.1111/1440-1630.12241. (Appendix B).

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Date of publication on-line: 12 November 2015

4.1 Introduction

Spinal cord injury (SCI) has significant consequences both at an individual and societal level (WHO & ISCOS, 2013). Due to advances in medical techniques there has been an increase in life expectancy for people following SCI (Krause et al., 2008). However, despite these advances there remain areas of significant concern for the long term health and well-being of people living with SCI both in Australia and internationally.

Following an SCI, the ability to participate in meaningful life roles and activities outside the home can change and diminish (Brown et al., 2002; Whiteneck et al., 2004). Participation in work, leisure and sporting activities greatly decreases (Tasiemski, Bergström, Savic, & Gardner, 2000) with an accompanying increase in time spent on individual home-based occupations such as watching television, listening to the radio, and reading (Barclay et al., 2011), potentially leading to social isolation (Brown et al., 2002). A major factor contributing to leading a “good life” following an acquired disability is establishing and maintaining close relationships (Dunn & Brody, 2008). Many meaningful connections are made through participation in activities outside the home, such as being involved in sporting groups, leisure activities, going to the local shops, working or studying. Social and community participation is now recognised as an important outcome for people with an SCI (Carpenter et al., 2007; WHO, 2001).

Searches of the databases OVID MEDLINE, AMED, CINAHL PLUS, and PSYCHINFO in the 14 years post introduction of the ICF, revealed studies that investigated the impact of environmental barriers and facilitators on participation following SCI (Carpenter et al., 2007; Isaksson et al., 2007; Lysack et al., 2007; Schopp et al., 2007; Whiteneck et al., 2004). Lack of appropriate transport has been found to hinder

community participation (Carpenter et al.), while social support (Isaksson; Lysack) and access to paid care (Schopp) have been found to facilitate participation.

Barclay, McDonald and Lentin (2015) undertook a critical review of current evidence related to social and community participation following SCI. Twenty-three studies were reviewed, of which 17 were quantitative and five were qualitative. They concluded that in-depth exploratory research methods are needed to further investigate influences on social and community participation, particularly in relation to transport, personal care assistance, social support, input by health professionals, and specialized equipment (Barclay et al., 2015). Hammell (2010) recommended that facilitators and barriers to participation need to be identified and addressed both at the level of the individual, but also in the communities in which people live. This two pronged approach both prepares the individual to participate and creates environments that promote opportunities for successful social and community participation.

This paper reports part of a larger study that aimed to explore the experience and meaning of social and community participation of people living with an acquired SCI in Victoria, Australia. The research question guiding the part of the study reported in this paper was: *What are the facilitators and barriers to social and community participation following acquired SCI?*

4.2 Methods

Qualitative research seeks to make sense of how the world is seen, understood and experienced from the persons' perspective (Braun & Clarke, 2013). Qualitative research methods of semi-structured interviews and thematic data analysis (Creswell, 2013;

Braun & Clarke) were chosen to answer the above research question (Liamputtong, 2009). Ethics approval was gained from the Monash University Human Research Ethics Committee.

4.2.1 Participants.

A purposive sampling approach (Creswell, 2013; Liamputtong, 2009) was utilised to recruit people who were living in the community with an acquired SCI, aged between 18 – 85 years. Advertisements were placed in SCI organisational newsletters and web-sites. Those with a diagnosed brain injury or intellectual disability, and those who could not understand written or spoken plain English were excluded. As the study progressed participant selection aimed at achieving a maximum variation sample that represented the broad range of people living with SCI. People of both genders, from a range of age groups, from different education and employment backgrounds, with varying lengths of time since injury, different levels and types of SCI, and with differing levels of participation were included. Data collection continued until there was sufficient data to address the research question (Liamputtong, 2009). The interviews of 17 participants were analysed for this paper.

Table 11 *Description of TSCI Participants*outlines the injury and demographic details of the participants, and the range of social and community activities they were engaged in. Pseudonyms are used in place of participants' actual names.

Table 11 *Description of TSCI Participants*

Name	Age at interview	Time since injury	Injury type	Funding	Living situation	Social & community activities	Work status
Jason	15-25 years	4 years	Incomplete tetraplegia	Motor insurance	Lives with parents and siblings	Active with family.	Studying full-time.
Nathan	20-30 years	10 years	Complete tetraplegia	Motor insurance	Lives with parent	Involved in physical activities.	Recently completed full-time study.
Jenny	30-40 years	5 years	Complete tetraplegia	Third party insurance	Lives with spouse/partner	Involved socially with family and friends.	Voluntary work – own organisation.
Craig	40-50 years	16 years	Complete paraplegia	Work insurance cover	Lives alone most of the time	Minimal other social activities.	Voluntary work one day per week.
Sam	40-50 years	14 years	Complete paraplegia (with multiple other injuries)	Work insurance cover	Lives with spouse/partner and parent	Numerous interests and social activities.	Paid employment one day/week Voluntary work one day/week.
Grant	40-50 years	14 years	High complete tetraplegia	Motor insurance	Lives with spouse/partner and off-spring	Other hobbies and social interests.	Paid employment three days per week.
Tim	50-60 years	5 years	Complete paraplegia	Unfunded to start, now has Third Party Insurance	Lives with spouse/partner and off-spring	Involved in sport.	Recently finished voluntary work.
Jake	50-60 years	17 years	Complete paraplegia	Work insurance cover	Lives with spouse/partner	Involved socially with family and friends.	Full-time paid employment. Also volunteers in community.
Laura	50-60 years	5 years	High complete tetraplegia	Motor insurance scheme	Lives with spouse/partner.	Involved in family activities.	Paid employment three days per week. Volunteers in community.
Lisa	60-70 years	28 years	Complete tetraplegia	Motor insurance	Lives alone	Many interests and hobbies.	Paid employment part-time.
Evan	50-60 years	15 years	Complete tetraplegia	Work insurance cover	Lives with parent.	Involved in family activities and exercise.	Casual paid employment.
John	30-40 years	17 years	Incomplete tetraplegia	Public funding	Lives with spouse/partner and off-spring	Involved in sport and social activities.	Full-time paid employment.
Heidi	40-50 years	14 years	Incomplete paraplegia	Public funding	Lives with parents and off-spring	Involved in social activities and other interests.	Paid employment four days per week
Ethan	40-50 years	23 years	Complete tetraplegia	Public funding	Lives with parents and sibling	Involved in sport and family activities.	Full-time paid employment.
Chris	40-50 years	29 years	Complete tetraplegia	Public funding	Lives alone	Minimal other social activities.	Paid employment four days per week
James	50-60 years	17 years	Incomplete tetraplegia	Public funding	Lives with parent	Goes to movies and shops.	Paid employment three days per week.
Mike	50-60 years	5 years	High complete tetraplegia	No compensation, income support through superannuation	Lives with spouse/partner and off-spring	No other specific leisure interests mentioned.	Some intermittent voluntary work.

4.2.2 Data collection.

An interview guide (see below) was developed following the nine steps described by Creswell (2013). A pilot interview was conducted with a person with SCI known to the first author, feedback was obtained about the content, and the questions altered accordingly. In qualitative inquiry, data analysis occurs as data is collected, therefore the questions and prompts developed further as a result of preliminary analysis of the transcribed data following each interview (Liamputtong, 2009).

After written consent was obtained, each participant was interviewed for between 60 – 90 minutes. Ten interviews were conducted face to face in a location selected by the participant, four were conducted over the telephone and three using Skype. Interviews were digitally recorded and later transcribed verbatim. Interviews were sent back to participants as a form of member checking, to seek feedback regarding their accuracy (Creswell, 2013). In addition, field notes following each interview and a reflective journal were kept to maximise trustworthiness of the data (Creswell).

4.2.3 Data analysis.

Data were analysed utilising the thematic analysis method as described by Braun and Clarke (Braun & Clarke, 2013). An iterative process was undertaken to generate codes, and then themes. Initial codes for the first three transcripts were generated by the first and second authors separately, and then discussed until consensus was reached. The remaining transcripts were then coded by the first author. These codes were collaboratively reviewed and discussed with the second author until final themes and sub-themes were decided.

4.3 Findings

Three themes with associated sub-themes were derived from the data. The themes were:

1. Resources and environmental accessibility impact social participation

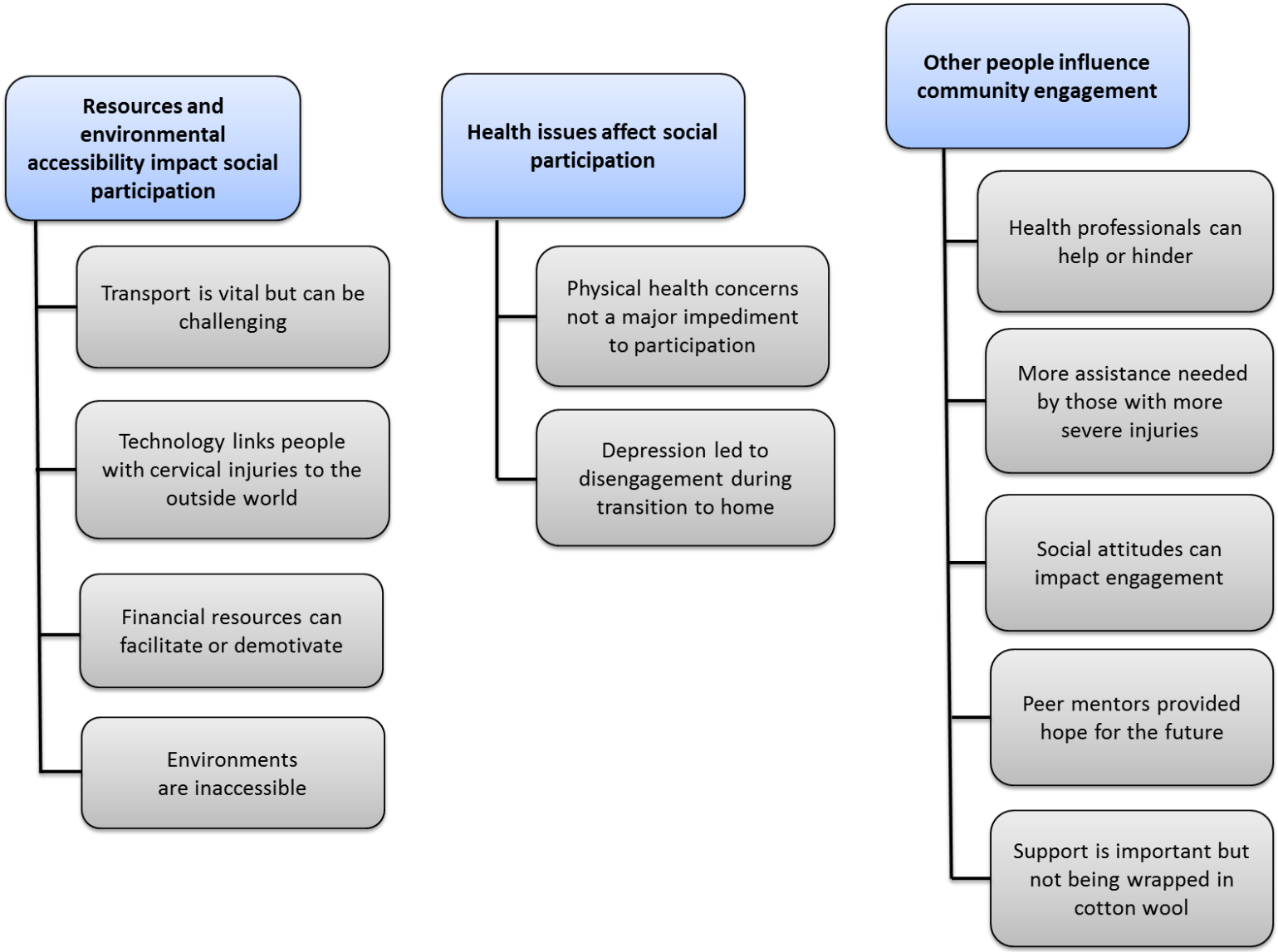
2. Other people influence community engagement

3. Health issues affect social participation

The themes and sub-themes are outlined below, together with quotes from participants.

Figure 7 illustrates the three themes and their sub-themes.

Figure 7 *Thematic map TSCI participants*



4.3.1 Theme One: Resources and environmental accessibility impact social participation.

Resources and the accessibility of the environment impacted on the ability of participants to participate fully in the community in the way that they wished.

Transport is vital but can be challenging.

Access to appropriate transport and infrastructure was vital for people to be able to get out and about in their community. This included public and private transport, the availability of car parks and access to petrol. For those that could drive, problems with access to parking spaces that were the correct size and design, and in an appropriate location, impacted significantly on their ability to participate in the community. In addition, policies relating to who was given a sticker to be able to park in specially designated parking spaces were considered ill-conceived. Nathan stated:

> Oh God, parking, the drama of my life. Yeah, well you've got to be very careful. I will admit that it's not that often that I see people parking that don't have [a] parking permit, but too many people have got them that shouldn't have them.

The sheer amount of effort needed to deal with the constant day to day battle of getting to and from the places that they wanted to go, and the energy needed to get petrol was commented on by some, including Jake:

> If it's late at night and [having to pull] the wheels across in front of you and getting dirty, put the wheelchair together, get in it, fill the petrol, go inside, take the wheelchair apart, put it back in then drive home, take the wheelchair out, put it back together again. That's a pain.

Lack of consideration for people with disabilities in relation to parking was experienced by a number of participants. Mike experienced such troubling problems with other people in relation to parking that he no longer attempted to access many places in the community. For those who could not drive themselves, being able to use accessible, affordable and appropriate public transport was vital.

Technology links people with cervical injuries to the outside world.

Digital technology was identified as being of great importance in linking those with cervical injuries to social networks and communities outside their home. Mike and James used voice activated software for email and internet, while Jenny relied heavily on her iPad for all her correspondence, communication and control of her home environment. She stated: “Yeah definitely technology's a huge link to the outside world; having my iPad and then I have my Facebook, therefore I'm linked with people.”

Technology was also identified as facilitating study, work, and enabling participation in hobbies and leisure activities, particularly for those with cervical injuries. Grant completed courses online which assisted him to obtain work, while Laura described the importance of being able to access information on-line such as accessible accommodation, and tips for planning travel.

Financial resources can facilitate or demotivate.

The need to have adequate financial resources to enable community participation was identified by all the participants. Most of the participants were reasonably satisfied with the amount of care, and the type of equipment they had access to, however, this was not the case for all. Those who were in receipt of a generous compensation scheme

recognised the important role this played in enabling them to participate in the way that they wanted, and stated that it made their home life and relationships easier. Sam stated:

> I suppose it just comes down to having that financial backing, you know, which is not only like you've got a pay coming in every week, you've got medical bills that are paid for. It's a lot more comfortable, and so then you've got more money to spend to do the things that you want to do.

Those that were in receipt of public funding only, stated that they relied on having paid work to enable them to live a satisfactory life. Ethan stated: "I was on a pension for years, before I found this [job] and got off the pension. And, also equipment. If you haven't got enough money to get what you want, you're stuck with second best, I guess."

Some participants, who did not have access to compensation, held a belief that having compensation could lead to lack of motivation or laziness. John stated:

> I see a lot of people with [insurance] and they get a dream run in terms of their modifications and the equipment and the care that they've got access to. Sometimes it can be a blessing but other times it really inhibits almost their motivation to see if they can maximise their potential function.

Environments are inaccessible.

Almost all participants described situations where they were prevented from participating in activities they wanted due to inaccessible natural or built environments. Disappointingly even new buildings, estates and parks have not been designed with the

needs of people with disabilities in mind. This was a consistent finding no matter where participants lived. Mike, who lives in a fairly new, built up area described this problem:

> Here's a new estate that's just been built. If I go into that estate, I have to stay on the bitumen road, because the gutters are too steep, I can't get up the gutters, and there is no footpath, it's just grass.

The outdoor environment proved to be challenging for many of the participants, preventing them from using public outdoor spaces in the way they would like. Craig stated: "Even the park across the road I either go on the grass which is wet and boggy and whatever or I walk [wheel] around the park basically on the concrete around the park so I'm not enjoying the park."

4.3.2 Theme Two: Other people influence community engagement.

The attitudes of other people in the participants' social environment greatly influenced both the practicalities of engaging in the community but also the quality of that engagement.

Health professionals can help or hinder

Few participants identified health professionals as facilitators of their social and community participation. When asked about how they were assisted to get back to work or into other community based activities, most either stated that they had done it on their own or with the help of friends or peers. Even some of those with access to generous compensation schemes did not identify workers or programs funded by these schemes as helpful. Participants' attitudes towards the role of health professionals ranged from positive, to indifferent, to quite negative. John stated: "You get stigmatised

in hospital as a specific level of injury, not as an individual and you don't know any different back then."

Craig's perception was that following his accident the vocational advice he was given was not suitable or of interest to him, and he did not get appropriate retraining. Mike felt that there were very few work options available to him due to the high level of his injury. However, some of the participants did feel that health professionals were of benefit. Jenny talked about some of her positive experiences with occupational therapists, while others, such as Jake, discussed the importance of having access to health professionals with clinical expertise and experience in SCI.

> [She's] a nice lady, knows her stuff and that's what you want. You see young registrars and they technically know what they're doing but it's a different feeling. I mean we're all young at some stage and you've got to learn your craft but it's nice to have someone like [Nurse N] and [Doctor S].

More assistance needed by those with more severe injuries.

Those with more severe injuries – that is, higher level spinal cord impairment - were considerably more dependent on others to assist them to get out of the house, and to complete household tasks for them. This factor resulted in significant differences between those participants who were in receipt of compensation and those that were not. Participants that were in receipt of compensation were able to get the paid care they needed, but those without compensation had more limited access to paid care and assistance, and were forced to rationalise how they used this limited resource, for example for self-care rather than going out. Ethan, who did not have compensation, lived at home with his parents and explained that he would have been much more

restricted if he needed to spend more time and energy on getting dressed, and completing household chores. Ethan stated:

> Especially with care, I think because when you're a quadriplegic as opposed to a paraplegic, you're a lot more dependent on people. Just getting dressed, having a shower. If you haven't got enough help to do those things, that means you can't use your care hours for other options, like leisure and socialising, shopping, just getting out there. So, you're very restricted.

Nathan, who had compensation, was living with his mother at the time of the interview. She did all the household chores, which saved Nathans insurer a great deal of money, and enabled him to study full-time.

Those with low tetraplegia or paraplegia did not need much if any assistance to do activities outside the home, and could usually plan around their limitations by doing activities with friends who were able to help them as needed. Sam, who has paraplegia, returned to four wheeled driving and camping with his cousin:

> I've got my cousin who comes along with me. Like we've been going for years, so we just continue doing it, and he helps me in areas where I can't get in. Then he'll go off and we just sort of keep in contact now with two-way radios. If I need anything he'll come back.

Social attitudes can impact engagement.

Many participants recounted examples of unsupportive social attitudes that they encountered in the community. Experiences ranged from indifference through to

outright abuse from the public. Examples were provided of being treated in either a condescending way, or being misunderstood. For some, such as Mike, who ventured to the annual agricultural show, the experience was so negative that he and his family decided never to go to the same event again:

> When you get into crowds, people are not tolerant of us. When everyone is in a hurry in crowds, they walk all over us and if we bump into anyone they get cranky at us. So I wouldn't go to that anymore.

It was observed by a number of participants who were unable to find paid work since their injury, that potential employers held low expectations and negative perceptions of people in wheelchairs. Tim stated:

> But you realise you've got to make a case, they don't exactly employ people, they don't invite people in wheelchairs to go and do this so you've got to make a case and after a while you get sick of always having to make your case.

In contrast, others such as John and Nathan, did not feel that the public were negative toward them. John stated: "Nowadays the younger generation don't really see disability. I don't have any problems with people in retail, I'm at [shops] three to four times a week and most people are friendly."

Peer mentors provided hope for the future

Learning from others who had been living with a similar injury was very beneficial for many of the participants. The timing of such involvement was important. The earlier people met mentors the sooner they were able to visualise their potential to participate

in society, thus providing hope for the future. Peers served as a buffer against the constraints of rehabilitation and the limits that health professionals sometimes placed on them. Ethan stated:

> I remember when I was going through [rehabilitation] there'd be some people that do what I do now, [peer support worker]. Seeing them and being able to talk to them and then telling their stories, it was not like reading it out of a book or seeing it on TV, and you saw that it was real, it wasn't just hyped up or anything like that.

Mentors were discovered directly through SCI organisations, but also informally through involvement in sporting activities. The male partipcants in particular benefited from meeting mentors through organised sport, which assisted them to find new roles, and facilitated new social connections. There were also some differences in the way that the men and women in this study perceived the role that mentors played in their adjustment process. The focus for men was on developing physical skills and strength, such as transferring or pushing up escalators. While for the women, peer support was helpful in reconnecting with their feminine identity, giving them confidence to again venture out into the world. Jenny stated:

> There's some things that I had to ask like from females and they put me in contact with other women who are living in the community with spinal cord injuries and that helped me with certain things like makeup and dressing and things like that; things that I couldn't kind of figure out on my own.

In this group, there was a contrast between the type of peer support needed by those with low tetraplegia or paraplegia, and that needed by those with high tetraplegia. Mike,

who had high tetraplegia, felt that the peer workers were not able to offer him anything. He believed that if you could not play sport, or push a wheelchair, then the workers were not interested in you.

Support is important but "not being wrapped in cotton wool".

Strong social support offered either by parents, immediate family, close friends, a partner or other family member (in one case an uncle), was articulated by many of the participants as being vital in helping them get back into community life. Analysis of the range of social support evident in people's lives indicated that the key factor was the type of support offered, not who was offering the support. Grant described being close to his family and how important they are to him, while Jenny talked about having enormous support from her family and friends, she stated:

> But I think the best thing is that in my situation is I just had ridiculous amounts of support. Like, I just had my family, my extended family, my now husband, all of my friends; even though they were away, they would come and visit me.

Not being treated as "different" or special and "not being wrapped in cotton wool" was seen as important in encouraging and motivating participants to re-engage in social and community life. Jason felt that his family did not give him special treatment, while John expressed it this way:

> Definitely my close friends and my immediate family never really treated me any differently. There are obviously some modifications you have to make to your lifestyle but they still treat me the same, my brothers will still punch me if I need punching. They've never said 'We can't go and do this because John is in a

> wheelchair,' they'll either work out a way for me to get involved or I just have to sit and watch.

Conversely, Craig lacked family support. He was estranged from his adoptive parents in his early teenage years. He did not identify anyone as having supported or encouraged him to be more involved in the community.

4.3.3 Theme Three: Health issues affect social participation.

Physical health problems were not identified as a major issue among this group of participants, and were minimized by most of them. However, mental health issues were prevalent and significantly impacted on community participation, particularly early on after returning home.

Physical health concerns not a major impediment to participation.

While nearly all had physical health concerns relating to their injury, most participants viewed these issues as a "bump in the road" rather than a major impediment to participation. Ways of managing or adapting to the health condition had been found in many cases, enabling people to continue to do what they wanted. Jake stated:

> I've had pressure sore issues and stuff like that and any health issues I've had they [employer] just accommodate and I am able to purchase extra leave, so I actually reduce my salary and have more leave.

Depression led to disengagement during transition home.

A number of the participants, for example Chris and Laura, talked about going through a stage early on after discharge of significant depression and deliberately isolating

themselves at home. This was a phase that often lasted for some years, but most participants eventually reached the point of being ready to reengage with the world outside their house and immediate family. Jenny stated:

> Back then, I mean look I was really depressed, like I was suicidal…. I think I didn't really want to go out…..I was very ashamed of like me and what I looked like, people staring at me. And, so for a while I just needed to get my head around that and I didn't really want to engage with people for a while until I felt confident.

4.4 Discussion

This paper reports part of a larger study that aimed to explore the experience and meaning of social and community participation of people living with an acquired SCI in Victoria, Australia. This paper presents the views of 17 adults with SCI living in the Australian community, regarding their experiences of the facilitators and barriers to social and community participation. The main findings are presented in relation to existing literature, and a number of issues of relevance to occupational therapists, other health professionals, and policy makers.

Strong social support was identified as important to facilitate the participants in this study to reconnect with the community. This finding is similar to other studies that identified supportive relationships with one or two key people as an important resource in reconstructing a life worth living (Boschen et al., 2003; Hammell, 2004a; Isaksson, Josephsson,Lexell, & Skär, 2007). In this and one other study, timing was identified as important, with most support needed early on after the injury, while participants articulated needing both practical and emotional support (Isaksson). Our findings

reinforce the conclusions of Hammell (2004), that close friends and family should be involved in the rehabilitation process. In particular during the transition to home, key support people need to be actively engaged in the facilitation of social and community activities as soon as possible. The notion of not being treated differently by friends and family was also raised as an important point by a number of participants in this study. No known previous research has described this specific approach by friends and families as enabling. This is an area that may be worth investigating further, as such information may benefit those who are building support around a person who experiences SCI.

Our findings reinforce previous research that has identified the important role that peer support workers or mentors play in assisting people to be able to visualise a positive future (Boschen et al., 2003; Price et al., 2011). Our study extends previous research in this area by describing the preference of people with new SCI to have mentors who are matched in terms of gender, personality, interests and in particular, injury severity. While it is more challenging to find appropriate peers for those with more severe injuries, our analysis identifies this group has having the most challenges in terms of social and community participation, therefore extra efforts need to be applied to this group. Informal peer programmes already exist in Australian spinal programmes, but our findings indicate a need for these programmes to be strengthened and to take a more central role during the transition to home.

It is evident from the findings that some new communities, shopping centres and public facilities continue to be built in Australia without full consideration of the needs of people who have reduced mobility. This is consistent with findings from other overseas studies (Giesbrecht, Ripat, Cooper, & Quanbury, 2011; Newman, 2010; Noreau, Fougeyrollas,

& Boschen, 2002b), however no other studies in Australia are known to have investigated this area in detail. Collectively occupational therapists and other health professionals have a responsibility to be proactive in advocating for incorporation of universal design principles in all new facilities, and in influencing the development of policies that reduce disability by addressing barriers in the physical environment (Sherlaw, Lucas, Jourdain, & Monaghan, 2014).

While there were a range of opinions regarding health professionals in the findings, the majority of participants were either indifferent to or perceived health professionals negatively. Analysis identified an apparent lack of access to health professionals to address social participation, once people returned home. Also highlighted was the need for advice to be provided by clinicians with knowledge about SCI, who were able to adopt a client-centred approach. Our findings are similar to other studies that reported respondents with SCI wanted access to more appropriate and tailored support from health professionals (Lysack et al., 2007; Schönherr et al., 2005). It is evident that current services, both inpatient and community based, should include a greater emphasis on providing the newly injured with strategies to manage the barriers they encounter in the community, both physical and societal, with more focus on reintegration into employment and social activities. Occupational therapists are well-placed to provide such interventions (Isaksson et al., 2007; Price et al., 2011). This may be a proactive step in preventing the development of mental health issues identified by a number of participants in this study.

If participants' needs were met in relation to equipment and assistance, then they had money and time for meaningful activities outside the home. For those without adequate financial resources, informal carers such as family members were heavily relied upon to

assist in instrumental daily activities enabling the person with SCI to keep their energy for activities of meaning to them. Hence more paid personal care, which is flexible in nature, and delivered by appropriately trained carers, is an important service that could be made available to people living with SCI. This has implications for the Australian National Disability Insurance Scheme (NDIS).

4.4.1 Limitations.

The majority of people in this sample were leading active, fulfilling lives at the time of the interviews however, this is not the case for many people with SCI. A significant challenge for this study was recruiting people who were *not* participating in a way that was satisfactory for them. While valuable information was gained from the participants in the aspect of the study reported in this paper, it is recognised that their views may be different to those who are less engaged in the community, and to the broader SCI community.

4.5 Conclusions

Participants identified that adequate financial resources and social support (from friends and family and from peer mentors) assisted their social participation, while the physical environment, unsupportive social attitudes and mental health issues were identified as barriers to community participation. Enabling engagement in meaningful activities in the community must be at the forefront of occupational therapy intervention, both at an individual client level and through advocacy and policy involvement, to improve the quality of life of people with SCI living in the community.

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Interview Guide

- What are the greatest difficulties or barriers you face when attempting to be involved in the community?
- Can you think of a situation recently when you faced some type of barrier or problem when you wanted to participate in a community based activity?
- What things help you/have helped you to be involved in the community in the way that you want?
- Has your social and community participation changed at any time since your injury? If so, how?

4.6 Impact of Study

Journal Impact Factor: 1.45

Journal rank: 35 of 65 Rehabilitation

4.7 Chapter Summary

The findings of the first phase of the study as presented in this chapter, informs occupational therapy and rehabilitation practice. The important role that friends, family and peer support workers have in facilitating social and community participation once people with TSCI are discharged from hospital was highlighted. Identified barriers such as inaccessible built environments, problems with appropriate paid care and adequate,

timely equipment provision, are areas that occupational therapists can assist with by working individually with their clients, but also through engagement in policy development. Following the first phase of the study, including data analysis, further review of existing evidence, and discussion with supervisors, it was apparent that the experiences of people with non-traumatically acquired SCI were not well-researched, particularly in relation to their social and community participation and ongoing health and well-being. Therefore, active recruitment of people with NTSCI was undertaken, and the second phase of the study completed. The findings from this phase are presented in Chapter Five.

Chapter Five

Understanding the factors that influence social and community participation as perceived by people with non-traumatic spinal cord injury (submitted manuscript)

Active recruitment of people with NTSCI was undertaken in the second phase of this study, resulting in a total of 17 participants with NTSCI being interviewed. This chapter presents the findings of data analysis in relation to the subsidiary research questions: *What is the experience of social and community participation for people with non-traumatic SCI? What are the facilitators and barriers to social and community participation following non-traumatic SCI?* The findings are reported, together with implications for occupational therapists, and other health professionals in the form of a manuscript submitted to *The British Journal of Occupational Therapy,* for consideration of inclusion in a special issue on living with a neurological condition.

5.1 Background

Traditionally, spinal cord injury (SCI) has been classified according to the cause of injury. The term traumatic spinal cord injury (TSCI) is used when the cause has been as a result of an external event such as a motor vehicle accident, fall or violence. In contrast, damage to the spinal cord from pathology such as spinal cord myelopathy, or transverse myelitis is referred to as non-traumatic SCI (NTSCI) (Guilcher, Parsons, Craven, Jaglal, & Verrier, 2016). SCI is a serious life event whereby an individual experiences permanent spinal cord damage, resulting in major physical and sensory disabilities (van Leeuwen, Post, Westers, van der Woude, & de Groot, 2012).

Global incidence of TSCI is estimated to be 23 cases per million of population (Lee, Cripps, Fitszharris and Wing, 2014). No data were found regarding the specific incidence in Britain, but regional data from Western Europe estimated the incidence of

TSCI to be 16 SCI per million of population. This does not include estimates of NTSCI. Incidence of NTSCI in Australia and other developed countries has not been consistently recorded partly due to the fragmented way in which people with a NTSCI receive rehabilitation services (New, 2006), and also due to the lack of standardized International Classification Diagnostic (ICD) codes for people with NSTCI (Guilcher et al., 2016). Only recently have researchers attempted to quantify incidence rates of NTSCI. Guilcher et al (2016) conducted a retrospective cohort study between April 2006 and March 2012 in Ontario, Canada, and found that of those people admitted to hospital with SCI 20.0% were categorized as having TSCI and 80.0% as having NTSCI. A population-based study conducted in Australia of new SCI inpatient admissions, found that 62.1% of admissions were for people with NTSCI (New, Simmonds and Stevemuer, 2011). Although the incidence of NTSCI is increasing in developed countries (Noreau et al., 2014), the specific issues and challenges that this group faces have not been well investigated.

People with NSTCI are usually older than those with TSCI, are 50% as likely to be female as male, more commonly experience incomplete paraplegia, are usually reliant on government pensions and experience more age related co-morbidities (Noreau et al., 2014; Guilcher et al., 2010). Hence, the issues facing people with NTSCI in the community cannot be assumed to be the same as those for people with TSCI (Ones et al., 2007).

Being an active and contributing member of society is highly valued for most people, including those living with disability (Magasi et al., 2008; Schönherr et al., 2005). It has been argued that measuring outcomes following rehabilitation needs to include returning to community life as this reflects the return to the “real world” (Cott et al.,

2007; Hammell, 2010). For the purpose of this study, social and community participation refers to activities that involve interaction with other people outside the home environment, and includes productivity roles (e.g. paid work, education or volunteering) and/or leisure roles (e.g. playing sport, or meeting friends). To date there has been limited research that has explored the factors that influence the social and community participation of people with NTSCI, from their perspective. This information is critical to inform occupational therapy practice, and to assist the development of responsive, targeted programs and interventions specific to the needs of this population.

This paper presents the findings of part of a larger study that investigated the experience and meaning of social and community participation of people with acquired SCI (traumatic and non-traumatic aetiology). The barriers and facilitators to social and community participation for people with TSCI have been previously published (Barclay, McDonald, Lentin and Bourke-Taylor, 2016). The objective of this paper is to present the experiences of social and community participation of adults living with NTSCI, and the factors that influence that participation. The research questions for this part of the study were*: What is the experience of social and community participation for people with non-traumatic SCI? What are the facilitators and barriers to social and community participation following non-traumatic SCI?*

5.2 Method

As the aim of the study was to explore the realities of social and community participation that are constructed by those living with NTSCI, a pragmatic qualitative design, underpinned by the constructivist paradigm was selected. A generic qualitative inquiry approach was considered appropriate (Patton, 2015). Once ethics approval was

gained from the appropriate human research ethics committees, purposive sampling was undertaken to recruit people who were living in the community with an acquired NTSCI, aged between 18 – 85 years. People with an additional diagnosis of brain injury or intellectual disability, and those who could not understand written or spoken English were excluded due to the need to be able to answer sometimes complex questions, and insufficient funding to employ interpreters. Potential participants contacted the researcher and were sent an Explanatory Statement and Consent Form to read. If they wished to participate the signed Consent Form was returned to the researcher.

Data were collected by conducting in-depth semi-structured interviews, using the same interview guide as the previous publication (Barclay et al., 2016). The interviews were conducted in the participants' homes. The questions formed part of the total interview, which lasted between 60 – 90 minutes. Questions were open ended and prompts were used to elicit further information. Dated field notes were made immediately after the interview, and stored together with the transcribed interview and demographic information of each participant. Details about the participant's environment, their appearance, demeanour, and non-verbal language were recorded. In addition, the researcher's reaction to the interview, meanings and significance of observations were noted (Patton, 2015). Field notes were referred to during data analysis and assisted in compiling a thick description of the context. A newsletter outlining preliminary results was prepared and disseminated to the participants as a form of member checking. Field notes and member checking were methods employed to maximise to the trustworthiness of the data (Patton, 2015).

Recruitment, data collection and data analysis continued until a sample was achieved that included a variety of people of different ages, gender and socio-economic

backgrounds, and when data saturation was achieved (when no new themes or sub-themes were identified) (Braun & Clarke, 2013).

The data were thematically analysed to inductively identify codes, categories and themes, using a constant comparative approach (Braun & Clarke, 2013; Creswell, 2013). Each transcript was coded by the first author, and five transcripts were coded by the second author. Coding is the process of examining data, and identifying and noting aspects that relate to the research question(s) (Braun & Clarke, 2013). Codes that had similarities were categorised, and then developed into themes and sub-themes. Themes are patterns of meaning across data that capture something important in relation to the research question(s) (Braun & Clarke, 2013). Discussion of the findings, themes and sub-themes occurred among all the authors to enhance the rigour of the findings (Patton, 2015).

5.3 Findings

Seventeen participants with NTSCI were interviewed. Table 12 *Description of NTSCI Participants*outlines the injury and demographic details of the participants including living situation, funding support, and the social and community activities they were engaged in. Pseudonyms are used in place of participants' actual names. The sample consisted of nine males (53%) and eight females. The most common causes of spinal cord damage were abdominal aortic aneurysm rupture (*n*= 4) or abscess or infection (*n*=4).

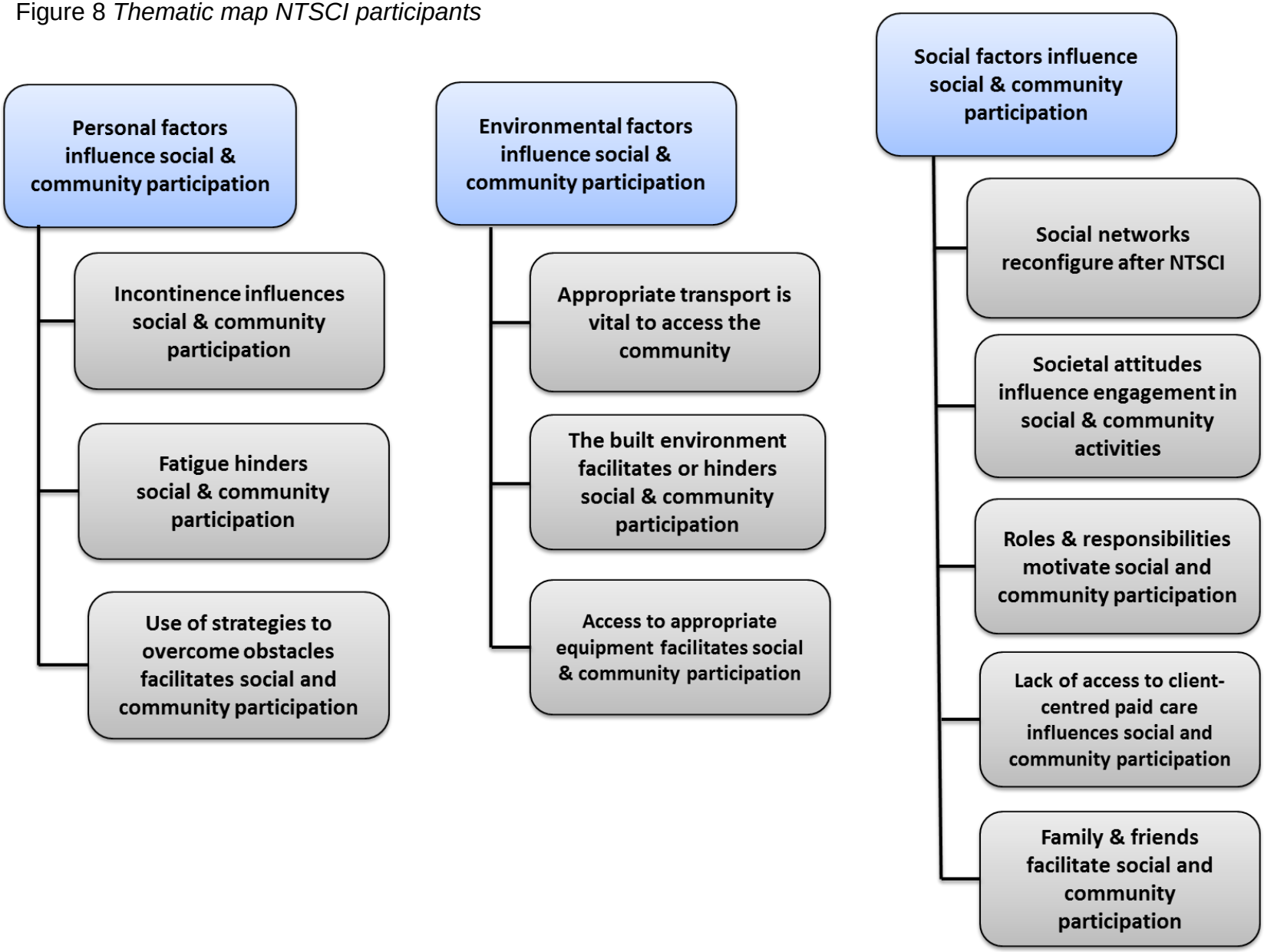
Table 12 *Description of NTSCI Participants*

Name	Age at interview	Time since damage	Level of damage & mobility status	Funding	Living situation	Social and community activities	Work status
Sue	59 years	8 years	Incomplete paraplegia. Walking frame	Pension. Public funding	Lives alone	Has many friends and very involved socially in community.	Currently not working – would like to.
George	69 years	10 years	Complete paraplegia. Wheelchair dependent	Pension. Public funding	Lives with spouse/partner.	Goes out 2-3 time per week with spouse.	Retired.
Aaron	33 years	Less than one year	Incomplete paraplegia - almost full recovery. Full mobility.	Public funding.	Lives with flat mate	Active socially with friends.	On sick leave from work. Employed full-time.
Betty	75 years	3 years	Incomplete paraplegia. Walking frame	Pension. Public funding	Lives alone	Very active in community.	Retired.
Fred	68 years	1 year	Incomplete paraplegia. Wheelchair dependent	Pension. Private health insurance.	Lives with spouse/partner	Limited social activities - mostly family related.	Retired.
Vladimir	70 years	1 ½ years	Incomplete paraplegia. Wheelchair dependent.	Pension. Public funding.	Lives with spouse/partner	Minimal social and community activities.	Retired after injury.
Richard	67 years	61 years	Complete paraplegia. Wheelchair dependent.	Pension. Public funding.	Lives with spouse/partner	Very active advocate in community. Sporting interests.	Voluntary work.
Brian	78 years	2 ½ years	Incomplete paraplegia. Wheelchair dependent.	Pension. Public funding.	Lives with spouse/partner	Minimal community based activities now. Family comes to visit.	Retirement after injury.
Christine	52 years	6 years	Incomplete paraplegia. Wheelchair dependent.	Pension. Public funding.	Lives with spouse/partner and off-spring	Involved in children's activities. Involved in other regular community activities.	Not working.
Valerie	53 years	Less than one year.	Incomplete tetraplegia. Walks with SPS outdoors.	Public funding.	Lives with spouse/partner	Enjoys travel with spouse. Some other social activities.	Was running own business. No longer able. Wants to work.
Simon	66 years	6 years	Incomplete paraplegia. Walks with SPS.	Self- employed. Public funding.	Lives with spouse/partner and niece	Self-employed. Minimal other social activities.	Self-employed. Some volunteer work.
Lisa	67 years	2 ½ years	Incomplete paraplegia. Walker for long distances.	On part pension. Public funding .	Lives alone	Travels with partner. Sees adult children irregularly.	Some voluntary work. Retired.
Shanti	43 years	7 years	Incomplete tetraplegia. SPS	Pension. Public	Lives with	Limited community based activities.	Not working.

			inside, crutch outside	funding.	spouse/partner and off-spring		
Henry	65 years	2 years	Incomplete tetraplegia. Walks with 2 x SPS.	Self-funded. Public funding for equipment.	Lives with spouse/partner	Limited community based activities.	Retired.
Sandra	75 years	4 years	Incomplete paraplegia. Wheelchair	Pension. Public funding.	Lives alone	Very few social outlets – no regular friends or social groups.	Not working.
Daisy	83 years	7 years	Incomplete paraplegia. Walker.	Pension. Public funding.	Lives alone	Very active. Goes out nearly every day.	Not working. Very active volunteer.
Michael	59 years	11 years	Incomplete paraplegia. Wheelchair dependent.	Compensation.	Lives alone	Goes to pub regularly. Does shopping, sees partner.	Not working. Retired.

The factors that influenced the experience of social and community participation of people with NTSCI were grouped into three broad areas: personal factors, environmental factors, and social factors. Figure 8 *Thematic map NTSCI participants*depicts the themes and associated sub-themes.

Figure 8 *Thematic map NTSCI participants*



5.3.1 Theme one: Personal factors influencing social and community participation.

A variety of personal factors that were unique to each person influenced their social and community participation. The most common influential factors described by participants were incontinence and fatigue. In addition, the individual's personal approach to managing the restrictions they faced influenced their social and community participation.

Incontinence influences social and community participation.

Fifteen of the 17 participants had an incomplete spinal injury, resulting in many having partial or total bladder and/or bowel incontinence. For most people, their bladder incontinence was not severe enough to warrant catheterisation, but resulted in urinary urgency. This impacted on their satisfaction with social and community participation, due to the need to be able to find a toilet immediately when required. This issue was very much in the forefront of many of the participants' minds, particularly the women.

Sandra said: "It affects you 'cause you're just not in control…and it's embarrassing if anything happens. I'm in a situation now that I have to know where the nearest toilet is. It worries me if I go somewhere."

Knowledge regarding the location of accessible toilets in the community was very important and often dictated where people would go and what they would participate in. Some of the participants had developed strategies to manage this problem, enabling them to feel comfortable enough to venture out in public. Strategies included going to the toilet prior to leaving the house, planning ahead and knowing where accessible toilets were located, taking a change of clothes, and only going to locations where they had been before or a family member had previously checked the amenities. Christine

described sometimes taking equipment such as a commode with her in case she couldn't access a toilet. For some of the participants, such as Shanti and Sandra, the possibility of having a bladder or bowel accident was too distressing and discouraged them from going out in public very often.

Fatigue hinders social and community participation.

Fatigue and the need to pace activities, was a major impediment to social and community participation for many. Steven stated that he could not sit up in the wheelchair all day as he became too tired, preventing him from being able to go out of the house for long. Daisy said that she became fatigued if she attempted to walk too far, restricting what community activities she could engage in. Both Valerie and Sue talked about fatigue being a major barrier to participating in paid employment, due to the need to pace their activities and take regular rest breaks. "That's why I've decided I just… haven't got the energy to work anymore, as well, in paid work." (*Sue*)

Use of strategies to overcome obstacles facilitates social and community participation.

Those who expressed most satisfaction with their social and community participation used a variety of problem solving strategies to overcome obstacles. Such strategies included: the willingness and ability to garner assistance; being able to plan ahead and be organised; maintaining a flexible attitude to manage unexpected occurrences (for example bladder or bowel accidents); doing research before going out; and the ability to find solutions to problems that arise (such as lack of accessible car parking). Christine said: "You've got to take all your stuff [equipment] with you. It's always a drama to take me somewhere no matter where we go. No matter what we do, we always have to be planning ahead."

Sue utilised a number of strategies, including calling on friends to assist her as needed and using the internet to get in contact with other people with similar disabilities, to find out how they manage. Richard relied heavily on the internet to research wheelchair access and equipment and stated: "Absolutely brilliant. I'd be absolutely lost without my best friend Google".

A number of participants emphasized the importance of having a positive attitude. Betty said: "It's all about your attitude". While Lisa stated: "The best thing you have to do is to think of the future … and make the most of it".

5.3.2 Theme Two: Environmental factors influence social and community participation.

Factors in the environment including availability of appropriate transport, accessibility of the built environment, financial resources and access to appropriate equipment influenced the social and community participation of participants.

Appropriate transport is vital to access the community.

Transport that was appropriate and affordable to enable people to get to the places they wanted and needed to go in the community was vital. Seven participants were totally reliant on their partner or spouse to take them out in a vehicle, either because they did not drive, or because they could not get their wheelchair or walker in and out of the car independently. George said: "I rely on someone to be with me all the time. Because of needing help to get the wheelchair in the back of the car, and all that business".

Those participants who had access to their own car discussed problems related to the number, design and location of parking spaces, and how this was detrimental to their ability to participate in the community.

> Yesterday I went and did the shopping for the first time on my own, and couldn't get the disability park at Safeway, because they've only got three, and one of them you can't even get out on the driver's side because the curb's there. Unbelievable. (*Sue*)

Betty, who could not drive, relied on public transport to get around, while Sue and Lisa often preferred public transport to driving. Public transport worked well most of the time but there were problems encountered in getting wheelchairs and walking frames onto buses and trams, and difficulty being able to move around once on board. Henry went on an extended train trip across Australia, and described the following issue: "We were led to believe that I could use the walker on the train, but in fact it didn't fit down the carriageways, so I was forced to use the sticks, and that was a mighty challenge."

The built environment facilitates or hinders social and community participation.

A number of participants recounted situations when they had difficulty accessing the built environment. Generally the larger chain stores and supermarkets were easier to get wheelchairs or walkers around compared to smaller boutique stores, restaurants, and theatres. Christine commented that her church was not accessible, Sue talked about difficulty getting into a building where there was a counselling service, and Fred noted that he could not get into the homes of his friends and family. "Because most houses have at least one or two steps, Don't they? There's very few that are just flat."

Access to appropriate equipment facilitates social and community.

Assistive equipment, such as wheelchairs, walkers, and scooters were identified as being facilitators for community access. However, participants discussed challenges in relation to existing equipment supply schemes, for example long waiting times for receiving equipment, lack of choice of equipment, and lack of funding for ongoing maintenance. Christine spoke of the difficulties dealing with the government equipment provider:

> This is where I get onto banging my head against a brick wall…because I've got funding for a wheelchair they won't give me funding for another scooter. So even though the scooter that they've given me has died, they won't give me anything more.

The extent to which mobility equipment facilitated community access was also influenced by where people lived. Brian lived in a built-up area and used his motorised wheelchair regularly to get to shops, whereas Henry, who lived in a rural area, was too far away from facilities to use his motorised wheelchair to reach them. In addition, the large size of motorised wheelchairs and scooters made it impossible to transport them in cars, resulting in a different wheelchair being needed for some community outings.

5.3.3 Theme Three: Social factors influence social and community participation.

Other people, including paid carers, friends, family, past work colleagues, health care professionals and the attitudes of the general public influenced the extent of and satisfaction with social and community participation.

Social networks reconfigure after NTSCI.

The social networks of many of the participants changed after the injury. Some participants, such as Fred, felt their friends had deserted them, and that they no longer shared common interests or activities. He said: “Some of our friends have deserted us you know….They’ve stayed in touch but [offered] no support and no assistance.” Those who were in full-time employment at the time of the injury, such as George and Brian, greatly missed the social contact that they had when working. Brian reflected:

> You’re socially involved, they invite you to their christenings, and weddings, and you know, so every weekend you’re going somewhere. …Because I never kept telephone numbers of my employees and all that- well, it was kept in the office, but I wouldn’t contact them [now].

Some people developed new or different social networks, through their experience of acquiring a NTSCI. Fred spoke of his personal care attendants becoming like family, Brian became more connected to his neighbours, and Shanti developed stronger links with her cultural community who stepped in to offer support and assistance. Others, such as Sue, who did not live with a partner, relied heavily on friends for support, and considered them family. “I mean my friends are always the most important part of my life. What are friends? I mean they’re there for you through good times and bad.” Henry, who had only had the NTSCI for 18 months, talked about feeling quite lonely since the injury. He had recently joined a men’s activity group and community charity to strengthen his links with the community.

Societal attitudes influence engagement in social and community activities.

There were a range of descriptions regarding the way that people in public acted toward the participants. Christine, Lisa, Shanti, Daisy, Steven and Betty felt that people were very helpful, and George acknowledged that he had received a lot of support from his previous work place. In contrast Sue, Brian and Fred talked about people being ignorant and rude, and Richard spoke of frequently encountering poor attitudes from members of the public. How participants responded to negative attitudes also varied. Henry utilised his sense of humour to manage potentially upsetting situations, and he described how he approached difficult interactions with people.

> Look I act as normally as I can, but I just make a mental note of what a “dick” he or she is. Look I don’t treat them with any malice at all, because I know back then [before injury] I was guilty of doing the same thing.

Roles and responsibilities motivate social and community participation.

Some participants had roles and responsibilities that were meaningful and valuable to them, which motivated them to participate in the community. For example, Fred and Daisy had dogs that they needed to walk. Fred also looked after his grandchildren regularly, which encouraged him and his wife to go to the park or other places with them. Shanti and Christine, who were both mothers, viewed it as their responsibility to attend their children’s school functions and other activities. Volunteering was also a motivator for social participation. Daisy and Richard were active volunteers and were regularly involved in community life as a result, which was very satisfying for them. Daisy spoke of how her occupational therapist facilitated her to get involved in voluntary work at a local plant nursery. “She was the most wonderful occupational therapist that

you could ever imagine. She really helped me. She actually took me down to the nursery just to say hello to the people and help me feel comfortable."

Lack of access to paid person-centred care influences social and community participation.

Most participants who needed paid care were reliant on government funded programs. Many of the participants perceived that they had limited hours of funded assistance available, and needed to prioritise personal care over social and community participation. Fred stated that if he had funding for extra care hours: "I would ask the carers, maybe they can take me to the shopping centres. It would release my wife to go and do her thing."

Reliance on the government funded care system sometimes resulted in lack of flexibility to fit in with individual needs. Richard, who volunteered as a disability advocate, talked about the need for adequately trained staff – both health providers and carers, and the need for person-centred services. In relation to the impending changes to disability services in Australia he stated: "Service providers need to come to terms with the fact…that people are individuals and they are going to learn that they have the right to say what they want to do."

Family and friends facilitate social and community participation.

Eleven of the 17 participants relied on the assistance of another person to access places or facilities in the community. They either needed someone to drive them, to help transfer them in and out of the car, or assist them with equipment such as wheelchairs and walkers. For some, assistance was needed to get into buildings and to use toilets. Sue, who lived alone, called on friends to assist, but for the other ten, their

partner or spouse was vital to enable them to live at home and from there access the community. It was acknowledged by George, Shanti and Christine that if they did not have a partner they would be much more housebound, and would probably need to live in an aged care facility. Christine did in fact live in an aged care facility for several months when her husband was having surgery. George spoke about his reliance on his wife Nancy: “I think you’re fairly restricted socially because of the work involved in getting out, and it just puts more stress on Nancy (wife). If I want to do something, she’s got to be involved as well.”

5.4 Discussion and implications

The objective of this paper was to present the findings of a study that explored the experiences of social and community participation of adults living with NTSCI, and the influences on that participation. The aspect of the study reported in this paper identified three main themes: Personal factors influence social and community participation; Environmental factors influence social and community participation; Social factors influence social and community participation.

There were a variety of personal factors influencing social and community participation, however bladder incontinence or urinary urgency, was one of the main impediments to satisfactory community participation described in this study. Gupta, Taly, Srivastava and Murali (2009) found that two of the top three complications following NTSCI were urinary tract infections and urinary incontinence. In our study, the women in particular, spoke of how the constant concern of having a bladder accident impacted on their confidence and engagement when out in public, or prevented them from going out in public. This is similar to findings from studies with other populations that have found urinary incontinence affects time use and activity patterns (Fultz et al., 2004), and can

lead to the avoidance of community outings, with associated feelings of embarrassment and stigma (White et al., 2014). It is important that occupational therapists advocate on behalf of their clients when bladder management methods are being discussed and selected to ensure that the management method allows the person with NTSCI to feel confident to engage in community activities. Fully engaging individuals in the decision making process, including assisting them to visualise the likely social activities they will be involved in and how different methods of bladder management will impact on those activities is an important part of the decision making process (Engkasan, 2014). When planning community based activities with their clients, occupational therapists can facilitate strategies such as using interpersonal and problem solving skills to manage stigma and promote confidence (White, 2014).

Fatigue was identified by the people with NTSCI in this study as restricting their ability to undertake paid employment and as a barrier to the number and type of community based activities people felt able to participate in. A scoping review of complications following SCI found fatigue was identified in the top seven most common complications, and worsened with increased age (Jensen et al, 2013). It is possible that the older age that people tend to acquire NTSCI, and/or the presence of age-related co-morbidities may influence the extent to which fatigue affects participation. Occupational therapists can assist people with NTSCI to manage fatigue by providing education on fatigue management strategies both during inpatient rehabilitation and once people have returned to their home environment. Such strategies include: developing an understanding and acceptance of one’s capabilities and limitations; identifying priorities and goals; and focussing on meaningful and rewarding activities that enhance the quality of one’s life (Hammell et al., 2009).

Barriers to social and community participation in this study included problems with private and public transport, problems with parking, inaccessible built and natural environments. These barriers are similar to those identified in other studies conducted with people following SCI (Barclay et al., 2016; Schopp et al., 2007). While there has been progress in policy and legislation related to building codes in countries such as Australia, there is an ongoing imperative to strengthen policies that aim to reduce barriers in the physical environment, and to incorporate universal design principles for the benefit of all users (Geisbrecht et al., 2011; Sherlaw et al., 2014).

There was a significant change to social networks and loss of productive roles for a number of people in this study. Without assistance from friends or family to overcome barriers to social and community participation, the outcome for some was to stay at home and try to be content with solitary activities. For people with NTSCI with limited social support, providing assistance to create new social networks in the community is vital to enhance their quality of life (Muller et al., 2013). Occupational therapists and other health professionals can facilitate this process by connecting their clients with support groups, and referral to local community based activities that are personally meaningful.

If there is a lack of access to paid care, personal care is often prioritised over assistance to access the community, thus necessitating reliance on family or friends to enable social and community participation. The important role that a key support person provides, usually a family member or friend, in facilitating a return to social and community participation following TSCI has been well documented (Barclay et al, 2016; Carpenter et al., 2007). As medical interventions improve and populations in Western countries age, the number of people with chronic health conditions, including NTSCI,

will continue to rise in the future (Guilcher et al., 2010). This has the potential to increase the support and assistance required from family members. Actively involving family and friends in all aspects and stages of rehabilitation is recommended (Hammell, 2004). In addition, occupational therapists can facilitate carers' access to information, can provide education and training, and can promote carers' engagement in meaningful activities to promote their own health and well-being (Barclay et al., 2016).

Peer support workers have been identified as providing hope for the future and facilitating social engagement for people with TSCI (Barclay et al., 2016; Veith et al., 2006). However, because people with NTSCI are not usually admitted to specialist spinal facilities, and the follow up services are often fragmented and not well coordinated (New, 2006). As a result they do not always have early access to peer support workers in the same way as those with TSCI do. Occupational therapists can facilitate these making these connections, or refer their clients to appropriate support agencies.

Limitations.

Approximately 70% of people in this study were recruited through the same metropolitan rehabilitation hospital, therefore many of the participants underwent a similar rehabilitation programme, with access to similar supports after discharge. The study sample consisted only of people over the age of 33 years, with few people from culturally and linguistically diverse backgrounds. Future studies could explore the issues for more people from non-English speaking backgrounds, and from other rehabilitation services.

5.5 Conclusions

In this study of seventeen people with NTSCI, access to appropriate transport, person-centred assistance from paid carers, social support and assistance from family and friends, access to appropriate equipment, having roles and responsibilities and being able to utilize strategies to overcome obstacles in the community, all enhanced people's ability to engage in social and community activities of their choosing. Incontinence and fatigue, limited access to paid care and equipment, inaccessible built environments, and negative social attitudes prevented some people from being involved in social and community activities in the way that they wished. These findings inform the understanding of occupational therapists and other health professionals regarding the social and community participation of people with NTSCI and how this can be facilitated.

Key Findings

- People living with non-traumatic spinal cord injuries experience a range of barriers to their participation in social and community activities
- Occupational therapists can assist in overcoming many of the barriers encountered

What the study has added

This study adds greater understanding of the issues facing people with non-traumatic spinal cord injury, informing the practice of occupational therapists working with these clients in the future.

5.6 Chapter Summary

The findings from the second phase of the study provides important, previously unreported information regarding the barriers and facilitators to social and community participation from the perspective of people living with NTSCI. Issues regarding incontinence and fatigue, minimal exposure to peer support workers, reduced access to appropriate equipment, and limited access to paid care resulting in reliance on family members, were findings that differed from those of phase one of the study, that is the barriers and facilitators to social and community participation of those with TSCI. There were some findings in common with the TSCI group, particularly in relation to employment, transport issues and the built environment. Examining the findings from these two phases of the study has important implications for policy and will be revisited in Chapter Seven.

Chapter Six

A qualitative study on how social and community participation following spinal cord injury influences self-worth (submitted manuscript)

Chapters Four and Five presented the findings of phases one and two of the study, that is the barriers and facilitators to social and community participation experienced by a sample of people with TSCI (*n* = 17) and the perceived influences on social and community participation of a sample of people with NTSCI (*n* = 17). Chapter Seven consists of the first of the discussion chapters and discusses some of these findings in the context of Australian disability, aged care and other service delivery systems.

This chapter presents the findings of the third phase of the study. The data from the interviews of 36 participants (19 people with TSCI and 17 people with NTCSI) were analysed and are presented in relation to the following research questions: *What is the experience of social and community participation for people living with an acquired SCI? How important is social and community participation from the perspective of people living with an acquired SCI? What are the meanings associated with social and community participation for people living with an acquired SCI?* This manuscript has been submitted to the journal *OTJR: Occupation, Participation and Health.*

6.1 Introduction

Acquired Spinal cord injury (SCI) is a serious life event whereby an individual experiences permanent spinal cord damage, resulting in major physical and sensory disabilities (van Leeuwen, Post, Westers, van der Woude, & de Groot, 2012). These disabilities can result in changes to time use, roles and occupations, and the person's social and community participation (WHO & ISCOS, 2013). The International Classification of Functioning, Disability and Health (ICF) provides recognition that

participation is a valued outcome following rehabilitation after an injury such as a spinal cord injury (SCI) (Carpenter, Forwell, Jongbloed, & Backman, 2007; WHO, 2001). The ICF highlights the important role that environmental factors play in restricting the participation of people with disabilities such as SCI, and gives weight to the argument that participation restrictions are not only due to people's physical impairments and personality characteristics, but also to their opportunities for equality of participation (Barclay, McDonald, Lentin, & Bourke-Taylor, 2016; Hammell, 2010). However, there continues to be debate regarding the conceptualisation of participation as included in the ICF (Noreau, Fougeyrollas, & Boschen, 2002b; Whiteneck & Dijkers, 2009), in addition to criticism for the lack of emphasis in the ICF on the satisfaction and meaning attributed to that participation by the individual (Brown, 2010; Hemmingson & Jonsson, 2005). It is evident that the definition of participation provided by the ICF (WHO, 2001) does not reflect the complexity or value of participation experienced by people with disabilities, or as Dijkers notes, there is more to participation than performance (Dijkers, 2010).

The current lack of consensus regarding definitions about participation has consequences for communication between professions and clinicians (Piskur et al., 2014), and for the development and selection of instruments to measure concepts such as social participation and community participation (Chang, Coster, & Helfrich, 2013; Whiteneck, 2010). However, the main concern is that if clinicians such as occupational therapists lack understanding of what participation means to the people they are working with, then their interventions cannot be truly client-centred.

A critical review conducted by the authors of the current evidence regarding social and community participation following SCI and the factors that influence that participation,

found that further research utilising in-depth, exploratory methods to investigate social and community participation following SCI was needed (Barclay, McDonald, & Lentin, 2015). Qualitative research is appropriate to use when a problem or issue needs to be explored (Creswell, 2013), allowing participants' voices to be heard, and the complexity of living with a disability to be uncovered (Hammell, 2001) thus adding to knowledge and understanding. Investigating how people with SCI are participating in their community, whether they value that social and community participation and whether it contributes to their health and well-being, will assist in the development of interventions to support people as they transition home after discharge from hospital.

This paper reports the third phase of a study aimed at exploring the social and community participation of people living with an acquired SCI in Victoria, Australia. The research questions guiding the part of the study reported in this paper were: What is the experience of social and community participation for people living with an acquired SCI? How important is social and community participation from the perspective of people living with an acquired SCI? What are the meanings associated with social and community participation for people living with an acquired SCI?

6.2 Methods

A purposive sampling approach (Liamputtong, 2009; Minichiello, Sullivan, Greenwood, & Axford, 2004) was utilised to recruit people who were living in the community with an acquired SCI, aged between 18 – 85 years. As interviews and analysis progressed participants with more diverse backgrounds were sought for inclusion. For example, people of both genders, from a range of age groups, from different education and employment backgrounds, with varying lengths of time since injury, different levels and types of SCI (both traumatic SCI and non-traumatic SCI) and a range of social and

community participation were included. Recruitment continued until no new themes or sub-themes were identified in the data (Braun & Clarke, 2013).

In-depth semi-structured interviews were conducted by the first author, the total interview time lasted between 60-90 minutes. The data analysed for this paper specifically related to the research questions listed above, and formed part of the total interview. In addition, dated field notes were made immediately after the interview, and stored together with the transcribed interview and demographic information of each participant (Patton, 2015). A reflective journal was kept by the first author to reflect on the progress of the research, observations and thoughts. Prior to commencing data collection, ethics approval was gained from the required ethics committees.

Data from 36 participants were analysed. Twenty-three interviews were conducted face to face in a location selected by the participants, ten were conducted over the telephone and three using Skype. Interviews were digitally recorded and later transcribed verbatim. Transcribed interviews were sent back to participants and they were asked to make comments regarding the authenticity of the transcripts and if there was anything further they wished to add (Patton, 2015). Only two minor alterations were made as a result of this process. Data from 36 participants were analysed. Twenty-three interviews were conducted face to face in a location selected by the participants, ten were conducted over the telephone and three using Skype. Interviews were digitally recorded and later transcribed verbatim.

Thematic analysis was undertaken by the first named author to inductively identify codes, categories and themes from the data (Braun & Clarke, 2013). Themes are patterned meaning across data that capture something important in relation to the

research question(s) (Braun & Clarke). Once potential themes were identified, a process of constant comparison was employed until final themes were decided on, named and defined. Discussion of the findings, themes and sub-themes occurred among the research team, providing opportunities to ensure the rigour of the findings (Curtin & Fossey, 2007). This form of researcher triangulation is used to try and compensate for single-researcher bias (Curtin & Fossey, 2007).

6.3 Findings

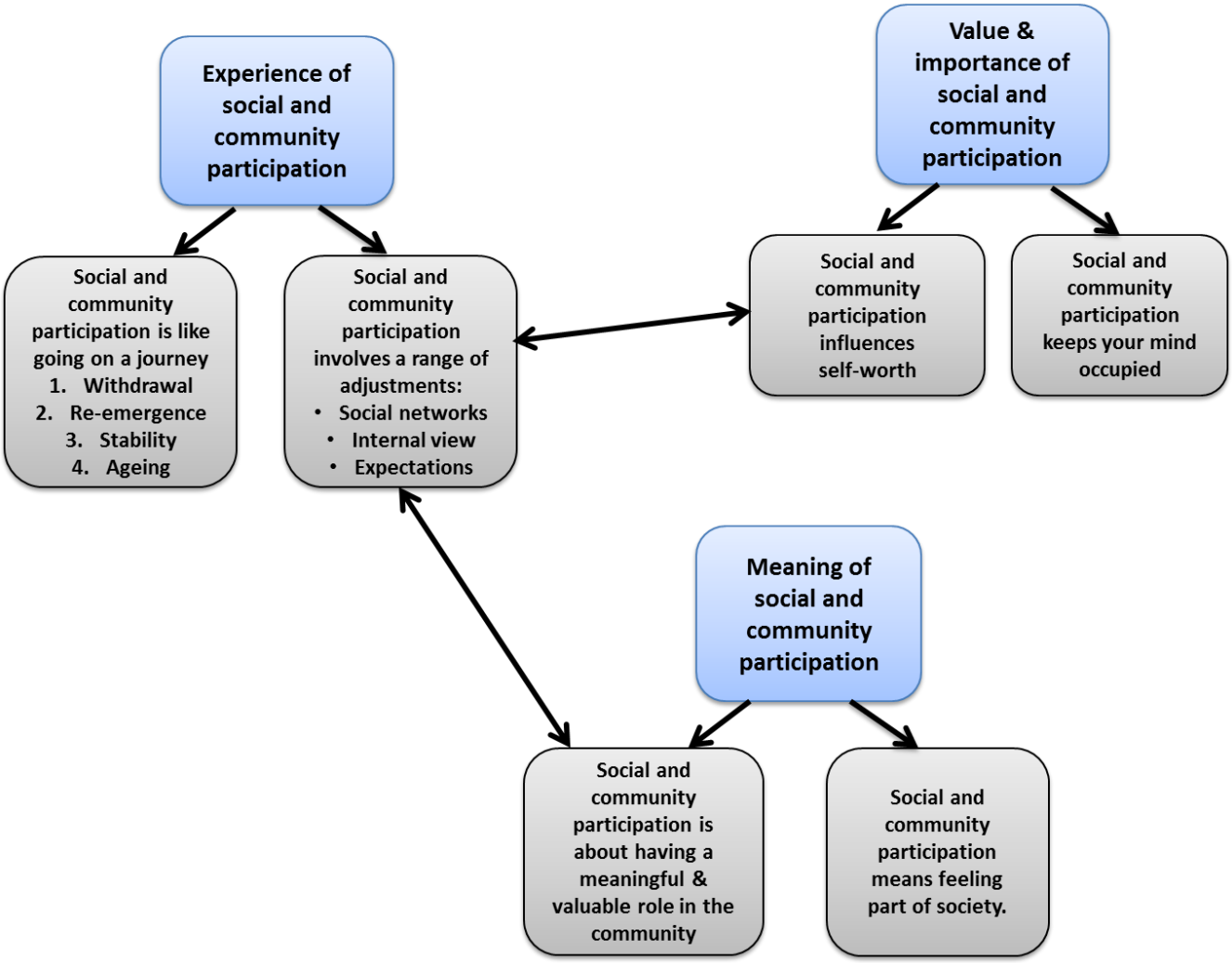
The characteristics of the 36 people interviewed are described in Table **13** *Characteristics of all participants*. Three themes and associated sub-themes relating to the research questions emerged from the analysis as depicted in Figure 9.

Table 13 *Characteristics of all participants*

Characteristic		Participants with traumatic SCI (*n*=19)	Participants with non-traumatic SCI (*n* = 17)
Gender			
	Male	14	9
	Female	5	8
Age at interview			
	19 years or under	1	0
	21-30 years	1	0
	31-40 years	3	1
	41-50 years	9	1
	51-60 years	4	4
	61-70 years	1	7
	71-80 years	0	3
	Over 80 years	0	1
Age at time of injury			
	0-20 years	6	1
	21-30 years	5	0
	31-40 years	4	2
	41-50 years	3	2
	51-60 years	1	2

	61-70 years	0	6
	71-80 years	0	4
Time since injury			
	Less than 2 years	1	4
	2-5 years	5	5
	6-10 years	1	6
	11-20 years	8	1
	21-30 years	3	0
	31-40 years	0	0
	Over 40 years	1	1
Level of injury			
	Incomplete paraplegia	3	12
	Complete paraplegia	4	2
	Incomplete tetraplegia	3	3
	Low complete tetraplegia	6	0
	High complete tetraplegia (C4 or above)	3	0
Compensation			
	Compensation	11	1
	No compensation	8	16
Living situation			
	Living alone	4	6
	Living with partner/spouse	8	10
	Living with parent(s)	6	0
	Living in residential care	1	0
	Living with flat mate	0	1
Work status			
	Unemployed	4	7
	Paid part-time work	8	0
	Paid full-time work	3	1
	Volunteer work only	2	3
	Full-time student	1	0
	On sick leave	0	1
	Retired	1	5

Figure 9 *Thematic map: experience, value and meaning of social and community participation*



6.3.1 Theme One: The experience of social and community participation.

Participants' experience of social and community participation was described in stages which rolled out over time, and involved making adjustments as they moved through the stages.

Social and community participation is like going on a journey.

Participants likened the experience of returning to social and community participation after SCI to a journey. Valerie described it this way: “I think it’s been more of a mental journey than it has been like a physical journey, for me at least.” Taking “one step at a time” was referred to, and analysis identified four stages of the journey that was common to many people. These were: 1. Withdrawal, 2. Re-emergence, 3.Stability, 4.Ageing. Some people moved on from each stage quite quickly to progress to the next, but for others these stages lasted longer, or they became stuck in one stage. Time since injury influenced this journey, with those who had only just returned home tending to focus more on their physical recovery, while those who had been living with their injury for longer, were further along the journey, and placed more emphasis on their social and community participation.

First stage- Withdrawal

The first stage of the journey occurred immediately after returning home from hospital. During this time it was common for people to withdraw from society as they came to terms with their new situation. Jackie said: “When I first came home, I guess I liked to be by myself a bit more, to adjust.” For most participants, such as Ann, this period of withdrawal lasted for several years. “I think it took about 2 ½ years to really be confident about how I was and just to be in my skin again and that surprised me, how long that actually took.”

During this stage, mental health issues including depression, anxiety and in some cases suicidal thoughts, were spoken of by a number of participants. George said:

> I did develop some bad anxiety about 18 months after my injury… when I was staying at this nursing home place I had this really bad attack but didn’t realise

> that's what it was at the time. I had really bad anxiety and panic attacks for a period.

In the period immediately after returning home, it was common for people to focus on their physical recovery. It was evident that there was a need to exhaust all avenues of physical improvement before people were ready to adjust to their new physical reality, and from there to re-engage with society in their new state. Justine and Michael, who were injured less than 12 months prior to the interviews, were still very involved with physiotherapy and focused on improving their physical function. Justine said: "Most days I'm trying to get into the habit of at least doing an hour's exercise. We've got a gym set up in one of the rooms - trying to get a few things going."

Chris, who had suffered a high tetraplegia approximately five years prior to the interview, continued to be very focused on his physical recovery. He said:

> I'm madly focussed on rehabilitating, so I've nearly become a complete hand controller from a chin controller, it's been a lot of work. So, every day if I can, I'll get out of the front gate, and practise driving up and down the street using my hand.

Second stage – Re-emergence

The next stage in the journey was a gradual re-emergence into society. Participants slowly tried new things, and pushed themselves to get out of the house. The men in particular spoke of setting themselves challenges or forcing themselves to take risks during this stage. "The main thing, I think, you have to get out of the fear factor of hiding yourself away and doing stuff just to test yourself, seeing how you're going to go with it." *Henry*

> The more time you spend isolated often the worse it actually gets and it's kind of a vicious cycle. I don't know what it was that sparked me out of it, whether I just looked at myself and said 'well I can't just do this for the rest of my life because I need to challenge myself again and get back out there. *George*

When attempts at social participation were successful, people felt encouraged to push themselves further and try more new activities. An integral part of this stage was gaining an understanding of what they could and couldn't do, and adapting to those changes or limitations. Terry stated:

> I think it's about adjusting to being in a wheelchair which I've done reasonably well, never perfectly, it still sometimes gives me the Jimmy Britts (shits). But finding what you can and can't do and realising your limitations and how they affect what you might have thought you could do during the day or on the weekend.

Some of the participants, who had been injured approximately six years earlier, were still in the first stage, and finding the experience of social and community participation to be a negative one. Chris described:

> I could do more but I choose not to cause it's difficult. For example, I've been to the Royal Show here. I've been to that once since I've been like this, but I wouldn't go again. When you're in crowds, they are not tolerant of us, they bump into us. So I wouldn't go to that anymore.

Third stage – Stability

The majority of participants who had been injured more than five years prior, had emerged from the second stage and entered a third stage, which was one of relative

satisfaction and stability in relation to their social and community participation. This stage was apparent once new meaningful roles in society had been established. Teresa, who had been living with her SCI for 28 years said: “I understand that I’ll never participate like I used to in a lot of activities, but it’s getting close to that as possible for me. So for me, it’s doing what I did before, just in a different way.”

Fourth stage - Ageing

Four of the participants had been injured more than 20 years earlier and were experiencing another stage of the journey, that of ageing with an SCI. This stage often involved development of secondary health conditions, overuse injuries, and loss of function, sometimes resulting in reduced social and community participation. James, who had been injured 51 years earlier, was suffering significant secondary health issues, including pain, fatigue and accompanying depression. In addition, he lived alone, and rarely ventured out of the house, finding it easier to stay at home. He said: “It sounds pretty awful, but look, I’m just happy to bomb out, to sleep at this stage.”

Social and community participation involves a range of adjustments.

Participants described three main areas of adjustment in relation to their social and community participation, these were: adjustment to their changed social networks; adjustment to their internal view of themselves; and adjustment to their expectations of what satisfactory social and community participation was for them.

Many participants experienced changes to their social networks, both positive and negative, following their SCI, which impacted on their social and community participation. For many of the men the changes were negative, and caused distress.

Steve described what happened for him: “Your friends – especially when you’re young, you know, they keep on going out and doing things [without you] and they drop off.”

The older male participants, who had been working all their life until they experienced a non-traumatic SCI, were no longer able to work in the job they were previously employed in. This caused major disruptions and losses to their social networks, which had previously revolved around work colleagues. Neil stated: “No, generally people don’t contact you [after injury], well don’t get in touch with you.”

However there were a number of female participants who were able to maintain some of their previous friendships in addition to developing new ones. Sue said: “My friends are always the most important part of my life. …They’re there for you through good times and bad.”

The experience of suffering a SCI challenged participants’ previously held views of their own identity and the accompanying plans they had for their lives. Some participants spoke of having to reconceptualise their internal expectations as to what they could now achieve or participate in. Adjustments to beliefs and expectations regarding satisfactory social and community participation were needed, for example, adapting to the loss of spontaneity and having to plan ahead when venturing out into the community. Planning in relation to wheelchair access, location of toilets, what equipment was required, and personal care routines, all impacted on the pleasure associated with participating in social and community activities. Steve summarised it as follows:

> There’s a lot more thought and planning that has to go into something. If I’m away somewhere [camping] and having a good time, and I want to stay longer, it’s like, no, you have to get back because I’ve got my routine to do. I found that

> difficult, and I continue to find that difficult, that's the process and you've just got to put up with it.

Some participants who had been living with their injury for many years had largely adjusted to the changes over time and were reasonably comfortable with their participation at the time of the interview. Teresa said:

> One of the things that I really learned along the way was to pick my battles and not to get preoccupied on what is not possible and to focus on what is possible. I still have challenges. I need to work out ways to do the things that I want to do.

6.3.2 Theme Two: The value and importance of social and community participation.

There were common views among participants as to the value and importance of social and community participation in their lives. The majority, but not all, of the participants placed a high value on being able to participate in the community. When speaking about social participation Betty stated: "I think it's invaluable. People who don't have those outlets, they're the people that are really suffering greatly."

Social and community participation keeps your mind occupied.

Social and community participation was considered valuable in that it kept the mind occupied, and provided mental stimulation. Getting out of the house and socialising with other people was important to maintain a positive state of mind, as it encouraged participants to take their mind off themselves and their own problems, and gave them something else to focus on. Michael said: "It's just nice to be with people. It takes your mind off your own problems and you either talk about general things or other subjects that you're both interested in….and you're not immersed in your own sorrow."

Social and community participation influences self-worth.

The SCI challenged participants' self-worth, as the resulting impairments often prevented the person from participating in previously valued social and community based activities (for example paid work, playing sport). Having skills to contribute to society and giving back to others, assisted participants to feel useful and valued, and facilitated a renewed sense of self-worth. Skills could be contributed through paid work, or in other ways such as volunteering or helping friends. Terry said:

> I think getting out in the community allows that [self-worth] to evolve and flourish a bit more. It doesn't matter what it is, just interacting with people, it gives you that I guess variety. Obviously now I have got knowledge to give and share, whether it's about basketball or a bit of Scouting.

Some of the older men who were forced to stop working due to their injury, were struggling to find other ways that they could use their skills and knowledge to contribute to others and thereby feel valued. Loss of their worker role impacted on their feelings of self-worth. Michael, who previously worked in a very senior role, had only recently been injured and was still adjusting to how the change to his circumstances impacted on his self-esteem. "So it's not the work for money that I necessarily need, but its work for activity and mental stimulation that I'm more interested in, but to be doing something menial is a little bit soul destroying."

However, James, who was having health problems as a result of ageing and complications of his long standing SCI, was content to look back over his life with satisfaction at what he had contributed. "I have no ambition. I used to be extremely

responsible for so many things that it's quite a relief not to have to worry about those things anymore."

6.3.3 Theme Three: The meaning of social and community participation.

Social and community participation meant feeling part of society and having a role that was meaningful to the participant, but also seen as valuable to the community.

Social and community participation means feeling part of society

Being seen and heard, and feeling part of society and the community was an important aspect of social and community participation. Getting out and enjoying life was also mentioned by several people including Greg who said: "Getting out and about and enjoying life, communicating with people, and being part of the community".

Some participants, including Michael, felt that they were no longer seen as "part" of society. He said: "You know, you become a…..not part of society. A very small minority and although some of the people who are disabled are very vocal, governments don't particularly give two hoots."

Social and community participation is about having a meaningful and valuable role in the community.

Participants commonly discussed their view that social and community participation was about having a role that was meaningful to them, and also of value to the community. Paul said: "I still want to be valued, I still want to work, I still want to be community minded, I still want all those things – a good father, a good husband."

Those who were most satisfied with their social and community participation were involved in a variety of different social roles, which gave meaning to their lives. Roles included being a paid worker, volunteer, parent, grandparent, friend, sportsperson, charity worker, and peer mentor. Betty said: “In those roles [swimming coach] you feel like you are contributing to society, which is really wonderful.”

The roles that people had previously participated in frequently changed after the injury. Betty, who was no longer able to participate in paid employment, had become involved in charity work, and had changed her view of what community participation meant to her:

> Well, for a long time I used to think it was just work. I’ve kind of redefined that now. I think for me, being part of the community is being able to socialise and have some kind of role in society.

6.4 Discussion

This paper presents the views of 36 adults with SCI living in the Australian community, regarding the meaning, experience and value of social and community participation following SCI. Participants in this study described the journey they went on as they adjusted to the changes in their social and community participation following SCI. The metaphor of going on a journey or taking one step at a time, has been reported in other qualitative studies conducted with people following SCI (Angel, Kirkevold, & Pederson, 2009; Chen, & Boore, 2008; Clifton, 2014). Stages or phases are described as people move from initial grief to later stages of resiliency (Clifton) or learning to live with their disability (Chen). The term response shift has been used by Schwartz, who describes ‘a change in the meaning of one’s self-evaluation of a subjective concept’, in this case social and community participation (Schwartz Andreson, Nosek, & Krahn, 2007).

Schwartz outlines five stages, the last four of which are similar to the experiences described by participants in this study. 1. Pre-injury; 2.Immediate post injury **(withdrawal**); 3.Intermediate post injury (**re-emergence**); 4. Long term post injury **(stability**); 5. Ageing (**ageing)**.

The initial transition home from hospital is a very challenging time for people, as they are removed from the safety of the artificial hospital environment with the associated supports, both physical and social, and plunged into environments that can be hostile towards people with disabilities (Barclay, McDonald, Lentin & Bourke-Taylor, 2016; Nunnerly, Hay-Smith, & Dean, 2013). People with SCI have described not feeling adequately prepared for the difficulties and barriers they are going to face in the real world (Nunnerly, Hay-Smith, & Dean, 2013; Schonner, Groothoff, Mulder, & Eisma, 2005).

It is important that during inpatient rehabilitation, people with SCI are exposed to as many opportunities as possible to experience the physical and psychosocial challenges they will encounter in the community, and prepare for them. This can be facilitated by occupational therapists taking clients out into the community to work with them to solve problems and identify strategies to overcome encountered barriers (Price, Stephensen, Krantz & Ward, 2011; Ward, Mitchell & Price, 2007), by assisting clients to redefine what satisfactory participation is for them, and by setting achievable client-centred goals that will lead to a sense of accomplishment. Occupational therapists can also encourage their clients to be organised, to plan ahead, and to view barriers as challenges (Van De Ven et al., 2008). Once home, assisting clients to adjust their expectations or modify the value or importance placed on certain activities or roles, for

example, placing less importance on physical abilities, and more on interpersonal relationships, may also be beneficial (Isaksson, Josephsson, Lexell, & Skär, 2007).

Participants who had been injured less than two years, tended to prioritise their physical recovery over other areas of their life. Physical recovery has been linked to hope and optimism (Angel, Kirkevold, & Pederson, 2009), and focusing on this can be a helpful strategy early on after injury. However, it may be counterproductive the longer the time since injury, as the focus on physical recovery can cause delays in people seeking employment or developing alternative social and leisure activities, resulting in social isolation once the hoped for recovery has not occurred (Nunnerly, Hay-Smith, & Dean, 2013). Many of our participants experienced a period of withdrawal or depression during the adjustment phase, which likely came about once hope and optimism faded with the realisation that the longed for physical recovery would not occur. Occupational therapists can work with clients with SCI to encourage and facilitate their return to social and community based activities that are meaningful to them, relative to the stages of adjustment identified.

As in this study, as people with SCI age, they may experience secondary complications and physical decline, which can significantly impact on the previously hard earned gains made in community participation (Hitzig, Campbell, McGikkivray, Boschen, & Craven, 2010). Specialised input from occupational therapists and other health professionals at this stage can be beneficial to implement additional supports, recommend alternative equipment and address environmental barriers through home, work or vehicle modifications (Callaway, Barclay, McDonald, Farnworth, & Casey, 2015).

According to Kielhofner (2008) values are beliefs and commitments about what is good, right or important, influence our sense of self-worth, and provide a sense of belonging (Kielhofner, 2008). Being able to contribute to the community fosters feelings of value and competence, connecting and belonging (Duggan & Dijkers, 2001; Van De Ven, Post, De Witte, & Van Den Heuvel, 2008). The self-worth of the participants in this study was influenced by the importance and meaning of the social and community activities they engaged in. The men and women managed their changed social and community participation differently. Men placed a high value on being able to participate in paid employment, including their ability to complete the physical tasks involved with working, and having skills to contribute to society. The men found it difficult to adjust to the loss of the worker role, and the associated impact on their self-worth. The men who were most satisfied with their community participation, had taken up sports, which likely provided them with the ability to continue to connect their identity and self-worth with their physicality, in addition to providing a new social network. By contrast, many of the women found the changes to their social and community participation easier, by either finding new friendship groups or social networks.

Re-establishing self-worth after an SCI may partly depend on the individual's ability to modify their standards and expectations regarding what they view as optimal social and community participation (Rochette, Korner-Bitesnsky, & Levasseur, 2006). One way to achieve this is to modify the way previously valued community activities are performed after the injury. Occupational therapists can assist their clients to do this by facilitating acceptance of appropriate assistive technology to enable desired activities to be undertaken, by modifying the techniques used to participate in valued activities, or implementing environmental modifications to facilitate participation (Rochette).

It has been argued that health promotion includes enabling determinants of health and engagement in meaningful activities (Moll, Gewurtz, Krupa, Law, & Lariviere, 2016). People with SCI in this study experienced periods of significant psychological distress after returning home, and in general did not appear well supported by health professionals to find new or alternative ways of engaging in meaningful activities in their communities. In a study by Turcotte, Carrier, Desrosiers and Levasseur (2015) (Turcotte, Carrier, Desrosiers, & Levasseur, 2015) that examined the roles and interventions of community based occupational therapists, few examples were identified of interventions that enabled engagement in meaningful social activities. Rarely did therapists identify community or social activities that were meaningful to their clients, or provide information about social or leisure opportunities in the community (Turcotte). One of the challenges for occupational therapists in taking a health promotion approach is the existing organisational structures within which they must work, including perceived barriers such as limited time, and the need to prioritise independence and safety over other occupational therapy interventions (Turcotte). Occupational therapists with their unique set of skills, can be agents of change by challenging the traditional medical model approach to client rehabilitation, and instead foster a pro-active health promoting approach.

Limitations

There were some limitations in the conduct of this study. While there were some people included from culturally diverse backgrounds, people who could not speak English were excluded, therefore their experiences were not analysed. The majority of people with NTSCI were recruited through the same health network, therefore their experiences of rehabilitation, and community supports would have been similar. The primary researcher is an occupational therapist with many years of clinical experience working

with people with SCI., which may have influenced the data analysis process. However, an advantage of this was the knowledge and understanding she had of people with SCI, which assisted in rapport development and asking questions of relevance to this group of people.

6.5 Conclusion

Social and community participation following SCI was likened to a journey, characterized by a range of adjustments. Having a meaningful role in the community contributed to the self-worth of the participants, highlighting the need for emphasis in the rehabilitation process and the transition home from hospital, in preparing people to participate in their communities in ways that they find meaningful. Occupational therapists are well placed to assist in this process.

Interview Guide (part of overall interview)

- Tell me a little about yourself and your background.
- Tell me a little about your participation in social and communtiy based activities.
- Could you tell me what social and community participation means to you?
- Is social and community partipcation important to you? Why? Prompt - How important is it for you to be able to partipcate in your community?What do you gain from doing this?
- Has your participation in society or the community changed at any particular time since your injury? If yes, why? How?
- Anything else you would like to add?

6.6 Chapter Summary

This chapter presented the findings of phase three of the study in the form of a manuscript submitted to the journal OTJR: Occupation, Participation and Health. Participating in meaningful roles in the community contributed to the self-worth of the people interviewed, reinforcing the need for this important area to be addressed adequately during rehabilitation, during the transition home from hospital and once people have returned home. Occupational therapists have skills that can assist people to make adjustments during the various stages of the journey that they travel. More details regarding evidence based occupational therapy interventions to facilitate social and community participation are presented in Chapter Eight.

Chapter Seven

Discussion One

Chapters Four and Five presented the findings relating to phases one and two of the study, which included the experience of, barriers and facilitators to social and community participation for people with TSCI and NTSCI. While some of the experiences and barriers and facilitators were similar between the sample with TSCI and the sample with NTSCI, there were also some differences. Chapter Six presented the findings of phase three of the study. It was concluded that participating in meaningful roles in the community contributed to self-worth, reinforcing the importance of social and community participation to people with SCI.

Review of the findings from the three phases of the study, identifies implications that fall broadly into two main areas. The first area is concerned with phases one and two of the study (Research questions: 1. *What is the experience of social and community participation for people living with an acquired SCI? 4. What are the facilitators and barriers to social and community participation following traumatic SCI? 5. What are the facilitators and barriers to social and community participation following non-traumatic SCI? 6. Are there differences in the social and community participation of those with non-traumatically acquired SCI compared to those with traumatically acquired SCI?*), and the impacts that the legislation, policy, systems and service delivery context has on the social and community participation of people living with SCI in Australia (and their family and carers'). The first discussion chapter, Chapter Seven, outlines the findings that specifically intersect with relevant legislation and policy, and the implications of these for people with SCI and their carers', the occupational therapists and other health professionals working with them, and the broader community.

The findings from all three study phases have implications for a second area, that is, occupational therapy practice. The second discussion chapter, Chapter Eight, will discuss the implications of the findings in relation to all the research questions, in the context of current literature and occupational therapy practice. The chapter concludes with the original contribution that this thesis makes to understanding the social and community participation of people with SCI.

7.1 Service and Policy context

As outlined in Chapter One, Australia is currently undergoing major reforms in the area of disability and aged care services and supports delivery, with the introduction of the National Disability Insurance Scheme (NDIS) (NDIS, 2016), and the Living Longer Living Better reforms (Department of Social Services, 2016). Broadly, both these reforms emphasise choice and control, consumer directed care, and improved social participation and facilitation of participants to manage their own health and wellbeing (NDIS, 2016; Department of Social Services, 2016). While these reforms are welcome, with the NDIS in particular aiming to improve the social and economic inclusion of people with disabilities, there are differences between systems as to the supports and services available. The age at which the injury occurs, whether they are eligible for the NDIS or for other compensation, or fall under the aged care system, determines their access to paid care and support, employment programs, and assistive technology. For example if a person in Victoria sustains an SCI from a traumatic cause, such as a work accident or motor vehicle accident, they are eligible for compensation through schemes such as Transport Accident Commission (TAC) and WorkSafe Victoria (WSV), and will fall outside the NDIS.

7.2 Sample characteristics

Table 13 *Characteristics of all participants*(page 171) provides a summary of the characteristics of all the participants in the study. The overall sample consisted of 19 people with TSCI and 17 people with NTSCI. Of those with NTSCI, most participants had incomplete paraplegia (82%), while thirteen (68%) of those with traumatic injuries had either complete paraplegia or complete tetraplegia. 94% of those with TSCI were eligible for compensation (for example TAC, WorkSafe or common lay payouts) compared to 6% of those with NTSCI. As outlined in Chapter One, people acquire their SCI either traumatically by an external event or non-traumatically from pathology or disease. There is some information regarding the social and community participation of people with TSCI, however there is almost nothing known about the experience of social and community participation of people with NTSCI, and in addition, whether their experience is similar or different to that of people with TSCI. People with NTSCI are usually older than people with TSCI, are 50% as likely to be female as male, more commonly experience an incomplete paraplegia, are usually reliant on government pensions and suffer more age related co-morbidities (Guilcher et al., 2010), therefore it is likely that their experiences, and the barriers and facilitators to their social and community participation will differ from those with TSCI.

7.3 Summary and discussion of findings relating to Research Questions 1, 4, 5 and 6

Comparing and contrasting the findings of the two samples (TSCI and NTCSI) in relation to research questions 1,4, 5 and 6, revealed some similar and some different experiences, barriers and facilitators to social and community participation. A number of these similarities and differences are strongly influenced by the policy and service delivery context in which they occur, and closer examination of these differences is

important in informing understanding in this area. Clinicians working with people working with SCI need to be aware of the different services and supports available to their clients depending on what funding scheme and services they are eligible for. These are described below.

7.3.1 Problems with transport, particularly access to appropriate carparks were identified as barriers.

Participants in both samples identified problems with having access to appropriate transport, significantly impacting on their ability to access the community. This is similar to findings of other studies with people with TSCI (Schopp et al, 2007; Carpenter, 2007). Continued improvement to the design and implementation of accessible public transport (buses, trains, trams) is needed, particularly in rural areas, where it was identified that there was significantly less availability of public transport and taxis compared to those living in larger urban areas.

Problems with the current Multi-Purpose Taxi Program and the availability and reliability of wheelchair accessible taxis (WAT) were described by many of the participants, indicating the need for significant improvements with regard to reliability and availability for people across suburbs and regional areas. These findings are similar to those of the WAT inquiry conducted by the Australian Human Rights Commission, which identified issues across the country that needed urgent addressing. Specifically in Victoria there were widespread problems of severely late arrival or non-arrival of WAT, low percentage of WAT (just over 6% of taxis), a significant lack of WAT in regional towns, and problems with design of taxis (Australian Human Rights Commission, 2016). At time of writing the Victorian Government was working with the National Disability Insurance Agency (NDIA) to finalise arrangements for how eligible Multi-Purpose Taxi

Program (MPTP) members will receive transport support through the National Disability Insurance Scheme (NDIS) (Victorian Equal Opportunity and Human Rights Commission, 2011; Taxi Services Commission, 2016).

A high priority for many of the study participants was the need for improvement to eligibility for disabled parking, and increased availability of disabled parking spaces at public and community facilities. Differences between state based and nationally based schemes creates unnecessary complexity and inconsistency across the country. In Victoria, VicRoads is working towards implementing the Australian Disability Parking Scheme, and addressing a number of long-standing issues with the operation of the current scheme (Vicroads, 2016). If these problems are addressed people with greatest need will have access to car spaces, enabling them to utilise community facilities more easily.

7.3.2 Inaccessible buildings and public spaces.

Participants from both samples reported problems with access to public buildings (e.g. no ramps available, or lack of accessible toilets), including theatres, sporting venues, cinemas and shops. This highlights that existing building codes and regulations do not adequately address access design issues in either new builds or renovation to existing public buildings, or are not fully monitored.

Problems with being able to use wheelchairs and walkers in parks, on roads, and on footpaths were identified by people in both samples. This highlights inadequacies in urban design, that results in people with disabilities (as well as older people with mobility impairments and people pushing prams) often being prevented from getting to the places they wished to go, and using public outdoor spaces. NDIS Priority One is to

promote inclusive and accessible communities (NDIS, 2016). It may be part of the role of the NDIS local area coordinator to work with local governments to address issues of access to buildings and parks in their particular locality (Australian Department of Human Services, 2016). However, this problem also falls within the broader context of State and Federal general legislation and policy, highlighting the lack of alignment between non-disability and disability specific policies and systems.

7.3.3 Employment following the injury was problematic for both groups.

People from both samples identified problems with returning to work following their SCI, but the issues were slightly different for each group. Of the 19 TSCI participants, 11 were in some form of paid employment. However, 64% of those employed were working in disability related fields, which included owning and running a wheelchair business, working as a peer mentor, working as a disability advocate, working in disability policy or occasional paid work as a public speaker on workplace safety and injuries, which were not the areas they were employed in prior to their SCI. On questioning, none of the participants who were in paid work identified receiving significant assistance from professionals (vocational or rehabilitation) in finding a new career path or gaining employment. While it is possible that some participants may have forgotten if this was the case (some people had been injured for more than 20 years), it does appear that the majority of people gained employment by utilising their own resources and networks, or by turning volunteer work into paid work (for example the paid peer mentors).

Of the NTSCI participants, ten people were aged between 18 – 67 years, potentially of working age. Eight of these ten participants had stopped working since their spinal injury, highlighting the challenge that people sustaining severe disability at an older age

(but possibly not yet old enough to be part of the aged care system) face in relation to employment. People injured between 40 and 70 years of age, who could have potentially continued in a paid work role, were forced into early retirement, as there were either not the appropriate supports to enable them to retrain or work in another capacity, or access to those supports was limited.

One of the aims of the NDIS is to facilitate higher participation in paid work by both people with disabilities and their family carers. This could be facilitated by more flexible and appropriate personal care to get people ready for work, and improved access to appropriate equipment and necessary modifications to enable the work role to be completed. However, broader systems issues (such as problems with public transport, and discrimination by employers) that serve as barriers to employment for people with disabilities will not be directly addressed by the NDIS, and therefore a broader societal strategy is required.

7.3.4 People with TSCI were more likely to have access to peer mentors who facilitated social and community participation.

Most of the people with NTSCI in this study, reported minimal or no contact with peer mentors. People with NTSCI are usually admitted to non-spinal specific rehabilitation centres, where automatic inclusion of peer mentors visiting people in hospital is not standard practice. It has been consistently demonstrated that connecting people with a peer mentor soon after TSCI assists in visualising a positive future (Boschen, Tonack, & Gargaro, 2003; Price, Stephenson, Krantz, & Ward, 2011). Important independent living skills and ways of overcoming challenges in the community can be learnt by observing others who have lived with their injury for some time (Van De Ven, Post, De Witte, & Ven Den Heuvel, 2005). It is important that people with both traumatic and non-

traumatic injuries are formally linked to peer mentors as soon as possible after their injury to facilitate social and community participation.

7.3.5 Those without compensation were heavily reliant on informal family carers in order to continue to live in their own home and to access the community.

Access to personal care and assistance, facilitated the social and community participation of many of the participants. Those who had access to compensation received sufficient paid care to enable them to get to work or to other places they wanted or needed to go. In most cases, this also reduced the need for the partner or spouse to act as the carer.

Participants from both samples discussed the importance of not having their intimate partner completing personal care tasks such as bladder and bowel care. While fewer of the NTSCI sample had severe or high injuries, they were older and consequently required more assistance to complete self-care tasks, and the majority had not been able to return to driving. In contrast to the TSCI sample, most NTSCI participants were not accessing any paid personal care, instead relying predominantly on their spouses or partners who took on significant responsibility for providing personal care assistance, completion of domestic tasks, and assistance with almost all community participation activities. This has implications for the relationship between the injured person and their partner (Krueter, 2000). No research has been identified that specifically explores the experience of the intimate partner of someone with NTSCI required to complete personal care assistance for their partner, and is an area that warrants investigation.

As populations in Western countries age, and medical care improves, the number of people with chronic health conditions, including NTSCI will continue to rise (Guilcher et al., 2010). People who sustain an NTSCI are older, and if injured over the age of 65 years, will not be eligible to be part of the NDIS, but instead will be reliant on services through the aged care system. This is likely to result in less paid care, and more reliance on family members to provide assistance. Additional resources will need to be directed towards providing unpaid carers (such as family) with support, both emotionally and practically.

The National Carer Recognition Framework (2010) and the National Carer Strategy Action Plan (2011- 2014) outline six priority areas: Recognition and respect; Information and access; Economic security; Services for carers; Education and training; and Health and well-being (Department of Social Services, 2010). This Australian Government's emphasis on supporting informal carers is necessary from an economic perspective. The total replacement cost of informal care in 2015 was estimated as $60.3 billion. Informal carers provided an estimated 1.9 billion hours of care in 2015, providing an average of nearly 673 hours of care per year or 13 hours per week (Carers Australia, 2015). In addition, due to the crucial role that informal carers have in supporting their family member's health and participation, it is vital that the carers' own health and well-being is maintained and promoted (Barclay, McDonald, Lentin, & Bourke-Taylor, 2016; Bourke-Taylor, 2016).

Changes to the aged care system have seen a shift to Consumer Directed Care (CDC) the essence of which is to provide recipients of home based care packages with more choice and control over how services are delivered and who will deliver them, and provide funding for people over aged 65 years that is sustainable and affordable

(Department of Social Services, 2016). This aligns with the NDIS which also aims to provide a sustainable support system that is person-centred and self-directed (NDIS, 2016). Clients in both systems are being afforded the opportunity to have more choice and control over how they utilise the services they are entitled to. For many people this is a welcome change, however, for others, this change presents significant challenges. An understanding of how to navigate systems and services will be needed, in addition to the ability to utilise technology to access services, the ability to assert their own wants and needs, and the skill to select and manage service providers (Russi, 2014). These may be skills that are beyond the capacity or desire of many people, who are already struggling day to day to live with significant levels of disability and disadvantage. These new services and systems must ensure that people are being provided with services and care from appropriately trained and monitored providers, that is flexible, and meeting the needs of the care recipients. In addition, rigorous checks and balances (such as professional panels, registration boards and advocates) need to be included.

7.3.6 People who sustain NTSCI are less likely to have compensation or insurance, providing them with less access to appropriate assistive equipment.

In this study 58% of those with TSCI had compensation such as Transport Accident Commission (TAC) or WorkSafe Victoria (WSV), compared to 6% of the NSTCI sample. Those with compensation had access to appropriate assistive equipment (e.g. modified vehicles, and wheelchairs), more readily and more frequently than those without, thus facilitating easier access to the community. A number of the NTSCI participants who were reliant on mobility equipment for social and community access outlined the frustrations they had in dealing with the current Statewide Assistive Technology

Program (SWEP) in Victoria (SWEP, 2016). Equipment assessment, supply and regulation will continue to be a major component of services required for those with SCI in Australia, but currently systems are poorly coordinated and inequitable. There is variation between states and access to funding differs depending on age at which injury occurs (over or under 65 years) and whether the person with that injury is eligible for compensation.

One step toward addressing equipment and assistive technology supply issues is the NDIS which is designed to provide reasonable and necessary supports in a timely and responsive manner to scheme participants (people under the age of 65 with a permanent and significant disability) (NDIS, 2016). In October 2015, the Assistive Technology Strategy was released (Australian Department of Human Services, 2016b). This document states that the aim is “to build an empowering, sustainable and consistent approach to ensuring NDIS participants have choice in, and access to, individualized assistive technology solutions that enable and enhance economic and community participation.” (NDIS, 2016,p.4).

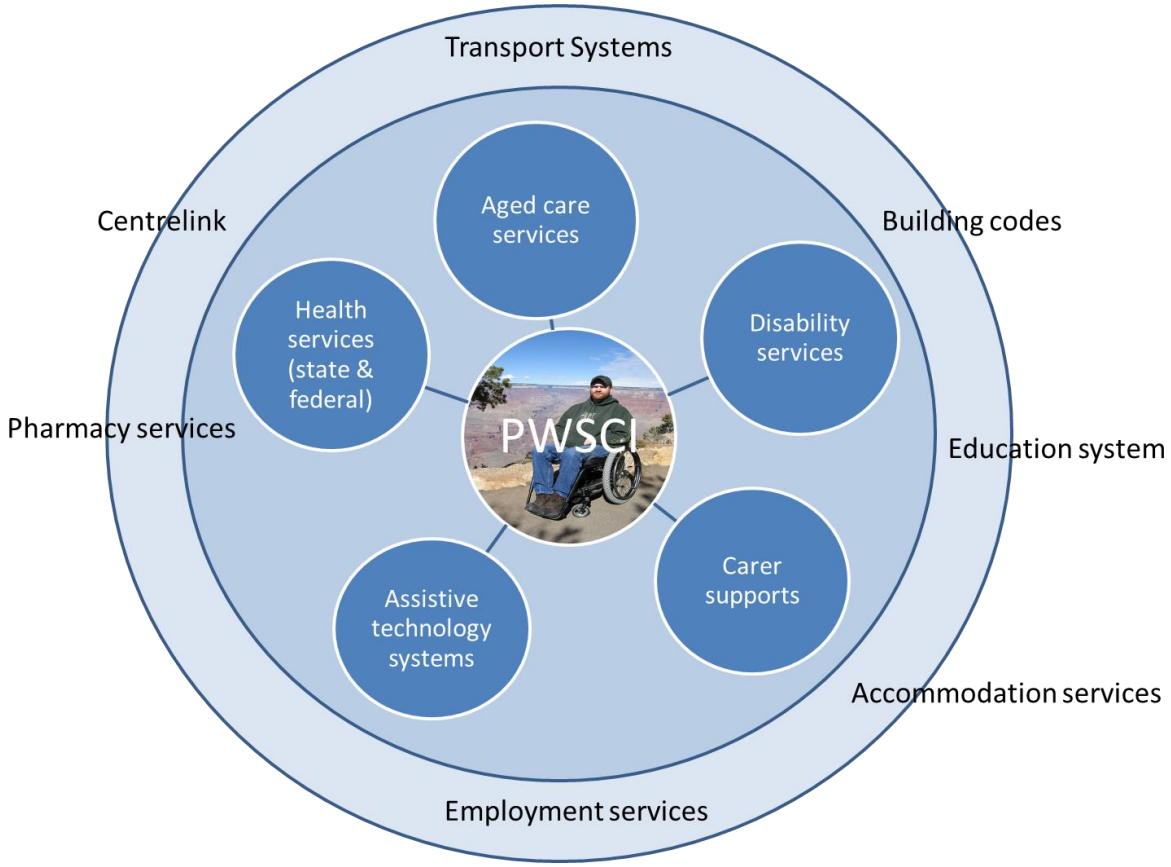
While this strategy is welcome for those under 65 years, it does not address the prescription of assistive technology and equipment for people over 65 years of age who suffer a non-compensable injury such as an SCI. The National Aged Care Alliance (NACA) recently released a discussion paper on improving the interface between the aged care and disability sectors (NACA, 2016). A crucial recommendation concerns the development of a national aids and equipment scheme for older people, aligned with the NDIS Assistive Technology Strategy, to redress the current inequitable access to aids and equipment and assistive technology. The paper also calls for the implementation of the National Injury Insurance Scheme Medical and General Accident

Streams to redress the current inadequate support for older people who suffer a non-compensable catastrophic injury (NACA, 2016).

7.4 Complex and fragmented systems impact people with SCI

The above discussion highlights the ways that various legislation, policy, systems and services impact the social and community participation of people with SCI. It is evident that these systems are complex and fragmented, and many operate in silos with minimal coordination between them. Some services are governed by states (for example SWEP) and others by federal bodies (for example carers' services). This makes it very challenging for people with SCI to navigate and manage the care and services they need to participate in activities in the community. This complexity and fragmentation is illustrated in Figure 10. In this diagram the universal systems (that is, non-disability or aged care specific) that affect people living in the Australian community are depicted in the outer circles. These include transport services, infrastructure and building codes, the education system, employment services, welfare such as Centrelink benefits, pharmaceutical services and accommodation services. Once people experience a SCI, they have interaction with a range of other systems and services including health services, disability or aged care services, assistive technology systems and potentially carer support services. These are depicted as impacting on the person with SCI (PWSCI) but may be lesser or greater at various times depending on the person's needs and life stage. For example, a young person with a TSCI may be fully independent and not need disability support services or carers until they are older or suffer secondary health conditions.

Figure 10 *Impact of multiple systems on person with SCI*



Health professionals working with people with SCI need to be aware of the different services and supports available to their clients as this has a significant influence on their practice (for example knowing what funding is available for assistive technology). There is also a responsibility for practitioners and professional associations to work with governments and appropriate departments to continue to strive for policy and legislation that will flow through to more cohesive services for their clients. Further discussion and recommendations for health professionals, and in particular occupational therapists is provided in Chapter Eight.

7.5 Chapter Summary

This chapter presented the first of the discussion chapters. The impact that legislation, policy, systems and services have on the social and community participation of people

living with SCI in Australia was discussed. The implications of the complex interactions between universal systems (such as transport services, infrastructure and building codes, the education system, employment services, welfare, pharmaceutical services and accommodation services) and disability and aged care services, assistive technology and carer supports were outlined in this chapter. Inequities and inconsistencies between the services available to people with SCI were also identified.

Chapter Eight, the second of the discussion chapters, integrates the findings of all phases of the study and discusses these in relation to the overall rehabilitation of people with SCI and the implications for health professionals (in particular occupational therapists) that work with them. The findings of the thesis are applied to the CMOP-E.

Chapter Eight

Discussion Two

Chapter Seven outlined the implications of legislation, policy, systems and services on the social and community participation of the 36 study participants. The complex interactions between universal systems and disability and aged care services were highlighted and illustrated in a diagram. Inequities and inconsistencies between the services available to people with SCI were also identified.

This, the second of the discussion chapters, outlines the implication of the findings from all phases of the study in relation to health professionals and specifically to occupational therapy practice. The CMOP-E (outlined in Chapter One) is revisited and examined in the context of the findings of the study. The original contribution that this thesis makes to understanding of the social and community participation of people with SCI is also outlined.

8.1 Findings applied to rehabilitation of people with SCI.

In addition to highlighting the complex systems that people who acquire SCI and their families must navigate, the findings of this thesis also have implications for the rehabilitation of people with SCI and the health professionals that provide this rehabilitation. For the participants in this study, it was apparent that services directed toward re-engaging them in meaningful community based activities (such as paid and unpaid work, social groups or hobbies) were either limited or non-existent, or were introduced at the wrong time or in the wrong way for maximum effect. Seemingly the traditional medical model predominates in acute, rehabilitation and community based services. The strict budgetary constraints and limited time frames within which health professionals working with this population are required to operate likely provide an

additional barrier to offering these types of services to people. This is an area that warrants further research in order to gain more understanding.

Occupational therapists are one of the health professions in a unique position to address some of the barriers highlighted by participants in this study. The reasons for this are two-fold:

1. The barriers and facilitators identified in this study (outlined in Chapters Four and Five) were due either to factors in the person's environment or were person related. The theoretical models which underpin occupational therapy professional practice recognise the importance of the dynamic interaction between the person and their environment on occupational performance and their satisfaction with that performance (Townsend & Polatajko, 2007; Kielhofner, 2008).

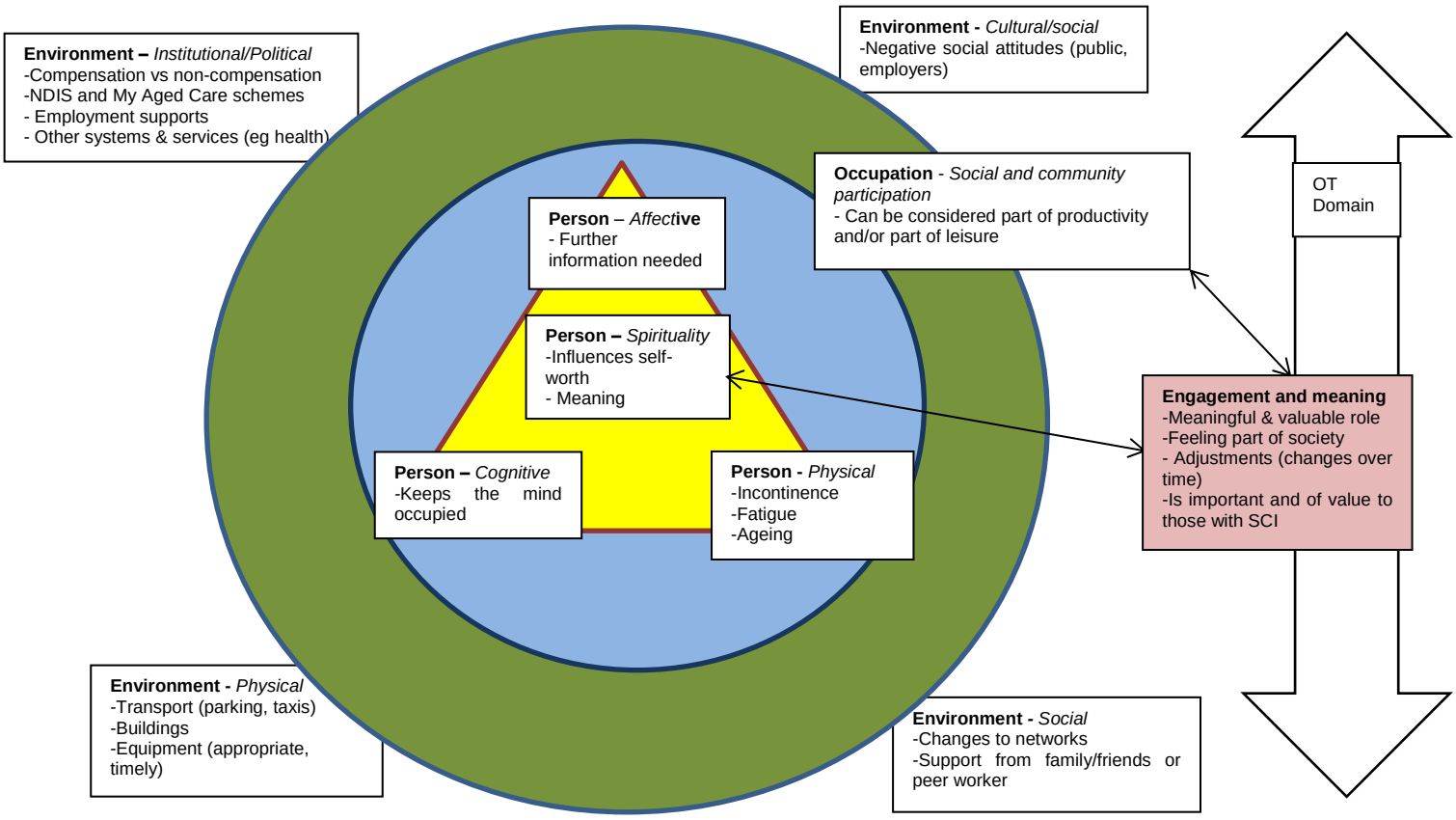
2. Occupational therapists are employed in acute, rehabilitation and community based settings, therefore are often involved with people with SCI along the continuum of their rehabilitation process. While the therapist may be referred someone with an SCI for the purpose of prescribing equipment, they can utilise the rapport they have developed with their client to take that opportunity to address other issues to address the person's social and community participation.

This being the case, the remainder of this chapter will discuss the findings in more detail and relate them to the model: The Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko et al., 2007), and present implications and recommendations for occupational therapy practice.

8.2 Findings applied to the Canadian Model of Occupational Performance and Engagement (CMOP-E).

Theoretical models such as The Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko et al., 2007) underpin occupational therapy practice (Figure 2 *Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko et al., 2007)*). The CMOP-E provides a three dimensional depiction of the dynamic relationship between the person, the occupation and the environment, and focuses on occupational performance and engagement. In order to provide a framework for the findings and discuss implications for occupational therapy practice, the findings from the three phases of the study have been aligned with the components of the CMOP-E (Figure 11).

Figure 11 *Findings applied to CMOP-E*



According to Polatakjo et al (2007), the CMOP-E is not only concerned with the performance of occupation, but also with occupational engagement. That is, the degree of importance as well as the satisfaction with performance that engagement in the occupation brings the individual. The term engagement encompasses all that we do, to "involve oneself or become occupied; participate" (Polatakjo et al. p.24). Furthermore, the authors highlight that this model offers a broad scope of practice by including a vision of health, well-being and justice through occupation. The findings from this study reinforce this, as the meaning and importance of social and community participation was clearly articulated by a number of the study participants.

However, the visual representation of the CMOP-E (Figure 2 *Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko et al., 2007)* does

not clearly **visually** represent the role of engagement in the model. The findings from this study as depicted in Figure 11, suggest that there is an important and dynamic relationship between the person's spirituality, engagement in the occupation (in this case social and community participation) and the meaning of that occupation. The finding that people with both TSCI and NTSCI view social and community participation as important, and as adding meaning to their lives, reinforces this as a crucial area for occupational therapy intervention.

8.3 Implications for Occupational Therapy practice

The findings of this study raise a number of important issues relevant to occupational therapy practice, these include individual performance but also issues within the environment (cultural, social, physical and institutional). Implications for occupational therapy under the key components of the CMOP-E (person and environment) are outlined below.

8.3.1 Person related implications.

Personal recovery or the recovery approach is generally associated with recovery from mental illness (Leamy et al., 2011). However it may also be applied when working with people following a loss or trauma, such as an SCI (Meadows et al., 2012). The term recovery used in this context, is not the restoration of a previous state, or a return to full health, but rather is a process of personal learning, growth and transformation (Meadows et al.). Elements of the recovery approach include developing a sense of agency, re-establishing meaning and purpose, and achieving social connectedness and integration (Onken, Craig, Ridgway, Ralph, & Cook, 2007).

The challenges to someone rehabilitating following an SCI, and aiming to return to social and community activities are similar to those for someone suffering a mental illness. They include: loss of power, loss of sense of self, loss of a valued identity, loss of meaning and hope, and barriers to participation and social inclusion (Meadows et al.). Recovery in this context has also been likened to a journey, highlighting the parallels found in this study, noted in Chapter 6 when participants characterised the process of returning to social and community participation as a journey (Angel, Kirkevold, & Pederson, 2009; Clifton, 2014; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). In taking a recovery approach, occupational therapists can work with clients with SCI to facilitate their return to social and community based activities that are meaningful to them during the four stages of adjustment identified in this study. This can be achieved in a number of ways, as outlined below.

Facilitating appropriate social skills when out in the community.

There was a significant change to social networks and loss of productive roles for a number of people in this study. For those with limited social support, assisting the creation of new social networks in the community is vital (Hand, Law, McColls, Hanna, & Elliott, 2014; Muller, Rauch, Cieza, & Geyh, 2013). In addition, educating clients regarding the use of positive social skills when influencing or dealing with other people (such as being assertive, having good verbal skills, using humour, having patience and using educational skills to make others feel at ease) (Muller et al., 2013; Van De Ven et al., 2008), are strategies that can lead to increased satisfaction with community participation. Assisting people to develop these skills could also be more formally incorporated into rehabilitation programs. This is an area of occupational therapy intervention that warrants more research, particularly in relation to those with NTSCI.

Working collaboratively to solve problems and overcome barriers in the community.

Barriers to social and community participation identified by participants in this and other studies, include problems with appropriate transport, and inaccessible built and natural environment (Boschen et al., 2003; Carpenter et al., 2007; Whiteneck et al., 2004). Using a client-centred approach, occupational therapists can work with their clients to solve problems as they arise to assist in removing barriers (Ward, Mitchell, & Price, 2007). Occupational therapists can also encourage their clients to be organised, to plan ahead, and to view barriers as problems to be solved (Van De Ven et al., 2008).

Assisting people to modify their expectations of community participation.

In order to assist people to feel more satisfied with their social and community participation, occupational therapists can facilitate people to modify or adjust their internal standards or ideals regarding what they view as optimal participation (Schwartz, Andresen, Nosek, & Krahn, 2007). One way to achieve this is to modify the way previously valued community activities are performed after the injury, for example, by accepting the use of assistive technology or by modifying the techniques used to participate in activities. Another way to adjust internal standards is to change the value or importance placed on certain activities or roles, for example, placing less importance on physical abilities, and more on interpersonal relationships, which can lead to greater satisfaction with participation (Rochette, Korner-Bitesnsky, & Levasseur, 2006).

Supporting and empowering people to advocate for themselves.

With the introduction of new models and systems of service delivery such as the NDIS and Aged Care reforms in Australia, occupational therapists can work with their clients

to develop self-advocacy skills, and educate them on the new systems. This will empower clients to negotiate the relevant systems, in order to access their required equipment, specialist care and support (Herrmann, Kirchberger, Stucki, & Cieza, 2011; Rochette et al., 2006; Russi, 2014).

8.3.2 Environment related implications.

In addressing barriers to social and community participation, there are a number of areas in the client's social and physical environment that occupational therapists can address.

Taking a health promotion approach to intervention.

It has been argued that health promotion includes enabling determinants of health and engagement in meaningful activities (Moll et al., 2015). One way in which occupational therapists can promote adults' health and well-being, is to optimise their participation in society (Bennett, 2005). Social participation is recognised by health services in Quebec, Canada as an important modifiable health determinant (Turcotte, Carrier, Desrosiers, & Levasseur, 2015). However, in studies conducted in Canada (Turcotte et al.) and Australia (Baum et al, 2014), that examined the roles and interventions of community based occupational therapists, few examples of interventions were identified to enable engagement in meaningful social activities. Rarely did therapists identify community or social activities that were meaningful to their clients, or provide information about social or leisure opportunities in the community (Turcotte et al.). One of the challenges for occupational therapists in taking a health promotion approach is the existing health framework in Australia within which they must work. The traditional medical model appears to predominate in acute, rehabilitation and community based services. Occupational therapists can be agents of change by challenging the traditional reactive

approach to client rehabilitation, and instead foster a pro-active health promoting approach.

Of the few studies that have investigated the use of a health promotion approach with people with SCI, most have focused on the use of physical activity programs (Wise et al., 2009) and education to prevent secondary health conditions (Warms, 1987). Evidence from this study supports the important role the occupational therapist has in facilitating people with SCI to participate in meaningful, community based activities, as a way of promoting their health and well-being, and quality of life. Investigating the extent to which this currently happens in practice in Australia, and any barriers that my impede this aspect of practice, is an important area for further investigation.

Assisting clients to strengthen existing social networks or create new ones.

Having the support of a key person, usually a family member or friend, was identified in this and other studies, as facilitating a return to social and community participation following SCI (Carpenter, Forwell, Jongbloed, & Backman, 2007; Hammell, 2004b; Isaksson, Lexell, & Skar, 2007). Practical and emotional support, have both been identified as important (Isaksson et al). Therefore, actively involving family and friends in all aspects and stages of rehabilitation is recommended (Hammell, 2004a). For those people with limited social support, assisting in the creation of new social networks in the community is vital (Hand, Law, McColls, Hanna, & Elliott, 2014; Muller, Rauch, Cieza, & Geyh, 2013). Occupational therapists could facilitate this process by connecting their clients with support groups, and referral to community based activities of interest to the injured person. This is an area of occupational therapy intervention that warrants more research, particularly in relation to those with NTSCI.

Facilitating access to peers and mentors.

Connecting people with a peer mentor soon after their injury has been shown to assist people to visualise a positive future (Boschen, Tonack, & Gargaro, 2003; Price, Stephenson, Krantz, & Ward, 2011), and was confirmed by the findings from this study. Important independent living skills and ways of overcoming challenges in the community can be learnt by observing others who have lived with their injury for some time (Van De Ven, Post, De Witte, & Ven Den Heuvel, 2005). Occupational therapists can facilitate these connections, and assist in appropriate peer matching (Price et al., 2011).

Supporting carers' health and well-being.

This study has highlighted the important role that informal carers play in facilitating social and community participation for people following SCI, particularly for those with NTSCI. It is important that family members receive appropriate preparation for their new caring role, and are fully involved in the rehabilitation process (Dickson et al., 2010). Occupational therapists are well placed to support carers in ways that align with some of the priority areas outlined in this strategy (Bourke-Taylor, 2016). Occupational therapists can facilitate carers' access to information, can provide education and training, and can promote carers' engagement in meaningful activities to promote their own health and well-being.

Advocating on behalf of their clients to change policy.

The social and community participation of people with SCI in Australia occurs within a political, social, cultural and institutional context. Chapter Seven outlined the findings of this study in relation to the current disability and aged care reforms, and other services and systems. Occupational therapists and other health professionals have a role to play in advocating on behalf of their clients to facilitate social and community participation by

working with governments across a number of policy and legislative areas. In summary these include:

- Advocating for improvement to the design and availability of wheelchair accessible taxis and making changes to the Multi-Purpose Taxi Program to improve cost effectiveness across all regions (rural and urban) and increase reliability and responsiveness.
- Advocating for improvement to the design of public transport, including buses, trams and trains and availability particularly in rural areas.
- Advocating for stronger building codes to ensure new public buildings, parks, roads and footpaths are fully accessible for people with mobility impairments.
- Highlighting inequities between the current funding systems and working to promote equality of access to assistive equipment regardless of how injury occurred or at what age.
- Highlighting inequities between the current funding systems and working to promote equality of access to paid care and support regardless of how injury occurred or at what age.
- Working to improve the access of unpaid carers of people with SCI to education, support and promotion of their own health and well-being.
- Working to improve the services currently offered to facilitate return to employment following injury regardless of how injury occurred or at what age.
- Raising awareness of the inequity of rehabilitation services based on cause or mechanism of injury, and age at which injury occurs, including but not limited to access to peer workers.

8.4 Contributions this Thesis makes to Knowledge Regarding Social and Community Participation following SCI.

8.4.1 Situating thesis in relation to previously conducted studies in this area.

Chapter Two consisted of a critical review of the available evidence up to and including 2013, regarding social and community participation following SCI and the factors that influence it. Twenty-four studies were included in the review, 17 quantitative, 5 qualitative and one mixed methods. Overall the quality of the studies was low, particularly the quantitative studies which had a mean overall score of 9.3/15 on the Critical Review Form Quantitative Studies (Law et al., 1998). There were no randomized-controlled trials and no intervention studies. Most of the studies were cross-sectional surveys, and the instruments used to measure participation were mostly developed prior to the release of the ICF (WHO, 2001), utilising the construct of handicap as a proxy for participation. There was variation and lack of clarity in the use of the terms participation, social participation and community participation. One mixed methods study was included which provided limited detail regarding the methods used, particularly the qualitative component. The mean rating of the qualitative studies was 16.7/24 on the Critical Review Form – Qualitative Studies Version 2 (Letts et al., 2007). There were limitations in procedural rigour, lack of detail regarding sample selection and data analysis. However, the findings from the qualitative studies highlighted that participants did not describe participation by amount of engagement but rather as a process to develop a sense of identity and establish meaning.

Following review of these papers research gaps were identified, and it was recommended that further investigation of the social and community participation of people with SCI utilizing in-depth exploratory approaches be undertaken. It was

recommended that more detailed information on environmental barriers and facilitators, and personal characteristics such as coping strategies was needed, and further investigation into what aspects of social and community participation are important to those living with SCI was also necessary (Barclay, McDonald & Lentin, 2015). An additional identified gap is that only two of the reviewed studies were conducted in Australia, and no studies specifically explored the social and community participation of people with NTSCI.

This thesis has addressed these identified gaps by:

- Exploring social and community participation from the perspective of those living with SCI (both traumatic and non-traumatically acquired) in Australia using rigorous qualitative methodology.
- Utilising in-depth interviews to elicit detailed information regarding barriers and facilitators to social and community participation and discussing the implications of these in the context of Australian disability and aged care policy, systems and services.
- Recruiting two samples, one with TSCI and one with NTSCI, and comparing the findings for each.
- Finding out what social and community participation means to people with SCI, and whether it is important and of value to them.

An updated search of relevant literature was conducted just prior to submission of this thesis. The same search terms and databases were searched as for the published critical review, but with dates of 2013 - current. An additional three articles that fit the inclusion criteria were located: Craig, Nicholson, Guest, Tran and Middleton (2015), Fritz, Lysack, Luborsky and Messinger (2015), and Ruoranen, Post, Juvalta and Reinhardt (2015). These will be discussed in the context of the findings from this thesis.

Craig, Nicholson, Guest, Tran and Middleton (2015) conducted a prospective longitudinal study to investigate inpatient factors that contribute to social participation of people with SCI after discharge. They administered a range of instruments to 71 participants, while in hospital, at discharge and then at six months post-discharge, and then used logistic regression models to establish factors that significantly predict social participation at six months post discharge. The IPAQ (Impact on Participation and Autonomy Questionnaire) (Cardol et al., 2001), was used to measure social participation. Craig et al. found that at six months 55% of their sample had significant difficulties with social participation. Factors found to significantly predict better social participation were: being younger, having less secondary health or medical problems, having better cognition, having greater self-efficacy and having higher perceived social support. This study was conducted in Sydney, Australia, making its results more applicable to the Australian context. The authors acknowledged some limitations with the statistical analysis. While they did identify people with NTSCI in their sample (10%), they did not differentiate results based on cause of injury. As in our study, the importance of social support was identified. Also, interestingly, chronic pain was not identified as a significant barrier, similarly pain was not a major issue for the participants in our study.

Fritz, Lysack, Luborksy and Messiner (2015) conducted a series of in-depth anthropological interviews with a 28 year old marine (Jake) with a C5/C6 TSCI. The purpose of the study was to characterise the long-term outcomes related to the community participation experienced by a military veteran who suffered a service-related TSCI. Three significant themes were identified: opportunities for better engaging socially meaningful others may not be adequately included in so-called

“client-centred” interventions; how management of the social self in interpersonal reactions and public spaces is critical to gaining broader social acceptance; and how meaningful age normative relationships and activities are essential to establish lasting inclusive social connections. While acknowledging that this study was conducted with one individual with a TSCI from military service, there were some parallel findings. Fritz et al. argued that rehabilitation primarily focuses on medical symptom management and physical functioning and less on ways people with SCI navigate their social world, and how systems support them in this. They recommended that client centred interventions should focus on not just the injured person but on those caring for the person. Jake identified that he could no longer participate in spontaneous activities, which was also a factor discussed by the participants in our study. Other than the methodological limitations of the study by Fritz et al., one major conceptual issue was the inconsistent and interchanging use of terms such as community reintegration, social participation, community participation, and a new term, social community reintegration, without attempts to define or conceptualise any of them.

The objective of the study by Ruoranen, Post, Juvalta and Reinhardt (2015) was to examine subjective understanding of participation and integration of people with SCI from five European countries and compare these to the ICF’s concept and meaning of participation. They conducted semi-structured interviews with 54 people with acquired SCI and three with Spina Bifida, and examined these using content analysis. They found that most participants spoke of integration as including social acceptance, ordinary performance and freedom of choice, while participation was defined more in terms of ordinary performance, but also included social acceptance and equality. The domains participants identified were: recreation, leisure, work, sport and going out. The authors concluded that feelings and experiences are missing from the ICF’s definition of

participation (Ruoranen, Post, Juvalta and Reinhardt, 2015). There was no differentiation or discussion about people with acquired NTSCI.

In summary, although the above more recent studies address some of the limitations identified by the critical review (lack of information from the perspective of those living with SCI), there was no investigation of people with NTSCI as a separate group with specific needs. In addition, only one of these studies was conducted in Australia.

8.5 Chapter Summary

In this chapter, the findings from all phases of the study were discussed in relation to rehabilitation, and in particular occupational therapy practice. The findings were applied to the CMOP-E. Implications and recommendations for occupational therapy practice at a person and environment level were outlined. The original contribution that this thesis makes to understanding the social and community participation of people with SCI was provided.

Chapter Nine

Conclusions

Chapter Seven discussed the findings from phases one and two of the study in the context of universal systems, and current disability and aged care legislation, policy, services and systems. Chapter Eight discussed the findings from all three phases of the study, and the implications for rehabilitation and occupational therapy practice at a person and environment level. This chapter concludes by providing a definition of social and community participation that has resulted from the study. Strengths and limitations of the study are outlined and recommendations for further research provided.

9.1 Definition of social and community participation.

It is evident that the definition of participation provided by the ICF (World Health Organisation, 2001) "*involvement in life situations*" does not reflect the complexity, value or experience of participation as described by the participants in this study. As Dijkers (2010) notes in his introduction to a special issue on participation in the Archives of Physical Medicine and Rehabilitation, there is more to participation than performance.

Having skills to contribute to society and giving back to others such as friends and family, was identified by the participants in this study as an important part of social and community participation. Being able to **contribute** to the community, through volunteer work, paid work or advocacy, assisted participants in this study to feel useful and valued, and facilitated a sense of **self-worth**. This finding is consistent with a number of other qualitative studies conducted with people with SCI, that found reciprocity or giving back to others in society was highly valued, and also made participants feel less

dependent (Hammell, 2004; Van De Ven et al., 2005; Van De Ven, Post, De Witte, & Ven Den Heuvel, 2008).

Being involved in **meaningful roles** (for example looking after grandchildren, or belonging to a gardening group) was important to the participants in this study. Other researchers have identified that participating in meaningful activities, interests or roles can assist a person to reframe their views on acquired disability (Dunn and Brody, 2008). Hammel et al (2008) conducted focus groups with 63 people with physical disabilities on what participation meant to them. One of the core themes they found was that participation was going beyond day to day survival to engaging in opportunities that were highly meaningful (Hammel et al., 2008).

For the people with SCI in this study, social and community participation involved getting out of the house and socialising with other people, which was important to a positive state of mind, and helped them to **feel part of society**. The importance of connection or having meaningful social interactions with others is reflected in the findings of almost all qualitative studies that explore social connectedness or social inclusion among people with disabilities (Van De Ven, Post, De Witte, & Van Den Heuvel, 2005; Isaksson, Josephsson, Lexell, & Skär, 2007; Hammel et al., 2008), and reinforces the empirical evidence that making connections with other people and socializing with others has an influence on living a good life (Diener & Seligman, 2002; Dunn & Brody, 2008).

In summary, our findings bring into focus four particular facets of participation not reflected in the ICF definition of participation. These are *giving back to the community, participating in meaningful roles, feeling as though one is part of society and*

contributing to self-worth. A new definition of social and community participation resulting from this study is:

Involvement in meaningful roles and activities outside the home, which include socialising with other people, and giving back to the community, enabling one to feel part of society and contributing to one's self-worth.

9.2 Strengths and limitations of thesis.

The constructivist's view is that there are multiple socially constructed realities whereby the researcher and the research participants co-construct meaning. Researchers need to have sufficient grounding in the culture of the communities in which they work to conduct research in ways which are credible and useful to members of those communities (Mertens et al., 2011). I came to this study as an Occupational Therapist with many years of experience working with people with SCI, and therefore had some pre-conceived ideas regarding what I might learn from study participants. However, the knowledge and understanding I had of the SCI community was an advantage, assisting me to ask relevant questions related to the challenges this group of people face. As a result of conducting this research, I have gained new knowledge and insights into the issues this group of people face in the community.

The TSCI sample did not reflect a typical TSCI sample, particularly in relation to social and community participation. The percentage of people in paid work (57%) was higher than most studies indicate (31-48%) (Schonner et al, 2005). In addition, overall the TSCI sample were leading active, fulfilling lives at the time of the interviews, and had strong social supports, however, this is not the case for many people with SCI. A

significant challenge for this study was recruiting people with TSCI who were *not* participating in a way that was satisfactory for them.

A significant number of participants from the two samples had been living with their SCI for many years. Fifteen participants experienced their spinal injury or damage more than ten years prior to the interviews. This may have contributed to recall bias, as some participants may not have remembered receiving assistance from health professionals to return to work, for retraining, or assistance to regain involvement in community based activities. Future research that includes interviewing people across different time points after their injury would provide greater insight into the type of assistance or programs people with SCI are involved with, and would reduce recall bias.

The NSTCI participants were primarily recruited through the same rehabilitation unit, as a result they would have experienced similar rehabilitation processes, and had similar care and support provided. Recruitment from a broader range of settings may have provided different participant perspectives. Although there were people from non-English speaking backgrounds, a greater proportion of people from culturally and linguistically diverse backgrounds would have increased the richness of the data.

The nature of qualitative research is that there is the possibility of the participants' perspectives not being authentically represented in the research process, and that data is made to fit the preconceived ideas that the researcher may have (Fossey et al., 2002). In order to maximise the trustworthiness of this study, a number of techniques were employed throughout the research process (Lincoln & Guba, 1985; Patton, 2015). These are outlined in section 3.9 Strategies to ensure trustworthiness.

9.3 Recommendations for Future Directions and Future Research

This study raises a number of issues that warrant further investigation.

- Research into the current approaches taken by occupational therapists working in the community with people with SCI would provide insight into whether there are barriers to working in a more proactive and health promoting way, and what those barriers are.
- It is recognised that social and community participation is important for quality of life, yet to my knowledge there has been no quantification of the value in economic terms. Collaborative research that provides data on the economic value of improving the social and community participation of people with SCI and other disabilities could potentially influence government to address some of the policy and systems issues raised in this thesis.
- The role that social media plays in facilitating (or not) social connectedness was not investigated in this study. This is an area that warrants further exploration, particularly as a means of connecting people in rural areas with peer workers.
- Interventions that enhance the social and community participation of people with SCI need to be implemented and evaluated.
- Further empirical evidence regarding the relationship between social and community participation and health and well-being is recommended. This would assist in prioritising service provision.
- Further research in developing instruments that quantify social and community participation utilising components identified in this study previously not included in such instruments, is recommended. This would enable outcomes of SCI rehabilitation from the perspective of those living with SCI to be more accurately recorded.

9.4 Thesis Summary and Conclusions

Currently there exists limited information regarding the experience and meaning of social and community participation from the perspective of people with TSCI and almost no information regarding the experience and meaning of social and community participation from the perspective of people with NTSCI. This thesis contributes to existing knowledge regarding the social and community participation of people with SCI by providing new insights from the perspective of those living with SCI, particularly those with SCI of non-traumatic aetiology. In summary these are:

- Social and community participation is important to people with SCI
- Social and community participation contributes to the self-worth of people with SCI
- There are different opportunities to participate in social and community based activities depending on age at injury, and which funding system the person falls under (NDIS, aged care or compensation)
- The legislation, policy, services and systems that impact the social and community participation of people with SCI are complex and fragmented
- People with disabilities such as SCI want and should be afforded the same opportunities as others in the community to participate in social and community based activities. Policies and services should be directed towards promoting those opportunities.
- Current health systems tend to focus on medical interventions and physical recovery, with limited funds and supports aimed at assisting people to re-establish meaningful social and community participation following discharge from hospital.

- Occupational therapists have a unique and important role to play in working with individual SCI clients, but also to advocate at a policy and service delivery level, to promote the social and community participation of people with SCI, and thereby their health and well-being.

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Appendices

Appendix A

Social and community participation following SCI: a critical review

Social and community participation following spinal cord injury: a critical review

Linda Barclay, Rachael McDonald and Primrose Lentin

Evaluation of rehabilitation outcomes following acquired disability should include participation in social and community life. Evidence is needed to guide clinical practice to ensure that it is client-centered; therefore, findings from studies that report on social and community participation following spinal cord injury (SCI) need to be reviewed and synthesized. The objectives of this critical literature review are to examine the available evidence on social and community participation following SCI and to examine the factors that influence that participation. The barriers and facilitators will be identified and described in terms of the contextual factors – personal or environmental, as outlined by the International Classification of Functioning, Disability and Health. An additional objective is to appraise the quality of the evidence examined. A systematic literature search was completed in the databases OVID MEDLINE, AMED, CINAHL PLUS, PSYCHINFO, and hand searches were carried out. Quantitative, qualitative, and mixed methods studies were included. Twenty-three studies fulfilled the inclusion criteria: 17 quantitative, five qualitative, and one mixed methods. In general, studies were of low methodological quality, and no intervention studies were identified. The terms participation, social participation, and community participation were used interchangeably often without clarification of meaning. Adequate personal care assistance, appropriate social support, having adequate specialized equipment, and appropriate occupational therapy input were found to facilitate social and community participation, whereas problems with transport, inaccessibility of the natural and built environment, issues with healthcare services and rehabilitation providers, and pain were identified as barriers. In-depth investigation into what aspects of social and community participation are important to those living with SCI is needed so that client-focused solutions and interventions can be identified and developed, aimed at creating and promoting opportunities for social and community participation. *International Journal of Rehabilitation Research* 38:1–19 Copyright © 2015 Wolters Kluwer Health, Inc. All rights reserved.

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Keywords: critical review, evidence, participation, spinal cord injury

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Introduction

Participation in meaningful occupations has been shown to have a positive influence on health and well-being, and is a vital part of the human condition and experience (Law, 2002). It is internationally recognized that all individuals, including those with disabilities, have a right to be able to fully participate in society (Whiteneck *et al.*, 2004). Participation has been shown to more strongly related to quality of life than either impairment or functional ability (Dijkers, 1997) and is therefore a highly valued rehabilitation outcome for individuals with disabilities (Magasi *et al.*, 2008).

In the 1980s, the 'International Classification of Impairment, Disability and Handicap' (ICIDH) was developed by the World Health Organization (WHO) (Bornman, 2004). Although the ICIDH was generally well received, disability rights groups and others were critical that the ICIDH was based on the medical model placing the problem of disability within the individual rather than within the context of society (Hemmingsson and Jonsson, 2005). Revisions started in the 1990s, which ultimately resulted in the International Classification of Functioning, Disability and Health (ICF), which was formally endorsed by the WHO in May 2001 (WHO, 2001). The ICF describes the impact of health conditions on individuals' lives and places functioning and disability in a context that includes both environmental and personal factors (Polatajko *et al.*, 2007).

Since the introduction of the ICF over 12 years ago, there has been scrutiny of its strengths and limitations. The ICF defines Participation as 'a person's involvement in a life situation' and Activity is defined as 'the execution of a task or action by an individual' (WHO, p. 213). In the diagrammatic representation of the ICF, Activity and Participation are depicted as two separate constructs, but these have not been differentiated between in the nine Activity and Participation domains listed (WHO, 2001). The lack of specificity or clear conceptual distinction between the terms Activity and Participation by the WHO has led to considerable debate among researchers and scholars about the difference in the meaning between these two terms (Noreau *et al.*, 2005; Whiteneck and Dijkers, 2009). The nine Activity and Participation

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Appendix B

Facilitators and barriers to social and community participation following TSCI

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Research Article

Facilitators and barriers to social and community participation following spinal cord injury

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Background/aim: *One of the factors known to contribute to a 'good life' following an acquired disability is making connections with others, often achieved through participation in activities outside the home. The majority of outcomes research following SCI has focussed on impairments and activity limitations with less emphasis on participation. This paper reports part of a larger study that explored the experience and meaning of social and community participation following SCI. The research question guiding the part of the study reported in this paper was: What are the facilitators and barriers to social and community participation following acquired SCI?*

Methods: *Semi-structured interviews were conducted with 17 adults with traumatically acquired spinal cord injury living in the community. Interviews were audio-recorded, transcribed verbatim and analysed using thematic analysis.*

Results: *Three main themes and 11 subthemes were identified. The main themes were: Resources and environmental accessibility impact social participation; other people influence community engagement; health issues affect social participation. Adequate financial resources and social support (from friends and family, and from peer mentors) were found to assist social participation, while the physical environment, unsupportive social attitudes and mental health issues were identified as barriers to community participation.*

Conclusions: *This study contributes to the evidence base regarding outcomes following SCI. Enabling engagement in meaningful activities in the community must be at the forefront of occupational therapy intervention, both at an individual client level and through advocacy and policy involvement, to improve the quality of life of people with SCI living in the community.*

KEY WORDS *community access and participation, domains of practice, OT process/competency standards, populations/conditions, qualitative research, service evaluation, spinal cord injury.*

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Introduction

Spinal cord injury (SCI) has significant consequences both at an individual and societal level (WHO & ISCOS, 2013). Due to advances in medical techniques there has been an increase in life expectancy for people following SCI (Krause, Carter, Pickelsimer & Wilson, 2008). However, despite these advances there remain areas of significant concern for the long term health and wellbeing of people living with SCI both in Australia and internationally.

Following an SCI, the ability to participate in meaningful life roles and activities outside the home can change and diminish (Brown, Gordon, Spielman & Haddad, 2002; Whiteneck *et al.*, 2004). Participation in work, leisure and sporting activities greatly decreases (Tasiemski, Bergström, Savic & Gardner, 2000), with an accompanying increase in time spent on individual home-based occupations such as watching television, listening to the radio, and reading (Barclay *et al.*, 2011), potentially leading to social isolation (Brown *et al.*, 2002). A major factor contributing to leading a 'good life' following an acquired disability is establishing and maintaining close relationships (Dunn & Brody, 2008). Many meaningful connections are made through participation in activities outside the home, such as being involved in sporting groups, leisure activities, going to the local shops, working or studying. Social and community participation is now recognised as an important outcome for people with an SCI (Carpenter, Forwell, Jongbloed & Backman, 2007; Schönherr, Groothoff, Mulder & Eisma, 2005; WHO, 2001).

Appendix C

Time use following spinal cord injury: an examination of the literature

Time use following spinal cord injury: an examination of the literature

Linda Barclay,[1] Libby Callaway,[2] Rachael McDonald,[3] Louise Farnworth,[4] Ted Brown[5] and Lisa Broom[6]

Key words:
Spinal cord injury, time use, participation, occupation.

Introduction: Meaningful time use provides an indicator of quality of life and is a key area of interest to occupational therapists. Spinal cord injury is a prevalent and catastrophic acquired neurological impairment, which occurs most commonly in early adulthood. Spinal cord injury has been found to have little impact on life expectancy, but has a profound influence on productivity and participation. Understanding how people with spinal cord injury use their time is imperative if rehabilitation and quality of life outcomes are to be influenced.

Method: A systematic review was completed and relevant studies located. These studies were then rated to discern their level of evidence.

Results: A total of four published articles, from two studies, were found that fitted the inclusion criteria. All published studies were cross-sectional surveys. The level of evidence provided in these studies is relatively low.

Conclusion: There has been limited research completed in the area of time use following spinal cord injury. There is a need for high quality evidence to inform occupational therapists about how people with spinal cord injury spend their time and how satisfied they are with the occupations in which they engage.

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Introduction

Human beings are occupational in nature (Wilcock 1998). Occupations that people engage in include self-care, play and leisure, paid work, volunteer work, caring for others, sleep and social participation (Law et al 2002). Engaging in a variety and balance of occupations enables us to structure time use, express ourselves and find meaning in our lives (Harvey and Pentland 2010). Time use data are increasingly used internationally to quantify time spent in non-market activities, informing planning and policy making (Harvey and Pentland 2010). Countries such as Canada, the United States (US), the United Kingdom (UK) and Australia recognise the importance of these data as a way of analysing how populations allocate their time to various activities, and use this information to plan services and resources and to allocate funds (Australian Bureau of Statistics 2008, Harvey and Pentland 2010). Consequently, significant data are available on the time use of non-disabled populations. In contrast, to date there has been limited information on the time use of disabled populations in general, or of specific diagnostic groups (Winkler et al 2005, Katz and Morris 2007, McKenna et al 2009).

A spinal cord injury (SCI) is defined as the occurrence of an acute, traumatic lesion of neural elements in the spinal canal, resulting in permanent sensory deficit, motor deficit or bladder/bowel dysfunction (Cripps 2008). When an individual experiences a trauma or permanent disability such as SCI, the ability to participate in daily activities and occupations can change dramatically. For example, the types of leisure interest that the person previously engaged in may no longer be possible. In addition, the individual's use of time may also change significantly. The person may need to spend increased time in self-care tasks, or may not be able to participate in full-time

paid employment or education as he or she did prior to the injury. The provision of interventions that promote health by enhancing the individual's skills, competencies and satisfaction in daily occupations is imperative to successful rehabilitation outcomes (Yerxa et al 1989). If targeted intervention is to improve the ability of people with SCI to engage in meaningful occupations, then knowledge of how people with SCI spend their time is imperative.

The purpose of this article is to examine existing literature on the time use of adults who have sustained SCI, and rate the quality of evidence of these studies.

Incidence and life expectancy following SCI

SCI is a universal disability, with an annual incidence of 15-40 per million (Sekhon and Fehlings 2001). In the UK, there are approximately 40,000 people living with SCI (Gall and Turner-Stokes 2008). The management of SCIs is a recognised specialist service in the National Health Service (Harrison 2006). The National Service Framework for Long-Term Conditions has enabled flexible rehabilitation pathways for people with newly diagnosed SCI (Harrison 2006) and, owing to improved first aid, rapid transportation to a specialist unit, and skilled medical, surgical and nursing care and rehabilitation, survival rates are increasing (Yeo et al 1998).

In 2006-07 in Australia, there were approximately 9000 individuals living with SCI (Cripps 2008). Access Economics Pty Ltd (2009) released a report in June 2009, which calculated the lifetime cost of SCI per person to be 4.9 million Australian Dollars (3.2 million Pounds Sterling) following paraplegia and A$7.6 million following quadriplegia (£4.9 million). Twenty-five per cent of newly injured individuals with SCI are aged between 15 and 24 years (Cripps 2008) and people have been found to have better survival rates the younger the age at which they are injured (Frankel et al 1998). In Australia, examination of mortality rates identified a mean life expectancy ranging from 70% to 92% of normal, depending on the severity of spinal injury (Yeo et al 1998).

SCI and mental health

An Australian study examining the mental health of 443 adults with SCI living in the community found that nearly half (48.5%) suffered mental health problems of depression (37%), anxiety (30%) and clinical-level or post-traumatic stress (33.4%), with an overall twofold or more increase in the probability of emotional disorders compared with the general population (Migliorini et al 2008). Barker et al (2009) found that quality of life was significantly poorer for people with SCI compared with the non-injured Australian population, with predictors of poor quality of life being secondary impairments, activity limitation and participation restrictions.

SCI and self-care

SCI has a significant impact on the ability to complete self-care (Noreau and Fougeyrollas 2000, Schopp et al 2007). The higher the level of the spinal cord lesion, and the more complete the injury, the greater the degree of disability. The self-care routine of individuals with cervical spinal lesions can require several hours to complete. This is time that may be otherwise spent on occupations such as leisure or paid work, pursuits that may offer greater individual satisfaction and self-efficacy.

Few studies have been identified that investigate time spent on personal or self-care activities among people with SCI. In a survey of 255 people with SCI in the US, Schopp et al (2007) found that participants reported needing substantial personal assistance to have adequate participation in major life activities. They also found that physical impairment was the most commonly cited barrier to engaging in life activities. Noreau and Fougeyrollas (2000) recruited 482 Canadian SCI participants to complete a questionnaire on handicap and impact on life habits. Significant disruption to the life habits of activities of daily living (including household work, outside maintenance, meal preparation and transportation) was found in 40-85% of respondents.

SCI and productivity

Law et al (2002) defined productivity as a means of contributing to the social and economic fabric of society. Productive activities, such as paid or volunteer work, provide people with a sense of purpose, give structure to their day, and offer social and economic rewards, influencing self-identity. In Australia in the time period 2006-07, the age group with the highest incidence of SCI was those aged 15-24 years (23%) (Cripps 2008). This is the time when a person is typically transitioning from adolescence to early adulthood, and commencing tertiary study or a chosen career. In the US, the average age of people injured is 31 years (SCI-Info-Pages 2010). According to Schönherr et al (2005), return-to-work rates around the world following SCI vary between 31% and 48%. Athanasou et al (1996) conducted a survey of 139 people with SCI previously discharged from a spinal rehabilitation unit in Victoria, Australia. Thirty-one per cent of this cohort were engaged in either part-time or full-time work, with the remaining two thirds unemployed. In this article, 24 studies on return-to-work outcomes among spinal injured people around the world were reviewed, and it was found that the overall return-to-work rate was 39.3% (Athanasou et al 1996). Therefore, there are large numbers of young adults, who would ordinarily be working and contributing to society, no longer doing so as a result of the SCI sustained.

Although there have been a number of studies investigating the rate of return to work following SCI (for example, Athanasou et al 1996, Tasiemski et al 2000, Murphy et al 2003, Schönherr et al 2005), very few studies have been located that identify the alternative activities in which people with SCI are participating in place of work, and what their levels of satisfaction are with these activities.

SCI and leisure

Reduced capacity to return to paid employment results in extra 'free time' that needs to be filled with other activities (Winkler et al 2005). Access to occupations that once had

meaning may become limited when a person sustains SCI (Taylor and McGruder 1996), requiring a need to forge new roles and meaning in daily tasks. Schönherr et al (2005) completed a survey of 57 people with SCI in the Netherlands, identifying that participation in vocational and leisure activities changed to a great extent following SCI. Reduced quality of life was also found to be associated with an unsatisfactory leisure situation. In a study conducted by Tasiemski et al (2000), in which 45 newly injured individuals were surveyed in the UK, it was found that frequency of involvement in sporting activities fell from 42% before the accident to 9% at the time they conducted their survey. Frequency of participation in recreational activities fell, with 42% being involved in recreation before the injury compared with 27% at the time of the survey (Tasiemski et al 2000).

Studying time use

The World Health Organisation (2001) recognised that activity limitation is a measure of disability. Time use studies are specifically designed to capture the context and flow of activities inherent in occupation (Harvey and Pentland 2010). Data are increasingly used internationally to quantify the time spent in non-productive activities and to inform planning and policy making among the general population (Australian Bureau of Statistics 2008, Harvey and Pentland 2010). These data are used to understand population trends across age groups and gender, and help to inform government policy, service development and resource allocation.

Time use data, when coupled with contextual information, including examination of physical and social environments within which tasks are performed, subjective experience of occupation and opportunities for choice and control, begin to provide insight into whether a person is engaged in occupations that he or she perceives as personally meaningful. Comparisons of the time use of a disabled population to that of the population as a whole can suggest where participation is restricted or strained (Farnworth 2003). Although there are some time use studies that have been conducted on various groups with disabilities (Winkler et al 2005, Katz and Morris 2007, McKenna et al 2009), there are only two studies, from the US and Canada, investigating the time use of people with SCI (Yerxa and Baum Locker 1990, Pentland et al 1998).

Method

A systematic review involves completing a comprehensive literature search for relevant studies on a specific topic (Brown and Burns 2001). For this paper, the process outlined by the National Health and Medical Research Council (NHMRC 2000, 2007) has been followed.

The following question was posed:

- How do adults who have returned to community living following a spinal cord injury use their time?

Search terms and search strategy

From the research question, key words or search terms were synthesised. The following search terms were used: spinal cord injury 'and' time use.

The following databases were searched: CINAHL Plus, Medline, PsycINFO, OTseeker, PubMed, Embase, EBM Reviews, AMED and Meditext. Limits included the publication years 1990-2010, and publication in the English language. In addition to electronic searches, a hand search of the reference lists from the relevant papers was conducted for articles missed by the initial electronic database search.

Abstracts for the annual scientific meetings of the International Spinal Cord Society were hand searched for the years 2004-2008.

Inclusion/exclusion criteria

Articles were included if they met the following criteria:

1. Published during 1990-2010. This was extended to 1986-2010 due to lack of studies located.
2. Publications were written in English.
3. Participants were aged 18 years and over. This was extended to 15 years and over due to lack of studies located.
4. Participants were living in the community, having completed their inpatient rehabilitation stay.
5. Primary research only was included in the review. Reviews of the literature and descriptive reports were not included.

Only three articles, stemming from two studies, were identified that met the original criteria (Yerxa and Baum Locker 1990, Pentland et al 1998, 1999). One additional publication was located (Yerxa and Baum 1986) through the hand search method. This article was published prior to the time cut-off but was included due to the low number of studies located.

Appraising the studies

The four articles were rated according to the following tools:

- The Oxford Centre for Evidence-Based Medicine's Levels of Evidence (Phillips et al 2009) consist of five levels, from strongest (Level 1 – randomised controlled trials) through to weakest (Level 5 – expert opinion).
- The McMaster Critical Review Form – quantitative studies (Law et al 1998) allows a more detailed appraisal of the study, with sections for comment on study purpose, literature, design, sample, outcomes, intervention, results and conclusions. A score out of 15 is given.

Results

Table 1 provides a summary of the four articles. Two raters reviewed and rated the studies according to the scales selected.

Appraisal of quality of articles

All studies were rated as 4 on the Oxford Scale (Phillips et al 2009). They were scored between 7 and 10 on the McMaster Critical Review Form (Law et al 1998).

Table 1. Summary of reviewed studies

Publication	Sample size	Methodology and aims	Data collection instruments
Yerxa and Baum (1986)	n = 15 people with SCI n = 12 non-disabled people (matched for age and sex)	Cross-sectional design Aims: ■ Explore how people with disabilities use their time ■ Explore how people with disabilities categorise their time ■ Degree to which engagement in activity is related to life satisfaction and happiness ■ Compare sex and age matched SCI and non-disabled group	■ General questionnaire ■ Activity Configuration Log ■ Satisfaction with Performance Scaled Questionnaire ■ Cantril ladder 'the best possible life for you' … 'the worst possible life for you' ■ One satisfaction question and one happiness question ■ Rotter I-E Scale (internal versus external locus of control)
Yerxa and Baum Locker (1990)	n = 15 people with SCI n = 12 non-disabled people (matched for age and sex) n = 10 experienced occupational therapists from a large rehabilitation centre	Cross-sectional design Aims: ■ Explore how people with disabilities categorise their time in comparison with a group of experienced occupational therapists ■ Explore how occupations were rated in terms of quality ■ Explore which occupations disabled and non-disabled people spent their time doing ■ Explore the content and number of goals for the future ■ Explore how quality ratings of occupations related to overall daily ratings	■ General questionnaire ■ Activity Configuration Log ■ Satisfaction with Performance Scaled Questionnaire ■ Cantril ladder 'the best possible life for you' … 'the worst possible life for you' ■ One satisfaction question and one happiness question ■ Rotter I-E Scale ■ Questions regarding goals for the future
Pentland et al (1998)	n = 312 SCI men (aged 15 years or over)	Cross-sectional design with multilinear regression analysis Aims: ■ To discover the effects of disability severity, time use, social support and socioeconomic status on psychosocial outcomes (specifically life satisfaction, perceived health, and adjustment to disability) in men with SCI	■ Satisfaction with Balance of Time Use – 7-point Likert statement ■ Social support – Interpersonal Support Evaluation List (ISEL) ■ Socioeconomic status – Financial Stress Scale ■ Functional Independence Measure ■ Moos Social Climate Scale ■ 12-item measure of life satisfaction ■ Perceive health measure ■ Sickness Impact Profile ■ Time use diary adapted from Occupational Questionnaire
Pentland et al (1999)	n = 312 men with SCI (aged 15 years or over) compared with n = 3617 able-bodied men from 1992 Canadian General Social Survey	Cross-sectional design with multilinear regression analysis Aims: ■ To provide preliminary descriptive and analytical information of the daily time use patterns of men with SCI ■ To compare this information with time use data of able-bodied men collected as part of the 1992 Canadian General Social Survey	■ Satisfaction with Balance of Time Use – 7-point Likert statement ■ Social support – Interpersonal Support Evaluation List (ISEL) ■ Socioeconomic status – Financial Stress Scale ■ Functional Independence Measure ■ Moos Social Climate Scale ■ 12-item measure of life satisfaction ■ Perceive health measure ■ Sickness Impact Profile ■ Time use diary adapted from Occupational Questionnaire

SCI = spinal cord injury.

All articles used cross-sectional surveys, therefore the level of evidence provided in these studies is relatively low.

Characteristics of samples

The articles by Yerxa and Baum (1986) and Yerxa and Baum Locker (1990) are both based on the same study. This study had a very low response rate (Yerxa and Baum 1986). Of the initial 152 people contacted to participate in the study, only 15 people with SCI and 15 matched adults completed the instruments. Three of the non-disabled participants were then found to have chronic disabilities, and were not included in the final results. Due to the small sample

size and convenience sampling method, limited inferences can be made to the general SCI population. In addition, it could be assumed that those individuals with SCI who did participate would have had high levels of motivation to have found and contacted a friend to participate in the study, further biasing the group studied. Yerxa and Baum (1986) acknowledged the limitations of their study in terms of 'small sample size, restricted geographical area' and 'possible lack of representativeness of the participating sample in comparison to the invited sample'. Their findings are interesting to the reader as a point of discussion and as an indicator for further research in the area of time use and life satisfaction, but have limited application in terms of evidence-based practice for those working with people with SCI.

In the study conducted by Pentland et al (1998), convenience sampling was used to select 312 SCI participants. No information is provided by the researchers regarding how the potential participants were first contacted other than the statement that they were contacted by telephone. The response rate is not discussed, therefore it is difficult to make a judgement regarding potential bias in the sample. Data were collected by telephone and mailed questionnaires.

Pentland et al (1999) drew on the same sample of SCI individuals that were used in the authors' 1998 article. The time use data of the SCI participants (n = 312) were compared with that of able-bodied men (n = 3617).

Instruments used

The time use instrument used by Yerxa and Baum (1986) and Yerxa and Baum Locker (1990) was the Activity Configuration Log. Participants were required to record all their occupations for 8 days and 8 nights. Yerxa and Baum (1986) stated that the instruments they used for data gathering had sufficiently documented reliability and validity, but had not previously been assessed for their psychometric properties. They provided some detail of the test-retest correlations they performed and concluded that the instrument was sufficiently reliable for use as a research tool.

Yerxa and Baum Locker (1990) sought to find out how participants categorised their occupations, and to compare the disabled and the non-disabled group. They did this by completing a content analysis of all the occupations listed in the Activity Configuration Log. They found that the SCI group were more detailed in their descriptions of the category 'self-maintenance' and that the same occupation was often classified into several different categories. The participants' categorisations were then compared with the way 10 experienced occupational therapists categorised all the occupations listed. Statistically, it was found that the occupational therapists agreed more with each other than with the disabled participants. These findings indicate that clear instrument guidelines are required so that results can be appropriately interpreted and applied to practice. In addition, it possibly points to the lack of validity of the Activity Configuration Log used, which is discussed below in the discussion section on time use methodologies.

Pentland et al (1999) provided more information regarding the instruments used for data collection than was given in their previous article (Pentland et al 1998). The time use diary used was adapted from the Occupational Questionnaire (Smith et al 1986) and from Section D of the 1986 and 1992 Canadian General Social Surveys. Activities were coded as personal care, leisure, productivity or sleep. The authors detailed the process used to determine the psychometric properties of the instruments and concluded that the internal consistency reliability was high. Time use diaries are explored in more detail in the discussion section.

Analysis

Pentland et al (1998) used multilinear regression analyses to examine the relationships between the variables of interest, and statistically significant outcomes were found between a number of the independent (for example, age, income and education) and dependent (for example, time spent in self-care, productivity and sleep) variables. For example, it was found that outcomes regressed on socioeconomic status had the highest R_2 values (39%) for life satisfaction, while outcomes regressed on social support had an R_2 value of 65% for life satisfaction.

Pentland et al (1999) used Mann Whitney U-tests to examine differences between the sample of non-disabled men and SCI men. There were statistically significant differences between the two groups for time spent in all occupational areas.

Yerxa and Baum (1986) compared the categories of 'work' and 'other' in the disabled and non-disabled groups using a two-tailed t-test. The difference in mean time spent in both work and other categories was statistically significant at the $p<0.05$ level. They examined the relationships between time use and overall life satisfaction by using chi-square analyses, but failed to demonstrate a statistically significant relationship between these variables.

Discussion

Yerxa and Baum (1986) found that the main differences between the SCI sample and the non-disabled group were that a number of the SCI group were unemployed (10 out of 15) and had a lower income. They found no significant relationships between time use and overall life satisfaction in either of the two groups. It was reported that the SCI group had a statistically significant lower level of satisfaction for performance on home maintenance skills and social/community problem-solving skills.

Time use was similar between the two groups except in the areas of 'work' and 'other'. The SCI group spent a mean of 3.58 hours per day in 'work' compared with 6.11 hours for the non-disabled group. A surprising finding was that the SCI group reported spending a mean of 3.34 hours per day on 'self-maintenance' compared with 3.74 hours for the non-disabled group. The authors hypothesised that this could be due to carers performing the more time consuming self-care tasks for the injured person. One third of the SCI

group reported home management skills as 'not applicable to me', which also possibly indicates that the injured group delegated such tasks to others to preserve energy for more meaningful activities or as a result of their physical limitations. Complete content analysis of the category 'other' was not included in the article, but would be helpful in analysing exactly what the SCI group spent their time doing because 'other' consisted of a mean of 4.30 hours of their day. Some examples of comments for this 'other' category were 'watch TV', 'sort mail' and 'study the Bible'. These activities are similar to those found by Pentland et al (1999) in their media and communication activities category.

Pentland et al (1998) found that disability severity did not influence time allocation or outcomes. Outcomes of life satisfaction, perceived health and adjustment to disability in men with SCI were influenced by other factors, such as social support, socioeconomic status and satisfaction with time use: key areas of interest for occupational therapists. Emotional support appeared to have the strongest influence on adjustment to disability. The authors found that individuals' satisfaction with the balance of their use of time in the areas of self-care, productivity, sleep and leisure was not related to the amount of time spent in those activities. However, satisfaction with this balance had a strong linear predictive relationship with all three outcomes of life satisfaction, perceived health and adjustment to disability.

In their second article, when Pentland et al (1999) compared the time use data of their recruited sample of 312 men with SCI with the time use data of 3617 able-bodied Canadian men, they found that the SCI sample spent 1.5 hours longer each day on personal care. The SCI group also spent 1.3 hours longer on media and communications activities (television, radio, reading, telephone and letters). Time spent in productive activity revealed the greatest differences, with the men with SCI spending 3 hours less per day on productivity-related activities. The authors did not report what percentage of each group was employed at the time of the study, but stated that the SCI sample spent 2.7 hours less each day in paid work.

Pentland et al (1999) provided a number of hypotheses as to the reasons for the above results. They surmised that lower productivity rates could be due to lower education levels and to physical limitations, such as lower endurance and limited mobility. Limited finances may be a contributing factor to the leisure profile of the SCI sample, with much leisure time being spent on activities that were inexpensive, such as watching television or reading. The authors discussed the potential social isolation of such leisure activities and the sedentary nature of them as possibly being detrimental to physical and emotional wellbeing, but they did not support this argument with evidence. No linear predictive relationship was found between severity of SCI and time spent in productivity activities. Therefore, they concluded that other factors that may reside in the environment (for example, social support, education or personality factors) could be the cause of this particular finding.

Of most interest is the finding by Pentland et al (1998) that time use *per se* matters less than the 'contextual intrinsic aspects of the time (meaningfulness, challenge, satisfaction) for the individual' (p20). Interestingly, this is similar to the statement made by Yerxa and Baum Locker (1990) that their 'study emphasises the significance of the subject's experience as important information in the activity analysis' (p324). Understanding of the personal meaning or experience of time use, therefore, may assist in the development of interventions to support the health of an individual. The amount of time spent in specific occupations tells us little about the quality of someone's life (Harvey and Pentland 2010). Methodologies to explore and examine elements of personally valued time use, including objective and subjective contexts and perceived skills, challenges and control within occupations (Csikszentmihalyi and Larson 1987), should be considered prior to intervention planning with people with SCI.

Time use methodologies

Pentland et al (1998) developed their own time diary instrument. A limitation of the study, and one that is commented on by the authors, is the fact that they only collected time use data over a 2-day period. They found only moderate correlations between the data collected over the 2 days, suggesting that data reliability may be increased by collecting data from the same individuals over more than one day. They also discussed the issue of error recall, which may have influenced the reliability of the data. However, acknowledging the limitations, time use diaries are a relatively straightforward and inexpensive way of collecting data for large populations.

Yerxa and Baum Locker (1990) used an Activity Configuration Log and required the participants to fill this in every 4 hours for 8 days and 8 nights. They found a difference in the way the SCI group categorised their occupations compared with the non-disabled group, and both of these were different again to the way that the occupational therapists categorised the occupations listed. This highlights the importance of selecting appropriate instruments for time use studies and ensuring that these instruments are clearly understood by the participants.

Relying only on quantitative tools, such as diaries or surveys, limits the opportunity for the researcher to find out other important information, most notably the subjective experience of time use. The experience sampling method (ESM) refers to a method of data collection in which participants respond to repeated assessments at moments over the course of time while functioning within their natural settings (Scollon et al 2003). This methodology uses a beeper or similar to signal the respondent to record information about his or her momentary situation and psychological state (Csikszentmihalyi and Larson 1987). One of the main advantages of ESM is that it 'uses the participant as a source of data while avoiding dependence upon recall' (Farnworth et al 1996, p5). It also provides insight into the person's internal states and his or her environmental context. Finally, ESM provides important information regarding these intrinsic aspects, including level of perceived skill, challenges, control

and satisfaction within the individual's time use, which Pentland et al (1998) have demonstrated may be more important than objective characteristics.

Qualitative methods, such as in-depth interviews and occupational histories (Kielhofner et al 2008), can provide rich time use data (Farnworth 2003). However, Pentland and McColl (1999) discussed their finding that face-to-face interviews can compromise the accuracy of information given by people with disabilities due to embarrassment. Face-to-face interviews are also more time consuming and expensive in comparison with telephone interviews (Pentland and McColl 1999). They concluded that time use data collected from people with disabilities is best done by telephone interview because this allows some anonymity. Given the age of these studies, technological advances in time use data gathering (for example, internet-based surveys and ambulatory assessment using hand-held devices such as personal digital assistants) were uncharted at that time. Such advances should be considered in future research design and offer greater anonymity of the respondent and easier physical access for the participant (particularly in the case of SCI), in addition to reducing the time demands of data gathering for both participants and researchers. However, depending on the population being studied and the goals of the researcher, it is likely that a combination of tools, both qualitative and quantitative, will be most successful in obtaining a cross-section of data that will provide the richest source of information to the researcher.

Conclusion

Knowledge of how and why people do what they do in the context of time is fundamental to occupational therapists (Molineux 2010) and allied health professionals assisting people to readjust to life following a catastrophic event such as SCI. When examining relationships between time use and health and wellbeing following SCI, Pentland et al (1998) found that objective characteristics (number of minutes) matter less than the intrinsic aspects of the time use (personal meaningfulness, perceived challenge and level of satisfaction experienced). These intrinsic factors may override objective time use and compensate for 'imbalance'; that is, little time spent doing a highly personally satisfying activity is more predictive of health and wellbeing than more time spent in minimally to moderately satisfying activities (Pentland et al 1998). This has implications for providers of health care and those working with people after SCI.

In order to understand issues related to health, wellbeing and ageing with SCI, in terms of social, psychological and medical costs, current empirical evidence is needed on how people with SCI organise and spend their time, and how satisfied they are with the occupations in which they participate. Comparison of patterns of time use of people with a disability with that of the population as a whole can suggest where activity participation of those with disabilities is altered or limited (Taylor and McGruder 1996). Using this information, areas of service provision that are lacking can be identified, and targeted intervention planned and implemented.

As demonstrated, there have been few publications examining the time use of people with disabilities, and even fewer examining the time use and participation of people with SCI. The two studies that have been completed with the SCI population were conducted in the US and Canada in the 1980s and 1990s, limiting the potential for generalisation to current international SCI populations. In addition, the studies are generally of low quality, which further limits the ability to apply the findings. It is, therefore, concluded that current well-designed studies, using a combination of high quality quantitative and qualitative methods, are lacking. The use of technology, such as personal digital assistants in ambulatory assessment, may offer accessibility and ease of data gathering with this population. The importance of personally meaningful time use, and its influence on health and wellbeing, is the core focus for occupational therapists. Knowledge of how and why people do what they do in the context of time and place is a foundation of occupational therapy (Harvey and Pentland 2010). Thus, occupational therapists are well placed to pursue this important research area.

Conflict of interest: None declared.

Key findings

- Few studies have been conducted that examine time use of people with SCI.
- Evidence is needed on how people with SCI use their time and how satisfied they are with their occupations.

What the study has added

The study of time use is important when planning intervention with people with SCI. Research is needed to determine if individuals with SCI are engaging in occupations they consider meaningful.

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Appendix D

Secondary health conditions experienced by people with SCI

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Research Article

Secondary health conditions experienced by people with spinal cord injury within community living: Implications for a National Disability Insurance Scheme

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Background: *Australia's National Disability Insurance Scheme (NDIS) provides supports for individuals, delivered through a personalised participant planning process, to influence choice and goal attainment.*

Aim: *This study aimed to use both quantitative and qualitative methods to examine the impact of secondary health conditions on the experiences of people with spinal cord injury (SCI) who have returned to community living, in the context of Australia's National Disability Strategy and recently launched NDIS. Exploration of lived experience of health conditions following SCI utilising this mixed methods approach may offer important insights for effective planning within an NDIS.*

Methods: *A cross-sectional survey using the Spinal Cord Injury Secondary Conditions Scale (SCISCS), demographic questionnaire and in-depth interview was undertaken with 33 people with SCI living in the community. Demographic and SCISCS data were reported using descriptive statistics. Interviews were audio-taped, transcribed and analysed thematically.*

Results: *Participants were on average 58.5 years of age and 20 years post-injury. Five key themes emerged relating to (i) spasm and pain; (ii) sexual dysfunction; (iii) pressure areas; (iv) fatigue; and (v) the impact of secondary health conditions on life role participation and choice of supports and equipment.*

Conclusion: *Secondary health conditions can significantly impact occupational participation following SCI. Appropriate intervention, including customised equipment and direct support, if delivered as part of an effective NDIS, may prevent or reduce the severity of these conditions and offer the potential to influence health and participation outcomes of people who have returned to community living.*

KEY WORDS *health promotion, mixed methods research, spinal cord injury.*

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Introduction

Spinal cord injury (SCI) is a serious life event whereby an individual experiences permanent spinal insult. Approximately 9000 Australians live with SCI (Cripps, 2008); however, this underestimates the total number of people living with spinal injury, as only traumatic injuries are included in these figures. SCI results in major physical and sensory impairments that can affect occupational participation (Price, Stephenson, Krantz & Ward, 2011; Russi, 2014; van Leeuwen *et al.*, 2012). These injuries may impose significant health, psychological and social consequences for the individual and their family, in addition to the economic impact on the broader community (Access Economics, 2009).

Improvements in medical and rehabilitation care have resulted in increased life expectancy for those with SCI both in Australia and internationally, whereas a range of risk factors for morbidity and mortality have been identified. These include the extent of neurological impairment and secondary conditions experienced over time (Krause & Saunders, 2011; Middleton *et al.*, 2012; Pershouse *et al.*, 2012). Secondary conditions are often managed in a community setting, not equipped to deal with the complexity of health conditions experienced following SCI (Hammell, 2010). Secondary health

conditions and complications experienced by people living with SCI include bladder and bowel complications, spasm and spasticity, acute and chronic joint or neuropathic pain, fractures, pressure sores, respiratory problems, kidney, cardiac and circulatory problems, and mental health disorders (Adriaansen *et al.*, 2013; Dorsett & Geraghty, 2008; Hammell; Krause & Saunders; Savic, Short, Weitzenkamp, Charlifue & Gardner, 2000). These conditions exacerbate the degree of disability for people with SCI and negatively impact on long-term health, quality of life, and productivity (Adriaansen *et al.*; Dorsett & Geraghty; Pershouse *et al.*). Specifically, secondary health conditions can impede independence in self-care, mobility and daily living. These conditions may affect the individual's ability to maintain employment or participate in other regular activities (Barker *et al.*, 2009). Some secondary health conditions, such as respiratory complications, autonomic dysreflexia and chronic pressure ulcers or resulting infection can be life threatening and result in hospitalisation, or even death (Krause & Saunders; Krause, Carter, Pickelsimer & Wilson, 2008; Middleton *et al.*). Other conditions, although not life threatening, may have significant impact on quality of life of the individual and their mental health (Hammell; Hoffman, Bombardier, Graves, Kalpakjian & Krause, 2011). In Australia, research has identified significantly lower quality of life outcomes for people with SCI ($n = 270$) compared with a normative sample, with presence of secondary impairments the most important predictor of outcome (Barker *et al.*). Following this, people with SCI who have better physical health have been found to be substantially less likely to experience depression, anxiety or stress (Migliorini, Tonge & Taleporos, 2008).

One of the major challenges for individuals living with a SCI, as well as policy makers and service providers, is to enable the person to maintain good physical and mental health, including preventing the development of secondary health conditions as they age (Guilcher *et al.*, 2013; Hitzig, Campbell, McGillivray, Boschen & Craven, 2010). The National Disability Strategy (NDS), formally endorsed by the Council for Australian Governments in 2011, sets out six priority areas within a 10-year plan for improving life for Australians living with disability (Department of Social Services, 2013). One of the key areas is promotion of health and wellbeing. This priority area focuses on the delivery of health services and health promotion, and the interaction between health and disability systems to improve wellbeing and enjoyment of life for the person with disability (Department of Social Services). This is particularly pertinent for people living with SCI. Evidence demonstrates continuing high levels of secondary health complications following SCI (Adriaansen *et al.*, 2013; Hammell, 2010; Jensen *et al.*, 2013), meaning people require ongoing, responsive health care, even many years post-injury, and across a range of community settings.

The endorsement of the NDS has been followed by a once-in-a-lifetime disability reform in Australia via a National Disability Insurance Scheme (NDIS; Commonwealth of Australia, 2013). Recommended by a Productivity Commission Inquiry into Disability Care and Support, the Scheme has been designed to reform a disability service system which is 'inequitable, underfunded, fragmented, and inefficient and gives people with disability little choice' (Productivity Commission, 2011, p. 2). Initially launched in July 2013 in four trial sites across Australia, the NDIS has been designed to support people with significant and permanent disability, including SCI, to identify, proactively plan for, and purchase the necessary and reasonable equipment, support and services that they require to achieve their personal goals for community living (Commonwealth of Australia). The Scheme is designed to empower people with disability, including SCI, to be actively involved in targeted planning for their individual goals, via the purchase of equipment and support they require. This disability reform has important implications for occupational therapists (Russi, 2014).

With the implementation of the NDIS, occupational therapists will be one of the key professionals involved in assisting people with SCI to achieve and maintain their optimal level of participation and thereby, occupational functioning. Occupational participation is a vital area of concern as a positive relationship has been identified between productivity and societal participation, satisfaction with level of performance in everyday activities, and community reintegration (Barker *et al.*, 2009; Boschen, Tonack & Gargaro, 2003). Occupational therapists aim to enhance function and independence, and implement strategies that address social and environmental challenges or barriers to participation, within an individual's chosen occupations (Herrmann, Kirchberger, Stucki & Cieza, 2011; Price *et al.*, 2011).

Secondary complications of SCI have been researched extensively from a medical perspective, primarily utilising quantitative methodologies. Studies have been conducted in relation to mortality (Cao, Sellasie & Krause, 2014; Krause *et al.*, 2008), prevalence (Adriaansen *et al.*, 2013; Hitzig *et al.*, 2010), hospital readmission rates (Dryden *et al.*, 2004), and ageing with SCI (Jensen *et al.*, 2013; Savic, Short, Weitzenkamp, Charlifue & Gardner, 2000). However, to date there has been only limited research investigating the lived experience of secondary health conditions for the person living with SCI, and how these conditions impact participation and personal goals for community living (Guilcher *et al.*, 2013; Kennedy, Lude, Elfstrom & Cox, 2013).

The aim of this pilot study was to investigate the incidence and severity of common secondary health conditions experienced by a group of people with SCI who had returned to community living. The study also aimed to examine the impact of these health conditions from the perspective of the individual. This study used

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a mixed methods approach to allow for in-depth analysis of the individual's lived experience. Mixed methods provide more detailed information regarding how secondary conditions impact on the daily life of the person with SCI and direct their decision making with regard to their productivity and inclusion. Such considerations are important for NDIS access planners, and allied health professionals, including occupational therapists, in the context of NDIS implementation. Findings are considered in the context of the major disability reform currently being undertaken with the launch of Australia's NDIS, and the person-centred planning central to the Scheme.

Methods

Inclusion criteria

The inclusion criteria were: the person should be above 18 years, be able to provide informed consent to participate in the study, have had acquired a SCI after birth and have had returned to community living following inpatient rehabilitation. Ethics approval for the study was gained from the relevant university Human Research Ethics Committee prior to project commencement. Thirty-three participants were recruited through a number of sources, including advertisements in the newsletters of peak bodies representing people with SCI, via outpatient clinics, and community-based allied health professionals working with people with SCI.

Data collection methods included:

1. A customised demographic questionnaire, consisting of questions relating to gender, age, level of injury, time since injury, cause of injury, level of paid and informal care received and living arrangements.
2. The Spinal Cord Injury Secondary Conditions Scale (SCISCS; Kalpakjian, Scelza, Forchheimer & Toussaint, 2007): The SCISCS consists of 16 common secondary health conditions in SCI. Each item is rated on a four-point scale as to whether the health condition was present or not in the preceding three months and, if it was present, how significant or chronic it was for the individual. The SCISCS has established validity and reliability (Kalpakjian *et al.*, 2007).
3. Semi-structured interviews using questions from the Occupational Performance History Interview (Version 2.0; Kielhofner *et al.*, 1998). The interview was designed to provide detailed understanding of a person's life history, the impact of a health event or disability, and goals for the future. All five categories on the OPHI-II – activity/occupational choices; critical life events; occupational roles; daily routine; and occupational behaviour setting – were explored. This included information from the participants about their subjective experience of their secondary health conditions experienced, and how these impacted on their participation in daily life, personal aspirations, choices, occupations and valued routines.
4. A field journal including daily schedule and logistics of the study; and reflections on the researcher's thoughts, feelings and ideas, was kept. This journal included the researcher's subjective thoughts and feelings as well as observations within, associated findings, and reflections upon the interview process with each participant. All data were gathered by the first author.

Quantitative data analysis

Results of the cross-sectional survey using the SCISCS and customised demographic questionnaire were entered into the Statistical Package for Social Sciences Version 19.0 (SPSS, 2010). SPSS was used for data storage, tabulation and the generation of descriptive statistics.

Qualitative data analysis

Interviews were audio-taped and transcribed verbatim. NVivo 9 (QSR International Pty Ltd, 2009) was used to facilitate the coding and retrieval of data for constant comparison, in conjunction with field notes from the reflective journals of the researcher. This ensured triangulation and in-depth understanding of interview data gathered (Krefting, 1991). Project partners provided peer examination to the researcher during data gathering. The researcher also undertook additional peer examination by review of the preliminary study findings with project partners involved in the study, as well as colleagues working in community practice with people with SCI.

Thematic analysis offered a rich and detailed exploration of individual experiences and provided insight into the environmental and societal impacts of living with SCI (Braun & Clarke, 2013). Using an inductive approach, themes identified were strongly linked to the data themselves (Patton, 2002) with coding of data undertaken without trying to fit it into a pre-existing coding frame (Braun & Clarke, 2013). To preserve participant anonymity, pseudonyms were given for each participant.

Results

Quantitative data

Participant demographics

Participants were on average 58.5 years of age and 20 years post-injury, with 67% being men. Sixty-one per cent of the group were married or in a defacto relationship, with the remaining 39% single or divorced. Forty-five per cent of the group were retired due to age, 22% were working full or part time and 33% were not looking for work or were unemployed. Sixty-one per cent of the group had sustained their injury through a road or

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TABLE 1: *Demographic data* (n = 33)

Variable	Result *n* (%)	Variable	Result *n* (%)
Characteristics		*Level of injury*	
Male	22 (66.7)	Cervical	11 (33)
Female	11 (33.3)	Thoracic	13 (39.4)
Age in years (M, SD)	58.64 (15.32)	Lumbar	8 (24.2)
Time in years since injury (M, SD)	20.32 (15.49)		
Marital status		*Location*	
Single/Divorced/Widowed	13 (39.4)	Metropolitan	29 (87.9)
Married/*De Facto*	20 (60.6)	Rural	4 (12.1)
Employment status		*Injury cause*	
Unemployed	2 (6.1)	Road accident	17 (51.5)
Not looking for work	9 (27.3)	Work accident	3 (9.1)
Employed part time	4 (12.1)	Other accident	5 (12.1)
Employed full-time	3 (9.1)	Non-traumatic cause	9 (27.3)
Retired	15 (45.5)		

M, mean; SD, standard deviation.

TABLE 2: *Prevalence of secondary health conditions* (n = 33)

Condition	Prevalence (%)
Muscle spasms (spasticity)	75.8
Joint and muscle pain	69.7
Circulatory problems	66.7
Bladder dysfunction	57.6
Chronic pain	57.6
Bowel dysfunction	45.5
Sexual dysfunction	42.4
Contractures	39.4
Urinary tract infection	39.4
Pressure sores	36.4
Autonomic dysreflexia	30.3
Injury due to loss of sensation	27.3
Respiratory problems	21.2
Diabetes	15.2
Postural hypotension	15.2
Heterotrophic bone ossification	9.1

workplace accident, 12% from some other form of trauma, with 27% of the group having sustained a non-traumatic SCI. The spread of level of injury was reasonably even: cervical (33%), thoracic (39%) and lumber (24%), with one participant unable to advise of his exact level of injury (Table 1).

Table 2 details the prevalence of secondary health conditions experienced by the group. Spasticity or muscle spasm (75.8%) and joint and muscle pain (69.7%) were the most common secondary health conditions reported in the preceding three months on the SCISCS. Chronic pain (27.3%), circulatory problems (21.2%), sexual dysfunction (21.2%), muscle spasm (18.2%) and contractures (18.2%) were the most significant or chronic issues reported.

Qualitative data

The qualitative data analysis identified five themes, four of which related to specific health issues (spasm and pain, sexual dysfunction, pressure sores and fatigue) experienced by participants. The fifth theme related to the impact of secondary health conditions on life role participation. These themes are detailed below, and discussed in relation to findings from participant responses on the SCISCS (Kalpakjian *et al.*, 2007).

Spasm and pain

Muscle spasm or spasticity was the most commonly reported secondary health condition and participants spoke of how significant spasm impacted their pain levels. Spasm impacted on participants' ability to complete self-care tasks such as transferring, bed mobility, dressing and showering and increased their reliance on paid or family support persons. Andrew commented: 'When I transfer from my bed to the commode, is usually when I will spasm the worst. I have been known to fall off the commode with [spasm]'.

Pain related to spasm, joint and muscle pain was reported by 69.7% of participants, being a moderate to significant problem for 33.4% of the group, and overall the second most frequently reported health condition. The participants distinguished between general chronic pain (27.3%) as the most frequently reported significant or chronic health problem that interfered with the ability to participate in activities, and specific joint and muscle pain (15.2%). Ben commented that: 'I've been swimming today and because of it, because I've stirred up my body, my pain level is probably running at about 9 out of 10 now'.

Participants spoke of how ongoing pain impacted their occupational choices. Some people detailed neck and shoulder pain preventing them sitting in their wheelchair, meaning they were unable to participate in many activities. Others talked about the need to return to bed to rest due to pain, or to consider the use of a motorised wheelchair as an alternative to pushing their manual chair. Some participants reported delays in access to equipment funding impacted timing of supply of this new equipment. People spoke of having to minimise overuse problems from occurring or learn to

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manage their body over time. Debora discussed the impact of pain on her work capacity, stating,

> I couldn't do any more than [part time work] – when I first went into the wheelchair I did full time work for about a year, it was too difficult sitting down for 8 hours a day…I needed a change of posture.

These findings have clear implications for NDIS planning in relation to the equipment and support required to facilitate social and economic participation.

Sexual dysfunction

Sexual dysfunction was the third most commonly reported chronic or significant condition, whereas overall prevalence of sexual dysfunction was reported. Sexual difficulties impacted on identity and sense of self efficacy. John stated, 'You don't feel complete, when you can't [achieve an erection]' while Bob said that the sexual dysfunction he experienced, 'It might sound trivial compared to all my other difficulties, but for me it [not being able to have sexual intercourse] has impacted so much'.

Sexual difficulties impacted on marital relationships. Marcus commented that he and his partner had accepted the change in his sexual function since the injury, reporting, 'My wife has given up on it [having sexual intercourse], we just accept now it isn't going to happen any more'. However, when asked if they were satisfied with this, he stated, 'Not really, but what can you do?' Alan felt he had not been given enough information about sexual function following SCI, stating, 'It would have been great to sit down with another person and say "how exactly do you do it [following SCI]?"' From these discussions it was apparent that the topic of sex and sexuality may not always be addressed during individualised planning.

Pressure sores

Thirty six per cent of participants reported mild to moderate problems with pressure sores within the last three months; however, none recorded significant or chronic problems within that time period. Severe pressure sores can result in hospitalisation, which can impact not only on the person with the SCI, but also on their family life, such as the strain placed on their partner and family when they were admitted to hospital. Hospitalisation meant they were not available to contribute to the usual household management, or alternatively their partner had to manage home and family duties, coupled with hospital visiting. The National Disability Insurance Agency has identified the need to 'consider and respect the role of family, carers and other persons who are significant in the life of the participant' (NDIS, 2014, p. 1). The impact of secondary health conditions on family (e.g., partners, children) was clearly articulated by participants in this study. John reported:

> So my wife and I have sort of swapped roles [since the SCI]…she works full time and I look after the kids…So when I end up in hospital [with a pressure area], she's trying to juggle all these balls in the air.

Hospitalisation also provided significant disruption to productivity roles for the person with SCI, such as being a paid worker. Frank described the mismanagement of a pressure area by a local medical service and the impact it had on his work, forcing early retirement:

> I retired…because of health. I had an area they had to excise on my bottom. And the local GP, local surgeon, did it…he cut it like a piece of steak. Not having that expertise in spinal cord injury, he just treated me like everybody else.

Matthew further highlighted the impact that skin problems can have on how much he could do in the day, stating: 'Usually two or three times a week I might go to bed early, particularly when I have a pressure sore. I have been in bed a lot the last few weeks'. Similarly, Susan went to bed to minimise the risk of getting pressure areas but this meant that she had to adapt her other life activities to do so: 'Yes there are days I have to spend in bed, but that to me is not a downer…you can stay the right side of pressure sores by looking at your skin'.

Fatigue

Participants in this study discussed the impact of fatigue, and how this in turn affected their daily routines, and further led them to spend more time in bed. Some participants noted that fatigue impacted on their ability to work full time or participate in physical fitness activities of their choosing. James said, 'I get home from work and am so tired, I can't even think about going back out [to gym]'. Fatigue also impacted on relationships, including the opportunity to spend time with a spouse. For example, Michael reported,

> I bed down normally at around 7.30 of a night, and I stretch that out because I try to spend what hours I can with my wife before I go to bed. But by 7.30, my body is completely drained and I have to be on the bed.

Impact of secondary health conditions on life role participation

Hospitalisation for secondary health conditions impacted on valued life roles including those of worker, hobbyist and home maintainer. Alan stated: 'I have stopped everything…work, basketball…I mean I keep in touch with people by phone or on email…having bad circulation means it takes longer to heal things…'.

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It was not just direct implications of the SCI but other consequences that it impacted. For example, Chris had an accidental burn to his feet, a consequence of lack of sensation. He described how this stopped him in engaging in a valued active leisure role that maintained his health and sense of wellbeing: '...I burnt my feet on one of those radiant heaters. It put me out of action [hand cycling] for a couple of years'.

Medical issues took people away from their everyday activities, but could also be life threatening. Jim who had recurrent chest infections over a long time said that this impacted on him so that 'I got quite depressed, thinking "will this be the last time" cause I ended up in ICU quite a bit and then intubated and then eventually they left the trache [ostomy] in because it was safer'. Pat's comments summarised the experiences of many of the participants by saying 'Life now, pretty much, seems to be medical...Medical appointment after medical appointment'. In the context of an NDIS, services harnessed through the Scheme will need to be designed to offer flexible and responsive support that can be reviewed in a timely manner in the case of exacerbation of disability-related health issues.

Discussion

This study investigated the incidence of secondary health conditions following SCI. The impact these conditions had from the perspective of the individual were examined, with findings considered in the context of Australia's NDS and implementation of a NDIS. The use of mixed methods in this research highlighted the participation restrictions faced by participants living with SCI in the community, associated with the health conditions experienced. The influence these conditions had on social and economic participation, as well as decisions regarding supports and equipment utilised, were also apparent.

As in other studies (Adriaansen *et al.*, 2013; Schopp, Clark, Hagglund, Sherman & Stout, 2007), pain management and spasm were found to be major issues negatively impacting role participation. Pain has been shown to impact both the physical and emotional dimensions of an individual, directly influencing the ability to engage in meaningful occupations and reintegration into the community (Donnelly & Eng, 2005). Past treatment focus has been predominantly pharmacological, but increasingly it is being recognised that psycho-social factors such as coping responses, attitudes and emotions, together with the social environment, have a significant impact on pain experiences and social functioning (Heutink, Post, Wollaars & van Asbeck, 2011).

This study has further identified the influence of extrinsic environmental factors on mental health and subjective wellbeing following SCI (Hoffman *et al.*, 2011; Migliorini, Callaway & New, 2013), and the association between pain and depression (Hammell, 2010). Further exploration of facilitators and barriers to participation is necessary, and is central to occupational therapy practice (Russi, 2014). Given the NDIS has been designed to provide reasonable and necessary supports in a timely and responsive manner, the option to secure customised equipment or direct support where it was previously lacking has potential to offer efficiencies in daily routines and influence pain management following SCI. This is an important area in both the NDIS planning process, as well as evaluation of Scheme impact, and warrants further investigation.

Many studies of secondary health conditions do not report on sexual difficulties due to the measures used. The SCISCS offers opportunity to engage in dialogue with people with SCI about sexual function. A number of respondents in this study identified dissatisfaction in this domain, consistent with other research findings (Noreau, Fougeyrollas, Post & Asano, 2005). Evidence provided at the Australian Government Joint Standing Committee Review on the NDIS identified a gap in provision of specialised services for people with disability with regard to sexuality and relationships (Commonwealth of Australia, 2014). In the NDIS trial sites, planners from the Launch Transition Agency are using 'planning and assessment tools to guide the [planning] conversation ... in a flexible way to reflect the participant's individual context and needs' (NDIS, 2014, p. 4). It will be important that the tools used are flexible enough to offer opportunity to discuss and plan for aspirations in relation to sexuality. Opportunities for intimacy and/or sexual activity, particularly where intercourse may not be possible, are important occupational issues that appeared neglected by health professionals for some people in this study. Occupational therapists, as part of a multidisciplinary team, can adopt an active role in the delivery of sexuality education for individuals with SCI; however, currently there is limited research available to direct practice in this area (Pollard & Sakellariou, 2007; Sakellariou, 2006).

Although the complexity of fatigue following SCI has been identified in the literature (Hammell, 2010; Schopp *et al.*, 2007), effective interventions for fatigue in SCI are undeveloped (Jensen *et al.*, as cited in Hammell). Participants in this study also identified that fatigue was a significant problem. Fatigue was not included in the SCISCS, so this important issue may have been missed if participants had not been interviewed. Fatigue after SCI is reported to have cognitive, emotional and physical dimensions (Hammell), again highlighting the need for a broader approach to intervention rather than focussing on body functions and structures. Hammell suggested that the complexity of fatigue and possible interconnections between this and other conditions, such as pain or depression, should not be underestimated. It is important for practitioners to facilitate matching the person with SCI to active or other leisure

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pursuits, which may offer physical, as well as cognitive and emotional benefits. Alternatively, partnering with people with SCI to develop energy conservation strategies and identify and plan for any further assistive technology that would facilitate personally valued participation is necessary. NDIS funding may facilitate timely provision of assistive technology. Russi (2014), an Australian occupational therapist with lived experience of SCI, noted the impact availability of funding for assistive technology can have on occupational performance following SCI. Education and training on the use and maintenance of equipment is an important role of occupational therapists (Herrmann *et al.*, 2011; Russi), and should be considered within NDIS planning.

This study provides further evidence of the importance of a well-coordinated interdisciplinary approach within long term follow up of people with SCI living in the community (Adriaansen *et al.*, 2013). Education regarding prevention of secondary health conditions is a key focus during the inpatient SCI rehabilitation process. However, there is a dearth of information on the effectiveness of these programs in reducing the occurrence, recurrence or severity of pressure sores. There is a pressing need for research in this area to identify factors that may reduce occurrence and severity of pressure areas (Hammell, 2010). Prediction of compliance with health promoting behaviours such as how to avoid pressure sores among the SCI population has been inconclusive and conflicting (Bloemen-Vrencken, de Witte, Post & van den Heuvel, 2007), so new ways of engaging with this, including education of practitioners as well as people with SCI on best available evidence is needed. Within an NDIS-context, early intervention to prevent these secondary conditions, and a coordinated health-disability interface, has been identified as necessary for all Australians with significant and permanent disability (Commonwealth of Australia, 2014).

This study has further highlighted that secondary health conditions experienced following SCI may increase the person's need for support, and decrease their economic and social participation. Careful consideration must be given to how this issue will be addressed in the new disability scheme being trialled. Alternative ways of engaging people with SCI in health behaviours, in addition to empowering self-advocacy, are needed. The NDIS has been designed to facilitate empowerment and early intervention, placing the person with disability at the centre of the planning process (Butteriss, 2012). Occupational therapists are ideally placed to assist negotiation of access to timely equipment and disability support for this population.

Limitations of the study

Given this was a pilot study of small sample size, generalisation of the findings to the wider SCI population is limited. In addition, the use of the SCISCS limited reporting of secondary health conditions to the preceding three months and thus may not have captured issues experienced prior to that time period. However, the mixed methods approach taken in this study allowed for more in-depth insight into the range and impact of secondary health conditions experienced by people living with SCI and consideration of these in the context of launch of an NDIS.

Conclusion

People living with SCI experience a range of significant secondary health conditions that impact on their occupational performance, social and economic participation, and life roles. This study further highlights the complexity of the development and consequent management of secondary health conditions following SCI. Study findings have implications for occupational therapists working with people living with SCI who have returned to community living, and for policy makers, service delivery providers and access planners within an NDIS. The findings from this study highlight current deficiencies in the way this group of people with SCI were supported in community settings, and how their health conditions have been managed. To meet the priorities identified by the NDS, it is imperative that people with SCI, and the service providers working with them, understand best practice in the prevention and management of secondary health conditions. Clearly, there is considerable research still required in this area; however, NDIS planning processes will require a targeted focus on timely provision of equipment and supports that may influence prevention or management of such conditions.

In the context of the self-directed, market-driven model espoused within the NDIS (Butteriss, 2012; Commonwealth of Australia, 2013), occupational therapists working in the community are ideally placed to assist people with SCI to better manage chronic health conditions. This may be achieved by supporting the development of self-advocacy skills, the negotiation of relevant service systems, and planning for and engagement and access to timely specialist and support services and equipment prescription within community living (Adriaansen *et al.*, 2013; Herrmann *et al.*, 2011; Russi, 2014). It is important that occupational therapists adopt preventative and lifespan approaches to recommendations regarding building modifications, equipment provision, and educating people regarding the long term consequences of the activity and assistive technology choices that they make on outcomes following SCI. Given this input, intermittent re-engagement with NDIS planners over time may be required to review a participant's plan. This is vital to ensuring that the health, wellbeing and participation of people with SCI who return to community living is maximised.

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Appendix E

Participation Measures

Measure	Purpose of measure	How developed	Domains assessed	Rating scale used	Number of items	Population	Psychometric properties	Advantages/limitations
IPAQ Cardol et al 2001	To profile disease severity	Developed for use as a profile for disease severity evaluation	Social relationships Autonomy in self-care Mobility Leisure Family role Work and education Overall perceived participation	Problems with participation uses 3 point scale (0=no problem to 2 = severe problem) Perceived participation uses 5 point scale (1=very good to 5=very poor)	31 problems with participation items, one 8 autonomy items	Neuromuscular disease SCI Stroke Rheumatoid arthritis Fibromyalgia	Homogeneity of subscales considered good Established content validity with a heterogeneous population Established construct validity with a heterogeneous population	Generic (not SCI specific)
CHART Whiteneck et al, 1992	Designed to measure the level of handicap in a community setting – tested with SCI population	Based on the dimensions of handicap described by ICIDH (1980)	Physical independence Mobility (includes transport) Social integration Economic self-sufficiency Time use	Varies some dichotomous (yes/no) some number of hours	7 areas with 32 items in all. There is a short form version which has only 19 items	Developed with and for SCI	High test-retest reliability Good validity. Ceiling effects	-Originally developed for use with SCI population -Based on observable criteria that are unlikely to be open to subjective interpretation -Does not investigate perceptions or attitudes -Commonly used in SCI research therefore can be used for comparison purposes -Some life domains are imprecisely measured, and others not measured at all
LIFE-H (v3.0) Noreau et al 2002	Designed to document the quality of social participation of individuals with disabilities.	Based on the conceptual model of the Handicap Creation Process and the ICIDH. Consumer groups and rehabilitation professionals.	*ADL:* Nutrition; fitness; personal care; communication; residence; mobility *Social roles:* responsibility; interpersonal relations; community; education; employment; recreation. Also asks about *environmental*	Level of difficulty to perform a life habit. Type of assistance required (technical, adaptation, human assistance). Level of satisfaction on a 5 point scale.	Short form has 69 life habits Long form has 240 life habits	Developed to assess impact of AT on life situations with multiple disability groups	High level of reliability (long form) among adults with SCI (interpersonal relationships and nutrition showed lower reliability levels) Moderate to high test-retest reliability among TBI good content validity good convergent validity between CHART and Life-H for SCI	-Measures quantity but also quality of social participation. -Includes environmental attributes that can facilitate or impede accomplishment of life habits –developed in Quebec therefore may be cultural issues

			facilitators ie. Technical aids, adaptation and/or human assistance.					
CIM McColl et al 2001	Client-centred measure of community integration	Based on authors' research into community integration with people with ABI	Know rules & how to follow them; Know way around; Acceptance; Leisure time; Productivity; Independence; Suitable living arrangements	5 option scoring from Always agree to Always disagree	10 items	ABI – not validated with SCI	Valid for use with adults with ABI, not other disabilities	Very short, easy to administer – does not address main participation issues relating to SCI. Is more appropriate for people with cognitive deficits
RNLI Wood-Dauphinee et al, 1988 Stark et al, 2005 Hitzig et al 2012	Short tool – can be administered in person or on telephone. A tool for measuring person-perceived participation	?	Mobility Self-care Work Recreation Social activities Family role Personal relationships	3 point scoring system (0 = does not describe my situation; to 2 = fully describes my situation)	11 items		Valid and reliable with stroke, cancer, patients from acute-care and rehabilitation settings, SCI, MS, CP, polio	Very short – good for large cohort studies – does not provide detailed information. Low respondent burden, and easy to score.
PM-PAC Gandek et al, 2007	Patient-reported participation measure	Based on extensive literature review. Initially based on ICIDH-2 and then modified when ICF came out. Items tested on patients and health professionals and modified before field testing	Mobility (includes transport) Role functioning Work Education Community, social and civic Interpersonal relationships Domestic life	Usually five point scale asking extent to which they are currently limited (not at all, a little, somewhat, very much, extremely)	51 items	Neurological ; musculoskeletal; medically complex	Test and retest scale scores did not differ significantly Construct validity- come back to this	Too lengthy to administer to many participants Variation between disability groups Not SCI specific
PAR-PRO Ostir et al, 2006	A measure for home and community participation – a USA rehabilitation programme outcome measure (for CARF purposes)	A panel with expertise in medical rehabilitation, CARF accreditation standards, and outcome assessment and instrument development.	Patient satisfaction (with rehabilitation) Work/employment School/education Volunteer/public service Meal prep/cooking Light housework Heavy housework Caregiver activities Money management Shopping Home maintenance	Five point scale (0 = did not participate through to 4 = participated almost daily) Assessed at admission, discharge and follow-up	20 items	Designed for use with disabled and non-disabled. Designed to complement FIM.	Good internal consistency Good Rasch person and item fit statistics. Potential floor effect identified.	Brief and practical to administer Purpose to evaluate rehabilitation for large numbers of patients Older age of sample (relevance to SCI) Not SCI specific

			Hobbies Socializing inside home Socializing outside home Travelling Movies/theatre/sports Playing sport/exercize Religious/spiritual Public transport Driving vehicle Intimate relationships					
IMPACT-S Post et al, 2008	Self-report for use in large epidemiological & outcome studies As a level 1 screening tool	First draft was administered to 11 road traffic accident victims and to a panel of 18 health professionals, and then it was modified.	Learning and plying knowledge General tasks and demands Communication Mobility Self-care Domestic life Interpersonal interactions & relationships Major life areas Community, social and civic life	3 level scoring method (No limitation Minor limitation Major limitation)	33 items in 9 scales	Designed for generic use.	Good internal consistency Test-retest reliability good Excellent concurrent validity	Road accident victims, not SCI specific. Closely aligned with ICF Possible biased results due to large non-participation Developed in Netherlands
PARTS/M Gray et al, 2006	Self-report survey of participation in major life activities by people with mobility impairments	Questions based on qualitative studies of participation of people with mobility impairments & health care professionals	Self-care; Mobility; domestic life; interpersonal interactions and relationships; Major life areas; community, social and civic life.	Scoring based on: frequency; health-related limitations; importance; support needed. Primarily Likert Scales used.	105 items in from 20 major life activities	SCI; MS; CP; stroke; postpolimyelitis	Good internal consistency and stability; convergent validity with the RNL to measure personal satisfaction in participation.	Assessment covers ADL in addition to social participation. Has a satisfaction AND importance component. Lengthy to administer (60 – 90 minutes) , however, sections can be completed as needed. Not appropriate for large cohort studies.

IPAQ = Impact on Participation and Autonomy Questionnaire
CHART= Craig Handicap Assessment and Reporting Technique
LIFE-H = The Assessment of Life Habits (v3.0) CIM = Community Integration Measure
RNL Index = Return to Normal Living Index
PM-PAC = Participation Measure for Post-Acute Care
PAR-PRO = a measure for home and community participation
IMPACT-S = ICF Measure of Participation and ACTivities (Screener)
PARTS/M = Participation Survey/Mobility

Appendix F

Interview Guide

The experience and meaning of social and community participation following acquired spinal cord injury or damage (SCI).

Participant _____Code no : _____

Date of interview :_____

Date injured:_____Type of injury:_____

Living circumstances:_____

Cultural background:_____

Other relevant information:

_____

_____

1. This research project is about how people living in the community with an SCI are involved in social and community participation. What ways do you currently participate in society/the community?

Prompts: *Do you do things with family or friends?*

Do you attend arts events or sporting events or go to cafes?

2. Could you tell me what social and community participation **means** to you?
How would you define social/community participation?

3. Is social participation **important** to you? If so why?
What aspects of your social or community participation are the most satisfying for you?

4. Has your participation in society or the community changed at any particular time since your injury? *If yes, why? How?*

5. Are there other ways that you would like to be able to be involved in the community/society that you currently are not? *(follow up with what hinders you from being involved in these ways if appropriate)?*

6. Can you think of a situation recently where you faced some type of barrier or problem when you wanted to participate in a community based activity?

7. What are the greatest difficulties/barriers that you face to being more involved in the community? *Prompts: transport issues (details); buildings access (details); health services; equipment issues; health issues (pain, fatigue); planning issues*

8. What aspects of your social and community participation are least satisfying for you?

9. What things help you to be involved in the community/in the way that you want?

Prompts: family; friends; community programs; internet access; peer support programs; rehabilitation professionals; assistive technology/equipment ; being able to plan ahead

10. Can you think of a situation recently where the attitude of someone affected your ability to participate in the community in the way that you wanted? How did you respond?

11. Do you have any other thoughts or ideas about this topic?

Appendix G

Explanatory Statement

MONASH University

THE EXPERIENCE AND MEANING OF PARTICIPATION FOLLOWING SPINAL CORD INJURY

This information sheet is for you to keep.

My name is Linda Barclay and I am conducting a research project with Dr Rachael McDonald, and Dr Primrose Lentin, Senior Lecturers and researchers in the Department of Occupational Therapy, towards a PhD at Monash University. This means that I will be writing a thesis which is the equivalent of a 300 page book.

You have been sent this Explanatory Statement after responding to an advertisement. You are invited to take part in this study. Please read this Explanatory Statement in full before making a decision.

Why were you chosen for this research?
The aim of this study is to explore the experience and meaning of participation for people living with a spinal cord injury in the community. Therefore participants are needed who are living with an acquired spinal cord injury in the Victorian community.

The aim/purpose of the research
The aim of this study is to explore the experience and meaning of participation for people living with an acquired spinal cord injury (SCI) living in Victoria.

Possible benefits
Information gained through this study may be used to guide future interventions and assist people with SCI to participate in social and community activities that have personal meaning to them and will enhance their quality of life.

What does the research involve?
The study involves a 1-2 hour semi-structured interviews conducted either in your home, over the telephone or in a location of your choice. This interview will be audio recorded.

How much time will the research take?
Time required will be 1-2 hours for the interview and a further 30-60 minutes to discuss and clarify the findings at a later time if necessary.

Inconvenience/discomfort
There will be no physical harm or discomfort for you in any way. It is possible that the nature of some of the questions may cause you some psychological discomfort. You

are not required to answer these questions if you choose not to. There will be no negative consequences if you choose not to answer certain questions. If at any time during or after the interview you experience any psychological distress the researchers will ensure that you have access to appropriate counselling or support services.

You can withdraw from the research
Being in this study is voluntary and you are under no obligation to consent to participate. However, if you do consent to participate, you may withdraw from further participation at any stage up until the data is analysed. There will be no negative consequences if you choose to withdraw. You are also able to refuse to answer any questions which you feel are too personal or intrusive with no negative consequences.

Confidentiality
All information provided by you will be kept confidential and only accessible to the researchers conducting the project. At no time will your name be used in any published documentation. Once the interview has been conducted your name will be de-identified through the use of a code, all data analysis will then occur using that code. No one other than the researchers will have access to the original transcript with your name on it. The interview transcript will be kept in a locked filing cabinet for five years, after which time it will be destroyed.

Storage of data
Data collected will be stored in accordance with Monash University regulations, kept on University premises, in a locked filing cabinet for five years, after which time it will be destroyed. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Results
You will be sent a written summary of the results once data analysis has occurred. If you would like additional information, please contact Ms Linda Barclay on 99044493 or email linda.barclay2@monash.edu.

If you would like to contact the researchers about any aspect of this study, please contact the Chief Investigator:	**If you have a complaint concerning the manner in which this research (cf13/1107-2013000540) is being conducted, please contact:**
Dr Rachael McDonald Department of Occupational Therapy School of Primary Health Care PO Box 527, **Frankston, 3199** **Telephone : 61 3 99044470;** **61 3 9902 4473** **Email: rachael.mcdonald@monash.edu**	Executive Officer Monash University Human Research Ethics Committee (MUHREC) Building 3e Room 111 Research Office Monash University VIC 3800 Tel: +61 3 9905 2052 Fax: +61 3 9905 3831 Email: muhrec@monash.edu

Thank you.
Linda Barclay

Appendix H

Consent Form

MONASH University

THE EXPERIENCE AND MEANING OF PARTICIPATION FOLLOWING SPINAL CORD INJURY.

NOTE: This consent form is for the purposes of research and will remain with the Monash University researcher for their records.

I understand I have been asked to take part in the Monash University research project specified above. I have had the project explained to me, and I have read the Explanatory Statement, which I will keep for my records.

I understand that:	YES	NO
- I will be asked to be interviewed by the researcher -	☐	☐
- unless I otherwise inform the researcher before the interview I agree to allow the interview to be audio-taped	☐	☐
- I agree to make myself available for a further interview if required	☐	☐
- I agree to make myself available to be contacted for further research in this area	☐	☐

And

I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.

and

I understand that any data that the researcher extracts from the interview for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.

and

I understand that I will be given a transcript of data concerning me for my approval before it is included in the write up of the research.

and

I understand that I may ask at any time prior to data analysis for my data to be withdrawn from the project.

and

I understand that no information I have provided that could lead to the identification of any other individual will be disclosed in any reports on the project, or to any other party.

and

I understand that data from the interview will be kept in secure storage and accessible only to the research team. I also understand that the data will be destroyed after a 5 year period unless I consent to it being used in future research.

and

I do not give permission to be identified by name and I understand I will remain anonymous at all times in any reports or publications from the project.

Participant's name:

_____

Signature: _____

Date: _____

Telephone number : _____

Appendix I

Ethics Approval Monash University

MONASH University

Monash University Human Research Ethics Committee (MUHREC)
Research Office

Human Ethics Certificate of Approval

Date:	**21 June 2013**
Project Number:	**CF13/1107 - 2013000540**
Project Title:	**The experience and meaning of participation following spinal cord injury**
Chief Investigator:	**Dr Rachael McDonald**
Approved:	**From: 21 June 2013 To: 21 June 2018**

Terms of approval

1. The Chief investigator is responsible for ensuring that permission letters are obtained, if relevant, and a copy forwarded to MUHREC before any data collection can occur at the specified organisation. **Failure to provide permission letters to MUHREC before data collection commences is in breach of the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research.**
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must contain your project number.
6. **Amendments to the approved project (including changes in personnel):** Requires the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

[redacted]

Professor Ben Canny
Chair, MUHREC

cc: Ms Linda Barclay, Dr Primrose Lentin

Postal – Monash University, Vic 3800, Australia
Building 3E, Room 111, Clayton Campus, Wellington Road, Clayton
Telephone +61 3 9905 5490 Facsimile +61 3 9905 3831
Email muhrec@monash.edu http://www.monash.edu.au/researchoffice/human/
ABN 12 377 614 012 CRICOS Provider #00008C

Appendix J

Ethics Approval Alfred Health

TheAlfred

ETHICS COMMITTEE CERTIFICATE OF APPROVAL

This is to certify that

Project No: 273/14

Project Title: The experience and meaning of social and community participation following spinal cord damage

Principal Researcher: Dr Rachel McDonald

was considered for Low Risk Review and ***APPROVED*** *on* **23 July 2014**

It is the Principal Researcher's responsibility to ensure that all researchers associated with this project are aware of the conditions of approval and which documents have been approved.

The Principal Researcher is required to notify the Secretary of the Ethics Committee, via amendment or report, of

- Any significant change to the project and the reason for that change, including an indication of ethical implications (if any);
- Serious adverse effects on participants and the action taken to address those effects;
- Any other unforeseen events or unexpected developments that merit notification;
- The inability of the Principal Researcher to continue in that role, or any other change in research personnel involved in the project;
- A delay of more than 12 months in the commencement of the project; and,
- Termination or closure of the project.

Additionally, the Principal Researcher is required to submit

- A Final Report on completion of the project.

Approval covers the project as described in the application (including any modifications made prior to approval). Low Risk projects are subject to audit and ethical approval may be withdrawn if the project deviates from that proposed and approved.

SPECIAL CONDITIONS

None

SIGNED:

[redacted]

R Frew
Secretary, Ethics Committee

Please quote project number and title in all correspondence

Appendix K

Amendment Alfred Health Ethics Approval

TheAlfred

Ethics Committee

Certificate of Approval of Amendments

This is to certify that amendments to

Project: **273/14 The experience and meaning of social and community participation following spinal cord damage**

Principal Researcher: **Dr Rachel McDonald**

Amendment:
Additional recruitment by accessing a database of people with non-traumatic spinal cord myelopathy who participated in Project No: 148/13 and agreed to be contacted about future research.

Letter of invitation Version 3 dated 17-12-2014

have been approved in accordance with your amendment application dated **12/11/2014** on the understanding that you observe the National Statement on Ethical Conduct in Human Research.

It is now your responsibility to ensure that all people associated with this particular research project are made aware of what has actually been approved and any caveats specified in correspondence with the Ethics Committee. Any further change to the application which is likely to have a significant impact on the ethical considerations of this project will require approval from the Ethics Committee.

[redacted]

Chair, Ethics Committee (or delegate) Date: **30/12/2014**

Professor John J. McNeil
Chair, Ethics Committee

All research subject to Alfred Hospital Ethics Committee review must be conducted in accordance with the National Statement on Ethical Conduct in Human Research (2007).

The Alfred Ethics Committee is a properly constituted Human Research Ethics Committee operating in accordance with the National Statement on Ethical Conduct in Human Research (2007).

Appendix L

Newsletter

SOCIAL AND COMMUNITY PARTICIPATION FOLLOWING SPINAL CORD INJURY

December 2015, Volume 1

Researcher:
Linda Barclay, PhD candidate

Welcome to the first newsletter about the study: Social and community participation following spinal cord injury.

This study explores the experience and meaning of social and community participation for adults living with an acquired spinal cord injury (SCI) in Victoria. I would like to thank all those who have given their time to participate in the study.

The information you have provided has given great insights into the challenges that people with spinal cord injuries face when out and about in the community. This information can be used to inform the future directions of rehabilitation, and how changes can be made in the larger community to support people with disabilities to fully participate in the community in the way they wish.

This newsletter will outline the findings from the first phase of the study. I welcome any comments you have about these findings. If you would like a copy of the journal publication outlining these results, please contact me.

Participants

17 people with traumatic spinal cord injury were interviewed for this phase of the study. There were a mixture of women and men, education levels, working and non-working, and different injury types and levels. The main focus of the information we sought for this part of the study, was to find out what facilitates and what hinders people's ability to participate in the community.

Theme One

Resources in the environment were identified as having significant impact on whether people could get around their local communities. Problems with the number and design of disabled car parks was an issue for quite a few people. Some people talked about having difficult encounters with other members of the public who had parked illegally in these spaces.

All participants talked about the importance of having enough money to do the things that they wanted. Differences were noted between people with compensation (for example TAC) and those without. In general those with compensation did have more access to equipment and paid care, but this did not always equate to satisfactory community participation. Harry stated: "*I was on a pension for years, before I found this [job] and got off the pension. And, also equipment. If you haven't got enough money to get what you want, you're stuck with second best, I guess.*"

Almost all the people interviewed described situations where buildings both new and old, parks and other environments were not accessible for them. George who lives in a new estate said: "*Here's a new estate that's just been built. If I go into that estate, I have to stay on the bitumen road, because the gutters are too steep, I can't get up the gutters, and there is no footpath, it's just grass.*"

Theme Two

Strong social support was identified as being important to help people reconnect with the community. Key support people such as family members, or peer mentors provided practical and emotional support to people and encouraged them to get back to previous activities, but perhaps in a different way. When talking about peer mentors, John stated: "*Seeing them and being able to talk to them and then telling their stories, it was not like reading it out of a book or seeing it on TV, and you saw that it was real, it wasn't just hyped up or anything like that.*"

One important factor highlighted was that the best way that family or friends can help is to provide support, but not be overly protective. "*Definitely my close friends and family never treated me any differently. There are obviously some modifications you have to make to your lifestyle but they still treat me the same.*" Some people who did not have key support people in their environment were often socially isolated as a consequence.

Theme Three

Health concerns were identified by some people as impacting negatively on their social and community participation. Some people had experienced problems with pressure sores, and bladder infections, but most people found that these did not interfere greatly with their community participation.

However, mental health issues were identified by a number of people as negatively impacting on them, particularly in the early stages of transitioning home. Jenny said: "*Back then, I mean look, I was really depressed, like I was suicidal, I think I didn't really want to go out...I was very ashamed of like me and what I looked like…people staring at me. And so for a while I just needed to get my head around that and I didn't really want to engage with people for a while until I felt confident.*"

Attitudes of other members of the public really affected whether people were willing to get out and enjoy community events. For those who had been injured fairly recently, negative social attitudes really impacted on them and often prevented them from participating. Others who had been injured years earlier, had developed strategies to deal with people in public, or simply did not see it as a problem. Sam said: "*Nowadays the younger generation don't really see disability. I don't have any problems with people in retail, I'm at [shops] three to four times a week and most people are friendly.*"

I am continuing to work on this study. I have just finished analysing the data from interviews with 17 people with non-traumatic spinal cord injuries and will release these results in the next newsletter. For more information about the information presented in this newsletter, or the other work that I am doing, please contact Linda Barclay on 99044493 or on linda.barclay2@monash.edu

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Appendix M

Poster ISCOS 2015

Social and community participation following spinal cord injury: a critical review

Ms Linda Barclay, A/Prof Rachael McDonald, Dr Primrose Lentin
Department of Occupational Therapy, Monash University

Introduction

Following an SCI, the ability to participate in meaningful life roles and activities of choice outside the home can significantly change and frequently diminish [1]. Participation in leisure and sporting activities greatly decreases [2], and there is an increase in the time spent on individual sedentary occupations [3]. ***One of the factors known to contribute to a "good life" following an acquired disability is making connections with others, that is, establishing and maintaining close relationships [4].***

Evaluation of rehabilitation outcomes following acquired disability should include participation in social and community life. ***Evidence is needed to guide clinical practice to ensure that it is client centred, therefore findings from studies that report on social and community participation following SCI need to be reviewed and synthesized [5].***

Objectives

To examine the available evidence regarding social and community participation following SCI, and factors that influence that participation, and to appraise the quality of the evidence examined.

Methods

Systematic search of the Databases: OVID MEDLINE; AMED; CINAHL PLUS; PSYCHINFO, and hand searches conducted.

Search terms: spinal cord injur* OR tetrapleg* OR parapleg*, AND community participation OR participat* OR life roles OR participation in activities OR social participation OR community role* OR role*, OR occupational engagement.

Quality ratings used:

The Critical Review Form- Quantitative Studies[6]

The Critical Review Form- Qualitative Studies Version 2 [7].

Quality of Studies

- Overall mean rating of the quantitative studies 9.3/15.
- Overall mean rating of the quantitative studies was 16.7/24.

Findings

International Classification of Functioning, Disability & Health (ICF) domains

Interpersonal Interactions & Relationships

The importance of family relationships was highlighted in four qualitative studies [8,9,10,11] and in one quantitative study that explored this aspect [12]

Social support was identified as motivating [8] and both emotional and practical support seen as important [11]

Problems with love life and sexuality were repeatedly mentioned by participants [13,14,15]

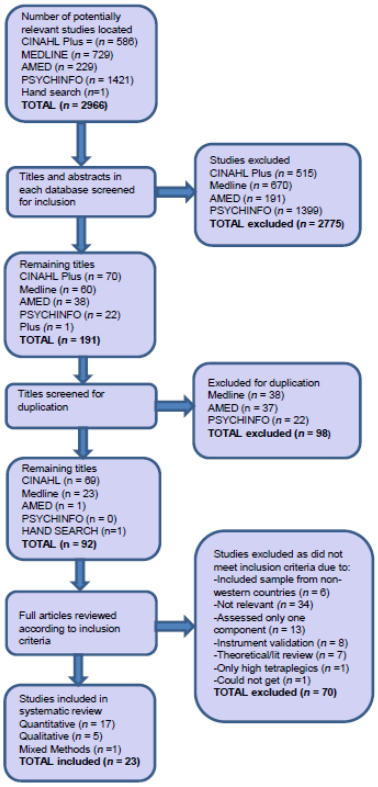

Figure 1. Flowchart of search process

Findings continued

ICF domains

Major Life Areas (School, education, employment)

- Lack of ability to engage in a satisfactory level of employment was a consistent finding [12, 13,16,17].

Community, Social and Civic Life

- Many people socially isolated [18]
- Ability to go on trips, attend sporting or recreational events and participate in sports diminished [19]
- Need to manage social attitudes towards disability, reflected on by some participants [10]

Factors that influence social and community participation

Environmental factors (ICF)

- Problems with adequate transport consistently stated [1,16,18,20,21,22,23,24].
- Practical support was particularly critical for community participation [11,24]
- Overall there was a general lack of satisfaction with health professionals and the rehabilitation process [21]
- Respondents felt unprepared for discharge, that poor attitude of health professionals could limit choice and control [17,21]
- Technology, adaptations and equipment were found to serve as both barriers and facilitators [22]
- Influence of built environment varied depending on country where study conducted [1,10,22]

Factors that influence social and community participation

Personal factors (ICF)

- Gender, age, cultural background, injury type and secondary health conditions were found to impact on the type and quality of participation[1,12,15,20].
- The most prominent finding relating to person factors was pain [14,21,22,24]

Conclusions

•Facilitators to participation were personal care assistance, social support, & OT input

•Barriers to participation were inadequate transport, built environment, access to health professionals

•The main person related barrier was pain

•These findings have implications for resource allocation and priorities for funding

•In-depth exploratory research is needed to obtain detailed information regarding barriers/facilitators

1. Whiteneck G, Meade M, Dijikers M, Tate D, Bushnik T, Forchheimer M (2004). Environmental factors and their role in participation and life satisfaction after spinal cord injury. *Arch Phys Med Rehabil* **85**:1793-1803.
2. Tasiemski, T., Bergström, E., Savic, G., & Gardner, B. P. (2000). Sports, recreation and employment following spinal cord injury -- a pilot study. *Spinal Cord*, **38**: 173-184.
3. Barclay L, Callaway L, McDonald R, Farnworth L, Brown T, & Broom L. (2011). Time use following spinal cord injury: an examination of the literature. *British Journal of Occupational Therapy*, **74**:1-9
4. Dunn D, & Brody C. (2008). Defining the good life following acquired physical disability. *Rehabilitation Psychology*, **53**: 413-425.
5. Barclay L, McDonald R, & Lentin P. (2015). Social and community participation following spinal cord injury: a critical review. *International Journal of Rehabilitation Research*, **38**:1-19.

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Correspondence: linda.barclay2@monash.edu

Appendix N

Poster ANZSCOS 2016

Understanding the factors that influence social and community participation following non-traumatic spinal cord injury

Linda Barclay[1]

Rachael McDonald[2], Primrose Lentin[1], Helen Bourke-Taylor[1]

[1] Department of Occupational Therapy, Monash University

[2] Swinburne University

BACKGROUND: Social and community participation influences quality of life (QOL) and is recognised as an important outcome of rehabilitation following spinal cord injury (SCI). However, there is limited research specifically exploring the social and community participation outcomes of people following non-traumatic SCI (NTSCI). People with NTSCI tend to be older than those with traumatic SCI (TSCI), are 50% more likely to be women, and are generally reliant on government pensions and funding, therefore their needs are different to people with TSCI. Increasing numbers of people with NTSCI warrants research that will lead to improved QOL.

METHODS:

- Semi-structured interviews (n=17)
- Data thematically analysed [1]
- Member checking, field notes, & reflective journal kept to maximise trustworthiness [2]

Personal factors influence social & community participation

- Incontinence impacted social & community participation
- Fatigue hindered social & community participation
- Use of strategies to overcome obstacles facilitated social and community participation

Resources in the environment influence social & community participation

- Transport was vital to access the community
- The built environment was a facilitator & barrier to social & community participation
- Lack of financial resources were a barrier to social & community participation
- Appropriate equipment facilitated social & community participation but had associated challenges

Social aspects of the environment influence social & community participation

- Social networks reconfigured after NTSCI
- Societal attitudes impacted engagement in social & community activities
- Roles & responsibilities were motivators for social and community participation
- Lack of access to client-centred paid care impacted social and community participation
- Family & friends were essential to facilitate social and community participation

- People with NTSCI are more likely to have incomplete injury, therefore continence issues more difficult to manage, impacting on social and community participation, especially for women.
- More education is needed regarding fatigue management once people return home.
- People with NTSCI over 65 years will not be eligible for the National Disability Insurance Scheme (NDIS) – possible inequity in services received.
- People most satisfied with their participation used strategies to manage attitudinal and physical barriers they encountered.
- People with NTSCI are more reliant on family members for care – carers therefore need appropriate preparation for their new caring role and ongoing support.
- Compared to people with TSCI, those with NTSCI have less access to appropriate equipment.
- People with NTSCI are less likely to be admitted to "specialist spinal rehabilitation" therefore less access to peer mentors, impacting their social and community participation.
- There are a lack of alternatives to paid employment especially for older men, who are being forced into early retirement.

[1] Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: a practical guide for beginners*. London: Sage Publications Ltd.

[2] Curtin, M., & Fossey, E. (2007). Appraising the trustworthiness of qualitative studies: Guidelines for occupational therapists. *Australian Occupational Therapy Journal, 54*, 88-94.

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