Employment outcomes for people following traumatic spinal cord injury

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Abstract

Background: Traumatic spinal cord injury (SCI) has devastating consequences, affecting the physical, psychological, social and vocational areas of a person's life. Employment potential in people with traumatic SCI appears unrealised, with rates of labour force participation lower than the general population and substantially lower than pre-injury employment levels. Research on this issue has been limited to date, but it suggests that the process of returning to work after SCI is complex and that vocational interventions should be tailored and flexible to respond to individual needs.

Overview: Chapter One of this thesis presents the background rationale for the research program. Chapter Two reviews and critiques the literature concerning vocational rehabilitation and the issues surrounding employment after SCI. The aims of the research are identified here. The third chapter provides a systematic review, appraisal and thematic synthesis of the qualitative literature that focuses on the experience of returning to work following SCI. Chapter Four describes an audit of patient medical records with the aim of identifying employment outcomes for people admitted to Austin Health with SCI over a four year period. Chapter Five presents the findings of a longitudinal cohort study that followed a group of people who participated in a newly implemented program of early intervention vocational rehabilitation. It examines the nature and extent of relationships between contextual factors and employment outcomes over time for these people. The sixth chapter presents an interpretative phenomenological analysis, undertaken to develop an in-depth understanding of the experiences and pathways of persons seeking and gaining

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employment after SCI. Chapter Seven reflects on the work presented throughout the thesis, discusses overall findings, identifies implications for practice, acknowledges the limitations of the thesis, and makes recommendations for future research. Chapter Eight presents conclusions from the research program.

Findings: Results from the program of research led to six main findings. First, early intervention vocational rehabilitation shows promise in enhancing employment outcomes for people following traumatic SCI. Second, the concept of worker identity includes the process of becoming a worker after SCI, and the meaning and value of being a worker postinjury. Third, secure relationships, social supports, and the presence of a positive employment culture in institutional and social environments appear facilitatory of labour force participation. The fourth finding is that people with access to loss of earning benefits or equivalent are less likely to return to the labour force, while the fifth finding showed that having a higher level of pre-injury education was positively related with participation in the labour force. Finally, higher levels of subjective wellbeing are predictive of labour force participation and are positively associated with higher levels of social participation. **Conclusions:** This thesis establishes the importance of paid employment in people's lives after traumatic SCI, while recognising the uniqueness of the employment journey for each individual. The experience of seeking, gaining and maintaining employment is complex. For people with SCI, the pathway to employment can be supported by involvement in an early intervention vocational rehabilitation program, gaining further education, and the existence of strong social supports. Seeking to re-establish worker identity, financial stability and subjective wellbeing are essential factors that facilitate an employment outcome.

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Abbreviations

AIHW	Australian Institute of Health and Welfare
AIS	American Spinal Injuries Association Impairment Scale
CMOP-E	Canadian Model of Occupational Performance and Engagement
DIC	Duration of initial care
EBSE	Evidence-based supported employment
EIVR	Early intervention vocational rehabilitation
ENTREQ	Enhancing transparency in reporting the synthesis of qualitative
	research
GLME	Generalised linear mixed effect
HADS	Hospital Anxiety and Depression Scale
ICF	International Classification of Function, Disability and Health
IPA	Interpretative phenomenological analysis
IPAQ	Impact on Participation and Autonomy Questionnaire

LOT-R	The revised Life Orientation Test
МОНО	Model of Human Occupation
NDIS	National Disability Insurance Scheme
NICE	National Institute for Health and Clinical Excellence
NPRS	Numeric Pain Rating Scale
PEO	Person Environment Occupation model
PWI	Personal Wellbeing Index
RTW	Return to work
SCI	Spinal cord injury
SCIM	Spinal Cord Independence Measure
SCIS	Spinal Community Integration Service
SWLS	Satisfaction With Life Scale
TAU	Treatment as usual
VHA	Veterans Health Administration
VR	Vocational rehabilitation

VSCS Victorian Spinal Cord Service

WHO World Health Organization

CHAPTER ONE

1 INTRODUCTION TO SPINAL CORD INJURY AND VOCATIONAL REINTEGRATION

1.1 OVERVIEW

Traumatic spinal cord injury (SCI) with persisting neurological sequelae is a devastating injury. The consequences of SCI can be significant and far-reaching, potentially impacting on all facets of life (Trieschmann, 1988). People who most frequently experience this type of injury are younger men (Lee, Cripps, Fitzharris, & Wing, 2014), who are healthy and active prior to injury (Whiteneck, Tate, & Charlifue, 1999) and who are then faced with a lengthy and challenging adjustment to their new circumstances (Trieschmann, 1988). Reengagement in vocational roles is held to be an important part of the adjustment process (Boschen, Tonack, & Gargaro, 2003; Krause, 1992). Yet despite the known benefits of work on personal health and wellbeing (Schonherr, Groothoff, Mulder, & Eisma, 2005; Tomassen, Post, & van Asbeck, 2000; Ville, 2005) and the vocational potential people with SCI have been observed to have (Young & Murphy, 2009), return to work rates after injury generally remain very low, typically being around 35-40% in developed nations, but often far less than this (Trenaman, Miller, & Escorpizo, 2014; Young & Murphy, 2009).

As this thesis has been prepared by an occupational therapist, the research is viewed through an occupational lens. This means that an emphasis on occupation will prevail through the studies undertaken and the information presented. Occupation is the core domain of concern for the occupational therapist and refers to the broad life purposes of self-care, productivity and leisure. This thesis will focus on the area of productivity, and more specifically on paid employment outcomes for Victorians of working age (15–65) who have sustained a traumatic SCI (with persisting neurology), regardless of whether they are returning to their pre-injury position, to the same employer but a different role, or to a new employer, or if they are commencing employment for the first time post-injury. This Victorian cohort are considered to be broadly representative of people with SCI in Australia and internationally. The demographic information for Australians with SCI, which includes those involved in this study, is described in section 1.2.2. The terms 'vocational intervention', 'vocational integration' and 'vocational rehabilitation' are related to the inputs or processes involved in facilitating an employment outcome for people following SCI, and they are used throughout the thesis. For the purpose of this thesis, employment is defined according to International Labour Organization (ILO) and Australian Bureau of Statistics (ABS) criteria, where to be employed is to receive remuneration for work in the open labour market for time in excess of one hour per week (Australian Bureau of Statistics, July 2014; International Labour Organization, 2013).

The program of research presented in this thesis was undertaken to understand the experiences of and differences for people in and out of the labour force following SCI and to explore the impact of changes to rehabilitation practice that aimed to enhance employment outcomes. Chapter One of this thesis presents the background rationale for the research program. It reviews pertinent literature to lay the foundation for the subsequent sections. Information is included on the impact of SCI physically, psychologically and socially, and more specifically on the challenges associated with returning to work post-injury and the

current vocational service system in Victoria, Australia. Chapter Two reviews and critiques the literature concerning vocational rehabilitation and the issues surrounding employment after SCI. The aims of the thesis are articulated at the end of Chapter Two. The third chapter provides a systematic review of the qualitative literature that focuses on the experience of returning to work following SCI, an appraisal of the quality of this literature, and a thematic synthesis of it. Chapter Four describes an audit of patient medical records. The audit aimed to identify employment outcomes for people admitted to Austin Health with traumatic SCI between July 2005 and December 2009. This was undertaken to provide a baseline of people's outcomes prior to the introduction of an Early Intervention Vocational Rehabilitation (EIVR) program, which aimed to improve employment outcomes for people post-SCI. In early 2010, service changes took place at Austin Health and the EIVR program was implemented.

Chapter Five presents the findings of a longitudinal cohort study that followed a group of people who participated in the EIVR program. The sixth chapter draws on the findings from the previous chapters and presents an interpretative phenomenological analysis, undertaken to develop an in-depth understanding of the experiences and pathways of persons seeking and gaining employment after traumatic SCI. Chapter Seven reflects on the work presented throughout the entire thesis, discusses overall findings, identifies implications for practice, acknowledges the limitations of the thesis, and makes recommendations for future research. Chapter Eight presents conclusions from the research program.

1.2 WHAT IS TRAUMATIC SPINAL CORD INJURY?

1.2.1 Overview

A traumatic SCI occurs when there is damage to the spinal cord, a primary substructure of the central nervous system. The spinal cord carries messages responsible for bodily functions to and from the brain and body. Cord damage results in loss or partial loss of motor and sensory function below the level of the lesion and can also affect the function of the autonomic nervous system (Maynard et al., 1997). Stretching or bruising of the spinal cord can result from flexion, compression or rotation forces to the vertebral column, and hyperextension and penetrating injuries can damage the cord without the vertebral column being involved (Sekhon & Fehlings, 2001). Spinal cord injuries are commonly referred to as tetraplegia or quadriplegia where cord damage is in the cervical region of the vertebral column, or as paraplegia where cord damage is below the first thoracic vertebra. The extent of impairment as a result of SCI relates to the neurological level of the lesion (that is, the site of injury) and the completeness of the injury. The American Spinal Injury Association Impairment Scale (AIS) was developed as a standard measure to assess and classify the neurological level and completeness of SCI (Kirshblum et al., 2011), and it will be used throughout this thesis.

A further important distinction of the current study is that the population of interest have a persisting SCI, which refers to an ongoing neurological deficit. This thesis will follow the definition of SCI as used by Australian Institute of Health and Welfare (AIHW), where

persisting cases of SCI had an AIS score of A to D either by 90 days post-injury or at discharge from inpatient rehabilitation (Norton, 2010). People who experience nontraumatic SCI (NTSCI), where there is damage to the spinal cord from disease, bleeding or an infection (Norton, 2010), are not a focus of this work. The cause and nature of NTSCI impairment is different, and hence the demographic and outcomes of the people most affected by this, particularly regarding employment, are not comparable to those of people who have sustained a traumatic SCI. Those people who acquire a NTSCI tend to be older and are more likely to be retired (McKinley, Seel, & Hardman, 1999) than people who experience traumatic SCI. They also have less severe impairment and are equally likely to be male or female (Norton, 2010; Young & Murphy, 2009). People with NTSCI are therefore at a higher risk of comorbidities related to ageing and are commonly less engaged in the workforce. Throughout this thesis, the acronym SCI will be used to refer to traumatic SCI, unless otherwise stated.

1.2.2 Epidemiology and demography

Spinal cord injury from traumatic causes is relatively rare. The incidence in Australia is 15 cases per million, as compared with 16 cases per million in Europe. In the United States of America, which has a higher rate of violence (such as gunshot wounds and stabbings) than Australia or Europe, acquired spinal cord injuries reach an incidence of up to 40 cases per million (Lee et al., 2014). There are around 300 new cases of SCI from traumatic causes registered in Australia each year (Norton, 2010), and in Victoria, approximately 60 (11.2 per

million) of these cases have persisting neurology and require rehabilitation (Norton, 2010). The duration of initial care (DIC) is used by the AIHW as a measure of length of stay, referring to the duration of time between the injury and final separation (discharge) from an inpatient spinal unit. In the recent report *Spinal Cord Injury, Australia 2007–8*, published by the AIHW, the extent of impairment was correlated with a longer DIC. The DIC for complete tetraplegia was a median of 221 days, with 144 days for complete paraplegia. The range (expressed as the 5th and 95th percentile) was 123–397 days for complete tetraplegia and 71–315 days for complete paraplegia. The median DIC for incomplete injuries was 117 (ranging 15–303) days and 111 (ranging 13–263) days for tetraplegia and paraplegia respectively (Norton, 2010).

The most frequent cause of SCI in Australia is related to road traffic accidents (around 50%), with falls comprising the next highest proportion (around 30%), followed by diving and sports-related injuries (around 18%). Injuries as a result of violence or self-harm are the least common cause of SCI in Australia (around 2%) (Cripps, 2009; Norton, 2010). The proportion of males in the population who experience SCI is around 80%, with a higher frequency of injuries occurring in those aged 15–24 or over 65 years (Cripps, 2009; Norton, 2010). These demographics are slowly changing in Australia, with the average age and the number of women injured both gradually increasing (Cripps, 2009; Norton, 2010). The most common diagnosis for SCI in recent years is incomplete tetraplegia (around 50–60%) (Cripps, 2009; Norton, 2010). Sixty-one per cent of people who sustained a traumatic SCI in 2007–8 were employed at the time of their injury. This is reflective of the annual labour

force participation rate published by the ABS for the same period (Norton, 2010). The impact and the lifelong management of SCI will be addressed in the next sections.

1.2.3 Impact of spinal cord injury

SCI is arguably a devastating acquired condition in its immediacy and extent (Bickenbach, Officer, Shakespeare, & von Groote, 2013). The sudden loss of independence, combined with usually permanent physical impairment, affects a person's participation in all of life's roles (Chhabra, 2015). In addition, there are changes to basic bodily functions—ranging from maintenance of core temperature to elimination of waste—that are not only difficult to understand but also challenging to manage effectively (Chhabra, 2015). Beyond immediate medical and physical needs, the psychological (cognitive, behavioural and emotional) and social (vocational, family, community, cultural, environmental and spiritual) impacts of SCI on a person's health and wellbeing have been well documented (Craig, Guest, Tran, & Middleton, 2016; K W Hammell, 2007; Levi, Hultling, & Seiger, 1996; Post & Van Leeuwen, 2012). People who are injured in this way are at risk of experiencing mental health issues such as depression and anxiety, with higher than average levels of distress and lower levels of life satisfaction recorded when compared with the general population (Post & Van Leeuwen, 2012). Chronic pain can become a major barrier to people's participation in society (Donnelly & Eng, 2005), while the relative risk of cognitive impairment in people with SCI has been documented as being almost thirteen times more likely than in the noninjured population (Craig et al., 2016). Subsequent to these physical and psychological

issues, SCI has been associated with social isolation, loss of identity and sense of purpose, unemployment and financial insecurity, breakdown in social networks, and reduced quality of life (K W Hammell, 2007; Levi et al., 1996; Lidal, Huynh, & Biering-Sorensen, 2007).

The International Classification of Functioning, Disability and Health (ICF) was developed as a scientific framework to allow for consistent and internationally comparable information about the experience of health and disability (World Health Organization, 2002). The ICF has been used throughout this thesis as a background for understanding the nature and impact of SCI. According to the ICF, the disability experienced by people with an SCI is dysfunction at one or more of three levels: the body or body part (impairment), the whole person (activity limitation), and the whole person in a social context (participation restriction) (World Health Organization, 2002). Contextual personal and environmental factors give further meaning to an individual's experience. Given the complexity of the impact of SCI and its secondary consequences, it is widely acknowledged that a comprehensive, specialised system of management promotes optimal recovery and adjustment (Bickenbach, Cieza, Rauch, & Stucki, 2012). This system is outlined in the following section.

1.2.4 Management of spinal cord injury

It is internationally recognised that there are three broad phases of formal management involved in supporting a person to live successfully with SCI (Bickenbach et al., 2013). These phases—acute, rehabilitation and community integration—must address the physical,

psychological and social impacts of SCI. In the first phase, acute management primarily focuses on impairment as a result of changes to a body's structure and function. The acute phase lasts for around four to six weeks and includes emergency treatment at the scene of the injury, along with early hospitalisation until the person is medically stable. Psychological support for the person and their family is offered as soon as possible. Inpatient rehabilitation follows, and depending on the setting, this can last from a few weeks up to several months. Ideally client-centred and goal-oriented, multidisciplinary rehabilitation addresses activity limitations and participation restrictions through therapeutic intervention and education. The psychosocial needs of the person are recognised and supported. Rehabilitation aims to assist the individual to achieve maximum functional autonomy, teach the skills required for effective daily living, and minimise the risk of secondary complications, such as urinary tract infection, pain, skin injuries (including pressure sores) or mental health issues (Bickenbach et al., 2013).

Community integration is the longest phase and can be an ongoing process for many years following injury. Success in this area "can be defined as being part of the mainstream of family and community life, fulfilling normal roles and responsibilities and being an active and contributing member of one's social groups and society as a whole" (Dijkers, 1998). The scope of formal support for the community integration phase will vary across settings and can include outpatient and/or community-based monitoring and intervention. In addition to the physical and psychosocial aspects of SCI, there is a general recognition that personal characteristics, such as resilience and an aptitude for managing change, are known to effect outcome (Bonanno, Kennedy, Galatzer-Levy, Lude, & Elfström, 2012; Craig, Nicholson Perry,

Guest, Tran, & Middleton, 2015). However, if these issues are put aside, then all individuals with SCI who have appropriate access to health care, adequate psychosocial support, personal assistance if required, and assistive devices should ultimately be able to live independently. They should also be able to return to study, make an economic contribution, and participate in family and community life.

At a personal level, accessing and engaging in these three 'recovery' phases is considered essential in the adjustment process, particularly if the person with SCI aims to reach the community integration goals of independent living, returning to work and/or study, and participating in community and family life (Bickenbach et al., 2013). It is also possible, however, that some people with a new SCI choose not to take advantage of all components of the services and resources offered to them under these formal phases of management and recovery. This cohort has not been studied explicitly, and therefore no empirical comparison can be made about their health and quality of life outcomes. Anecdotally, there are only small numbers in this cohort, making it a difficult group to study. Further research is required to help to identify the possible impact on this group of disengagement from injury management.

In addition to personal factors, the broader environmental context, as described in the ICF, in many ways influences the day-to-day management and experience of SCI (K W Hammell, 2007; Leggat, Foreman, & Murphy, 2007). Successful community integration involves the navigation of environmental factors that include social policy, funding arrangements, the physical environment and societal attitudes, all of which can vary significantly across
different countries and jurisdictions (K W Hammell, 2007). Table 1 offers a comparison of SCI management within these different environmental contexts, including government compensation schemes and social welfare policy. The countries included in this comparison were purposely chosen to demonstrate differences in environmental contexts, however, these examples are not exhaustive of the possible matrix of scenarios. By bringing together this publically available information, Table 1 demonstrates the inherent complexity of navigating supports and services within each country. Furthermore, the extent of variation shown in Table 1 suggests a need to be mindful when comparing the experiences and outcomes of service users. These details will inform further discussion in section 1.3.5, in relation to the provision of vocational rehabilitation, and in section 2.5.1, regarding the exact nature and extent of the relationship between receipt of disability benefits or compensation and returning to work following SCI. At the conclusion of this thesis, the findings are broadly transferable internationally. However, the nuances of supports and services within each country do affect the generalisability of these findings.

Table 1

Environmental contextual factors influencing SCI management internationally

	Funding approach	Australia	Canada	United States of America
	Public	Federal and state funded universal health care under Medicare (<u>http://www.aihw.gov.au/australias-</u> <u>health/2014/health-system/</u>)	Federally funded provincially or territorially provided universal health care (<u>http://www.canadian- healthcare.org/)</u>	National government funded organisations, such as Medicare (social insurance for people >65 and those with disability) and Medicaid (means-tested social insurance for low income earners) (<u>https://www.ssa.gov/)</u>
Health care policy	Private/ compensation	State legislated no-fault transport accident social insurance systems (https://niis.qld.gov.au/the-scheme/national- disability-schemes/) (provided by all states and territories) and federally legislated work- related accident social insurance system (http://understandinsurance.com.au/types-of- insurance/workers-compensation). Voluntary personal private health insurance through individual contributions (encouraged through tax incentives).	Personal accident insurance (decentralised) through automobile insurer. Voluntary personal private accident and health insurance through individual contributions	Personal private health insurance provided through employer. Veterans Health Administration (VHA) (<u>http://www.sci.va.gov/)</u> covers hospital and the like.
Benefit/ social security policy, including	Public	Federally funded social security system through the Disability Support Pension (<u>https://www.humanservices.gov.au/customer/ser</u> <u>vices/centrelink/disability-support-pension</u>) (strict criteria/application process applies).	Provinces responsible for 'social programs' (<u>http://www.canadabenefits.gc.ca/f.1.2ch.4me@.jsp),</u> including means-tested disability welfare.	Federally funded social security/disability pension to those eligible (means-tested).

income support	Private/ compensation	Compensation: variable, based on place of residence and eligibility for no-fault accident insurance system. Work accident insurance and transport accident insurance (in three out of eight states and territories) may be available for loss of earnings or equivalent benefit if there is no capacity to return to work. Private personal insurance: variable, depending on level and type of cover.	Unable to ascertain.	VHA: Disability compensation benefit available to eligible veterans. Personal private health insurance: variable, depending on level and type of cover
SCI service models	Public	Five state spinal cord injury services with dedicated acute and rehabilitation facilities, catering for public and private/compensated (<u>http://www.anzscos.org/).</u>	Eleven dedicated spinal rehabilitation centres.	Fourteen spinal centres operating under SCI Model Systems (<u>http://www.msktc.org/sci/model-system- centers)</u> framework. Over 50 rehabilitation centres offering varying degrees of specialty in SCI.
	Private/ compensation	As above.	As above.	VHA provides 24 Spinal Cord Injury and Disorders Systems of Care coordinated continuum of services for veterans.
Funding for personal care support, assistive technology and environ- mental modifica- tion	Public	Combined federal and state funding for disability services, ceilings, gap payments, and priority waitlists, all where clinically justified. From 2015, nationwide rollout of National Disability Insurance System (https://www.pwc.com.au/industry/government/a ssets/disability-in-australia.pdf) to meet needs associated with cost of chronic disability.	Variable support across provinces, usually means- tested and requiring client contributions.	Variable according to administrator. Medicare has Durable Medical Equipment program, with strict eligibility and co-payment requirement.

		Variable according to insurer.	Variable according to insurance cover.
Private/ compensation	Insurance scheme dependent, with standard full coverage where clinically justified.	Compensation for disability-related costs can be	VHA full coverage where clinically justified.
		sought through litigation where appropriate.	Compensation for disability-related costs can be sought through litigation where appropriate.

Table 1

Environmental contextual factors influencing SCI management internationally (continued)

	Funding approach	New Zealand	Switzerland	The Netherlands	United Kingdom
Health care policy	Public	National universal health care (<u>https://www.health.govt.nz/new-</u> <u>zealand-health-system</u>), provided by district health boards.	Federal Social Insurance Office (<u>http://www.bag.admin.ch/themen/kranken</u> <u>versicherung/index.html?lang=en</u>) subsidises residents unable to make payments on compulsory basic health insurance.	Government funded primary health care (<u>https://www.government.nl/topics/soc</u> <u>ial-policy/contents/the-principles-of-</u> <u>the-social-policy-of-the-netherlands</u>).	Universal health care provided through National Health Service (NHS).
	Private/ compensation	National no-fault accident compensation (social insurance), Accident Compensation Corporation (ACC) (<u>http://www.acc.co.nz/)</u>	Compulsory private health insurance through individual contributions.	Compulsory basic private health insurance (<u>https://www.government.nl/topics/hea</u> <u>Ith-insurance).</u>	Voluntary private health insurance.

	Public	Government funded Supported Living Payment (<u>https://www.workandincome.govt.nz/p</u> roducts/a-z-benefits/supported-living- payment.html), available to eligible people.	Unable to ascertain.	Unable to ascertain.	Personal Independence Payment (https://www.gov.uk/pip/overview), available to eligible people, made up of daily living and mobility components.
Benefit/ social security policy, including income support	Private/ compensation	ACC can provide weekly compensation for loss of potential earnings to people who are eligible.	Compulsory private pension plans and accident insurance with contributions from employer. Contributions for unemployment insurance split between employer and employee. Invalidity insurance ('subsidiary' of health insurance), paid when professional (re)integration is impossible. Swiss Paraplegic Foundation (<u>http://www.paraplegie.ch/en/pub/sps/abo</u> <u>ut_us/swiss_paraplegic_group_to.htm</u>) members eligible to receive 200,000 Swiss Francs in the event of spinal paralysis.	Employers provide income support for two years to eligible injured employees. Government provides income support (at lesser rate than salary) after two years.	Nationally available Industrial Injuries Disablement Benefit (<u>https://www.gov.uk/industrial-injuries-</u> <u>disablement-benefit/overview)</u> provides income support to eligible workers.
SCI service	Public	Two dedicated spinal centres with acute care and rehabilitation, catering for public and private/compensated.	See below.	Eight dedicated SCI rehabilitation units (Post, Dallmeijer, Van Asbeck, & Van der Woude, 2005).	Eleven dedicated spinal rehabilitation centres (<u>https://www.spinal.co.uk/).</u>
SCI service . models	Private/ compensation	As above.	Swiss Paraplegic Centre, privately owned clinic, funded through Swiss Paraplegic Foundation (SPF). Two thirds of SCI cases seen here. SPF is member-	As above.	As above.

			based and also supports hardship cases. Provides services across Switzerland.		
Funding for personal care support, assistive technology	Public	Government funded Equipment and Modification Service for eligible people. Individualised funding available for personal care and the like.	Unable to ascertain.	Unable to ascertain.	Variable funding and support, need- and means-tested, available through local council.
and environ mental modifica- tion	Private/ compensation	Full coverage where clinically justified under national no-fault accident scheme.	Variable according to insurance fund.	Unable to ascertain.	Compensation for disability-related costs can be sought through litigation where appropriate.

1.2.5 Summary

Traumatic SCI with neurological sequelae is a complex condition resulting from trauma to the spinal cord (Bickenbach et al., 2013). It can affect both central and peripheral nervous systems. While incidence and prevalence are relatively low (Norton, 2010), the impact of SCI on the person and their participation in life roles can be devastating. A comprehensive system of management and targeted education is recognised as ideal in supporting the person to achieve optimal long-term outcomes (Bickenbach et al., 2013). As shown in Table 1, systems of support for the spinal injured person vary across the world, influenced by different policy and social environments (Leggat et al., 2007). The next section of this review introduces occupational therapy theory and explores an occupational therapist's role in the community integration phase of management of people with SCI, particularly in relation to social participation and vocational reintegration.

1.3 COMMUNITY INTEGRATION FOLLOWING SPINAL CORD INJURY

1.3.1 Overview of community integration following spinal cord injury, with a focus on returning to work

The primary goals of rehabilitation are prevention of secondary complications, maximisation of physical functioning, and re-integration to the community (Bickenbach et al., 2013). It is therefore important that a person develops the skills, knowledge and confidence during rehabilitation to return to and engage with their community. The term community integration includes social and vocational integration. The focus of this thesis is on vocational integration and specifically on the return to paid employment following SCI. Therefore, the vocational components of community integration are discussed in this section. A range of health professionals work with people following SCI towards achieving the goal of community integration. Hence, employment can be considered from different professional perspectives. A rehabilitation counsellor, for example, provides vocational counselling, vocational training, job placement and case management, in order to support the individual to achieve an employment outcome (Australian Society of Rehabilitation Counsellors, 2016). On the other hand, a physiotherapist working in the area of vocational rehabilitation will focus on a person's physical limitations and recovery, with the aim of assisting the individual to manage their physical conditions effectively, so they can carry out their required vocational tasks safely (Australian Physiotherapy Association, 2016).

The occupational therapist understands that gaining and maintaining employment is a multifaceted and complex process. Occupational therapists are concerned with supporting people to overcome occupational performance issues across the domains of self-care, leisure and productivity, in order that they may be better prepared to participate in meaningful activity. Gaining or returning to paid employment after SCI can provide individuals with meaning, a sense of purpose and an opportunity to contribute to society. Many people would consider employment as the ultimate goal of community integration and an indication of successful rehabilitation (Guttmann, 1954; Krause, 1990). Occupational therapy theories guide clinicians when helping people return to work following SCI.

There are several occupational therapy theories that can guide and underpin clinical practice. These include the Model of Human Occupation (MOHO) (Kielhofner, 2008), the Person Environment Occupation (PEO) model (Law et al., 1996), and the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Townsend & Polatajko, 2007). Of these, the framework that best suits an occupational therapy approach to vocational reintegration is the CMOP-E. This model explicitly focuses on occupation, with a key component being productivity. Both the MOHO and PEO models are also useful in considering vocational reintegration, however, the MOHO gives greater emphasis to personal volition and habituation, and the PEO does not overtly focus on occupation. Therefore, the work in this thesis is framed by the CMOP-E. The next section outlines the CMOP-E as a theoretical model. It explains what the CMOP-E offers and why it is useful in understanding the return to paid employment following SCI. The outcomes of social participation and vocational reintegration in relation to CMOP-E are also discussed. Finally, a discussion is provided of the known barriers to vocational reintegration and the current limitations for the role of occupational therapists and vocational rehabilitation professionals in addressing these barriers.

1.3.2 Using the Canadian Model of Occupational Performance and Engagement to understand return to work following SCI, and the role of the occupational therapist in enabling occupational potential

The CMOP-E assumes that engagement in meaningful occupation is central to health and wellbeing (Polatajko, Townsend, & Craik, 2007a), where 'occupation' refers to all the things we do as part of everyday life. The International Classification of Functioning, Disability and Health (ICF) is used throughout this thesis to assist in understanding the nature and impact of SCI. The CMOP-E provides further opportunity to comprehend these challenges. It offers an occupational perspective on the experience of impairment for the spinal injured person. The CMOP-E, as presented in Figure 1, specifies the occupational therapist's domain of concern. The model conceptualises occupational performance as the dynamic interplay between the person, their occupation and the environment. The model promotes the exploration and identification of occupational performance issues across the areas of selfcare, leisure and productivity, within the contexts of a person's spiritual, cognitive, affective and physical status, along with their physical, institutional, cultural and social environments.

According to the model, the occupational therapist's role is to promote social justice by enabling people to participate as valued members of society, despite diverse or limited occupational potential. Indeed, occupational therapy has been defined as the "art and science ... of enabling people to perform the occupations that foster health and wellbeing" (Townsend & Polatajko, 2007). Sustaining a SCI may significantly limit—physically, psychologically and socially—the range of a person's occupational capacities. Therefore, the

occupational therapist's role in drawing on enablement skills as articulated in the CMOP-E is paramount in facilitating the person to overcome their occupational performance problems and fulfil their occupational potential. These enablement skills are adapting, collaborating, designing, educating, and engaging. CMOP-E also highlights the importance of engagement in the therapeutic process in order to achieve the optimal post-injury physical, psychological and social outcomes, as described in section 1.2.4 (Townsend & Polatajko, 2007). Social participation and returning to paid employment following SCI are two such outcomes and will be explored further in the next section. The literature in Chapter Two (for example, in sections 2.5 and 2.6) are organised using the CMOP-E framework. The discussion in Chapter Seven will return to the framework to help summarise the findings.



A.¹ Referred to as the CMOP in *Enabling Occupation* (1997a, 2002) and CMOP-E as of this edition B. Trans-sectional view

Polatajko, H. J., Townsend, E. A., Craik, J. (2007). Canadian Model of Occupational Performance and Engagement (CMOP-E). In E. A. Townsend and H. J. Polatajko, Enabling Occupation II: Advancing an Occupational Therapy Vision of Health, Well-being, & Justice through Occupation. p.23 Ottawa, ON: CAOT Publications ACE.

Figure 1. Canadian Model of Occupational Performance and Engagement (CMOP-E)

(Polatajko, Townsend, & Craik, 2007b)

Note. The above figure has been reproduced on a single-use basis only with permission (see Appendix A) from the CAOT Publications ACE as per the following citation:

Figure 1.3 (CMOP-E) Canadian Model of Occupational Performance in Polatajko H., Townsend E., and Craik, J. (2007). *Enabling Occupation II: Advancing an Occupational Therapy Vision for Health, Wellbeing, & Justice through Occupation*. Ottawa, ON, CAOT Publications ACE. p. 23.

1.3.3 Social participation and vocational reintegration

Since the development of the first SCI rehabilitation centres, gaining paid employment has been considered an indicator of achieving optimal community integration (Guttmann, 1954) and a measure of rehabilitation success (Britell, 1991; Guttmann, 1954; Krause, 1996; Levi et al., 1996; Rusk, 1949). The health-promoting benefits of work are well recognised in the general population (Ezzy, 1993; Jahoda, Lazarsfield, & Zeisel, 1971) as well as for those postsignificant-injury, such as SCI (Krause, 1992; McKee-Ryan, Song, Wanberg, & Kinicki, 2005; Murphy & Athanasou, 1999). The CMOP-E explicitly articulates that engagement in occupation is fundamental to health and wellbeing, and productivity is treated as a core component of occupational performance (Polatajko et al., 2007a). Returning to employment can assist individuals in their adjustment to disability (Hay-Smith, Dickson, Nunnerley, & Sinnott, 2013; Krause, 1992) as well as offering benefits such as financial security (Chapin & Holbert, 2010) and improved self-efficacy (Hess, Meade, Forchheimer, & Tate, 2004). In offering an opportunity to contribute to society, work can provide people with a life purpose (Schonherr, Groothoff, Mulder, Schoppen, & Eisma, 2004; Tomassen et al., 2000; Ville & Ravaud, 1996) and has been associated with a higher quality of life (Manns & Chad, 2001).

When considering the benefits of work after spinal cord injury, it is also important to acknowledge the relationship between employment and other outcomes, such as functional independence, the maintenance of health and wellness, and social participation. Returning to employment cannot be considered in isolation from these interrelated factors, as trauma

such as SCI can impact in many ways on occupational performance. From an occupationbased enablement perspective, as expressed in the CMOP-E, returning to employment requires consideration of the person, their occupations and the environment. Simply addressing physical access issues in the pre-injury workplace, for example, is only one step of many in overcoming the barriers to achieving successful vocational reintegration.

Drawing from the SCI adjustment model, developed by Middleton and Craig (Middleton & Craig, 2008), social participation has been used as an indicator of adjustment following spinal cord injury (Craig et al., 2015). Craig and colleagues (Craig et al., 2015) define social participation as the degree to which a person integrates and interacts with their community. Inadequate perceptions of control or self-efficacy and low levels of social support have been found to predict and contribute to poor social participation (Craig et al., 2015; Dijkers, Yavuzer, Ergin, Weitzenkamp, & Whiteneck, 2002; Kennedy, Lude, & Taylor, 2006; Whiteneck et al., 2004). Moreover, these limitations to social participation have also been identified as significant barriers to employment after SCI (Lidal et al., 2007). A longitudinal cohort study by Craig et al. (2015) found that at six months following injury, the odds against employment for an adult with poor social participation were 8.4 to 1. While the focus of this thesis is on the achievement of employment after SCI, Craig et al.'s (2015) findings reinforce that employment should not be considered in isolation from other important and related outcomes such as social participation.

1.3.4 Barriers to vocational reintegration

Despite the recognised benefits of returning to work and the association of work being perceived as 'normal' (Fadyl & McPherson, 2010; Hay-Smith et al., 2013), it appears that many people with SCI are not meeting their full vocational potential (Athanasou, Brown, & Murphy, 1996). People experiencing SCI self-report difficulty in their ability to seek and/or maintain employment (Levi et al., 1996). Reasons for this obstacle to positive employment outcomes have been explored empirically and summarised in a review by Lidal and colleagues in 2007. They found that key barriers to returning to work include: navigation of systems, health and physical limitations, transportation, and workplace discrimination. Similarly, a lack of pre-injury education or training, together with disincentives to return to work associated with loss of benefits, have also been found to negatively influence employment outcomes (Lidal et al., 2007). A detailed critique of this literature on employment after SCI is provided in Chapter Two.

The utility of a vocational focus within rehabilitation service delivery aligns with the philosophy of the CMOP-E and the overwhelming majority of the scientific literature, which describes a relationship between employment and improved health and wellbeing (McKee-Ryan et al., 2005; Murphy & Athanasou, 1999; Townsend & Polatajko, 2007). However, the international literature suggests that the focus on, and provision of specialist skills by occupational therapists and others in vocational reintegration as part of rehabilitation, may be insufficient to support optimal employment outcomes (Murphy, 2009; Ottomanelli, Barnett, & Toscano, 2014). This issue of insufficient focus and specialist skills in vocational

rehabilitation is explored in the next section. The roles of the occupational therapist and vocational rehabilitation professional are also explored in relation to addressing vocational reintegration.

1.3.5 The role of occupational therapy in vocational rehabilitation

The occupational therapist in the rehabilitation team works closely with professionals from other disciplines and is tasked with enabling the person with SCI to reach optimal functioning and autonomy in the areas of self-care, leisure and productivity (K W Hammell, 2013). Waghorn and Hielscher (2014) recognise the unique skills that occupational therapists have in addressing vocational goals, describing their work as holistic, clientcentred, evidence-based and intensive. Using the CMOP-E, an occupational therapist assists the person with SCI to identify their occupational performance issues, while promoting a sense of hope and possibility for what that person can achieve. The occupational therapist and the person they are working with plan and develop strategies and engage in occupations that build confidence and begin to address the person's various needs. In the context of a goal to return to employment, this may include:

- assisting the person to coordinate a personal care plan so that the timing fits with their future employment requirements
- engaging in trials of using public transport to identify options for travelling to and from employment

- advocating for and collaborating with the person's employer regarding workplace adaptations and routines
- designing a workstation to enable specific vocational duties.

Despite the specific skills an occupational therapist holds in enabling community integration—which includes returning to or gaining employment—competing demands in the inpatient rehabilitation setting can create conflict for the clinician who has a primary focus on maximising functional independence so as to facilitate discharge from hospital (Leggat et al., 2007). This takes precedence over commencing community integration goals. It has also been suggested that insufficient training resources are available to help occupational therapists understand and negotiate the multifaceted and frequently changing vocational sector (Leggat et al., 2007). Ottomanelli et al. (2009) also observed a negative culture toward addressing return to work goals in the inpatient setting. This manifested in the form of perceptions about it being too early for people with SCI to return to work. Hence, vocational reintegration goals become postponed till after discharge and are referred on to generalist community-based occupational therapists. It is increasingly apparent, however, that community-based occupational therapists rarely have the required specialist knowledge of and capacity for dealing with SCI and vocationally-oriented goals (Leggat et al., 2007; Piccenna, Lewis, Gruen, & Bragge, 2015). As such, the path to employment for individuals soon after SCI remains fragmented and largely unsupported.

As noted earlier, in section 1.3.1, occupational therapists are not the sole provider of vocational rehabilitation. Escorpizo and colleagues (2011, p. 126) have defined vocational

rehabilitation as a "multi-professional approach that is provided to individuals of working age with health-related impairments, limitations, or restrictions with work functioning and whose primary aim is to optimize work participation". This definition, in line with the ICF, acknowledges that vocational rehabilitation is reliant on contributions from a number of disciplines with a common objective. The provision of vocational rehabilitation services around the world for people with SCI is highly variable. As shown in Table 1, differing policy and funding environments influence this. Table 2 summarises the contextual influences in the provision of vocational rehabilitation. This table shows that in Australia, where this research program was conducted, there are many differences in how vocational rehabilitation is provided across states and settings. For example, a dual funding system exists across the public and private sectors, with state and federal funders responsible for different components of vocational rehabilitation in the public sector. While there are some similarities with this in New Zealand, where a social model of accident insurance exists, vocational rehabilitation service provision in that country appears more streamlined and equitable across regions and settings. Further contrasts exist internationally, as is evident in varying funding models and the degree of specialist SCI service provision. SCI rehabilitation and supports in the United States of America, for example, are largely driven by private health insurance policies. However, generic, community based vocational rehabilitation is federally funded.

Historically, the disability movement and deinstitutionalisation policies of the 1970–80s fundamentally changed the way vocational rehabilitation services were designed and implemented in Australia (Oliver & Barnes, 2012; Price Waterhouse Coopers, 2011). As a

result, vocational rehabilitation became a predominantly community-based goal, rather than being delivered as part of inpatient or centre-based care. Community-based vocational rehabilitation professionals with expertise in SCI are rare (Department of Social Services, 2015; Ottomanelli et al., 2009; Waddell, Burton, & Kendall, 2008). The lack of any prerequisite knowledge or training in SCI for vocational rehabilitation professionals (Piccenna et al., 2015) adds to the apparent disparity in attention to this important area (Murphy, 2009). This service gap is discussed further in the following section.

Table 2

International provision of vocational rehabilitation

	Funding model	Australia	Canada	US
Vocational rehabilitation model for people with spinal cord injury	Public	Centre-based: Variable across SCI centres. Three of the five centres offer specialist SCI vocational rehabilitation that is integrated into inpatient rehabilitation. Others have no dedicated vocational rehabilitation. Community-based: Federally funded disability employment program (JobAccess https://www.jobaccess.gov.au/employme nt-assistance-fund-eaf) includes community-based generic vocational rehabilitation services, along with funding for workplace modifications and assistive technology.	Centre-based: Variable across SCI centres. Community-based: Specialist SCI vocational rehabilitation is available in eight out of thirteen provinces/territories, delivered by respective spinal cord injury association (http://www.sciontario.org/service/employm ent).	Centre-based: No systematic provision of vocational rehabilitation in the SCI Model System. Community-based: Relevant government departments offer and manage generic vocational rehabilitation programs (Meade, Armstrong, Barrett, Ellenbogen, & Jackson, 2006) in each state. Access varies across states and usually entails a referral process to establish eligibility. Waitlist times are dependent on severity of impairment. Funding for workplace supports is available and means-tested. Participants may be liable for some costs associated with the program, depending on resources available to them.
	Private	Variable, based on state accident insurance schemes. Generic vocational rehabilitation available from private providers.	Unable to ascertain	Veteran's Health Administration (VHA) programs provide free vocational rehabilitation services for individuals who have been injured on the job.

Table 2

International provision of vocational rehabilitation (continued)

	Funding model	NZ	Switzerland	The Netherlands	UK
Vocational rehabilitation model for people with spinal cord injury	Public	Centre-based: Specialist SCI vocational rehabilitation fully integrated into inpatient and community across two SCI centres and delivered by external disabled people's organisation, the NZ Spinal Trust (https://nzspinaltrust.org.nz /support/rehabilitation/kalei doscope-background-and- overview/).	See below.	Unable to ascertain.	Centre-based: No systematic provision of vocational rehabilitation in any of the eleven SCI centres. Best practice guidelines for vocational rehabilitation are currently under development (http://www.mascip.co.uk/best- practice/mascip-best-practice/#). Generic government funded programs to support people with disability to work, such as Access to Work, which provides a grant to pay for workplace modifications and assistive technology, and requires employers to make reasonable adjustments for disabled workers.
	Private	As above.	Vocational rehabilitation fully integrated into inpatient and community-based Swiss Paraplegic Centre services (<u>http://www.paraplegie.ch/en/pub/spz/are</u> <u>as/institute for vocational guida.htm</u>).	Centre-based: No systematic provision of vocational rehabilitation in Dutch SCI rehabilitation centres. Community-based: Generic individual job counselling and vocational services available to people with a disability.	

1.3.6 Identification of the need for dedicated vocational rehabilitation in Victorian SCI services

The research program reported in this thesis was conducted in Victoria, Australia, where dedicated SCI services have existed since 1957. With medical and rehabilitation advancements, services have continued to evolve, all with the aim of minimising dysfunction and maximising autonomy and quality of life post-SCI. However, by the early 21st century it became apparent that a number of local and systemic issues were negatively impacting on people's ability to reengage with their community. Tangible issues included:

- a protracted home modification process
- limited access to peer support
- limited access to community-based psychological support
- no access to specialist SCI vocational rehabilitation (as discussed in the previous section)
- inconsistent access to assistive technology devices
- significant waiting times for personal care support when required (Leggat et al., 2007).

In 2010, in response to these identified service gaps, the Spinal Community Integration Service (SCIS) was implemented in Victoria to provide up to 12 months of post-discharge specialist community support to individuals with newly acquired SCI. The initiative was supported by a collaboration between the Victorian Government's Health Department and the Victorian motor accident social insurance scheme, known as the Transport Accident Corporation (TAC). The SCIS was designed by occupational therapists with the intention that it would be delivered by a multidisciplinary team. The role of the SCIS was to focus on improving community integration, vocational and quality of life outcomes. Drawing on a community development approach, the service also acted as a specialist SCI resource for community providers who required extra support in working with people with SCI. A core component of SCIS and a primary interest of this thesis was the delivery of the Early Intervention Vocational Rehabilitation (EIVR) program, interfacing with the inpatient rehabilitation setting. The development of the EIVR program is described in section 1.3.7. Vocational rehabilitation professionals were specifically recruited to provide early vocational interventions for people with SCI and also to focus on enhancing the return to work culture within the rehabilitation setting. As part of the program, vocational rehabilitation professionals made initial contact with the person with SCI within two to four weeks of their admission to inpatient rehabilitation, in order to encourage early, positive expectations about work (Schonherr et al., 2004).

While anecdotal evidence suggests a shift in rehabilitation culture to support vocational reintegration after the implementation of the EIVR program, the effectiveness of the EIVR program and SCIS in meeting their goals needs to be demonstrated. Longitudinal research is required to determine if client outcomes are improved following participation in this program. The first step in developing this research was to establish baseline data about employment outcomes of people with SCI receiving services prior to the commencement of the EIVR program. Ideally, a randomised control trial would then have been implemented to test the effectiveness of the new intervention. As this was not possible due to the ethical

concerns over withholding the EIVR program from people with SCI, once its benefits had been established, a longitudinal study was designed instead. The second step was therefore to implement a longitudinal cohort study of people receiving the EIVR program. The third step was to compare the outcomes of the two groups. The full research methodology and results of these two studies are presented in Chapter Four and Chapter Five. An introduction to the EIVR program is presented in the next section.

1.3.7 Description of the Early Intervention Vocational Rehabilitation (EIVR) program as an intervention

The SCIS was implemented in 2010 to provide 12 months of specialist support in transitioning home after a period of hospitalisation and rehabilitation for individuals with newly-acquired SCI. The initiative was supported by a collaboration between the Victorian Government's Health Department and the Victorian motor accident social insurance scheme. By working in partnership with each person, focusing on their strengths and supporting them to have a central role in managing their SCI, the aim of SCIS was to facilitate improved community integration and to enhance vocational and quality of life outcomes. The service also acted as a specialist SCI resource for community providers who required extra support in working with people with a SCI. As previously noted, a core component of SCIS was the delivery of the EIVR program within two to four weeks of admission to inpatient rehabilitation.

The SCIS staff comprised 15 individuals with approximately seven full-time equivalent (FTE) positions. Professions represented include allied health (physiotherapy, occupational therapy and exercise physiology) (1.5 FTE), nursing and sexual health counselling (0.7 FTE), medical (0.1 FTE), vocational rehabilitation (1.0 FTE), leisure (0.4 FTE), formal peer support (0.9 FTE), psychology (1.0 FTE), building consultancy (0.2 FTE), and a program manager (1.0 FTE). A predominant and unique feature was the recruitment of vocational rehabilitation professionals to focus on enhancing the return to work culture within the rehabilitation setting, in order to encourage early, positive expectations about work (Schonherr et al., 2004) and to provide vocational interventions to encourage and facilitate vocational pathways and employment outcomes. Theoretical underpinnings of SCIS work were drawn from the concepts of occupational performance (Polatajko et al., 2007a), participation (Whiteneck et al., 2004) and community development (Bhattacharyya, 2004). The service also drew on the experiences and knowledge of existing programs in other states of Australia and in New Zealand, such as the Spinal Outreach Service in New South Wales (Middleton et al., 2008), the Transitional Rehabilitation program in Queensland (Kendall, Ungerer, & Dorsett, 2003) and Kaleidoscope in New Zealand (Hay-Smith et al., 2013).

A coordination team (comprising a project coordinator, who is the thesis researcher, and the SCIS program manager) led the implementation of SCIS, including the development and delivery of a training package to reinforce both theoretical underpinnings and a consistent practice approach. Training sessions focused on building skills in engaging and establishing a relationship with the individual with SCI, motivational interviewing (Miller & Rollnick, 2012), goal planning, and community development. The training also included an introduction to

vocational rehabilitation theory and practice, including guiding principles for an early intervention approach (Murphy, 2009).

The establishment of the EIVR program was modelled from Kaleidoscope, a program of vocational rehabilitation established by the New Zealand Spinal Trust in the Burwood Spinal Unit in 2003 (Kelly, 2014). Kaleidoscope's foundation is built around four key distinctions: early intervention to set expectations, detailed career planning, workplace support, and a motivated and supportive local business community. Drawing on Kaleidoscope's practice, the driving philosophy of the EIVR program as part of SCIS was to instil as early as possible a sense of hope and possibility in the individual about returning to or gaining work following SCI. The vocational rehabilitation professionals from SCIS aimed to make initial contact with the individual within two to four weeks of admission to inpatient rehabilitation, unless advised otherwise by the inpatient treating team. Their role included acknowledging the vocational identity of the individual, exploring vocational options, assisting the person to form a vocational plan, and tailoring interventions to suit their goals and situation. While outcomes such as study or volunteer work were legitimate achievements and considered an important part of the vocational pathway, the ultimate goal of the EIVR program was for the person to achieve a paid employment outcome. In this, there were no constraints on process or timeline, as it was recognised that each individual needed to assume their own journey of recovery, learning and adjustment post-injury. A summary of the EIVR program's practice guidelines is presented in Table 3. Further supporting documents are available in Appendix B: Spinal Community Integration Service: A new service approach for Victorians with spinal cord injury.

Table 3

The Early Intervention Vocational Rehabilitation program practice guidelines

Process	Timeline	Tasks
Establish relationship with individual	First meeting in inpatient rehabilitation setting	Gather background demographic information, including education and employment history
Establish vocational identity of individual	Within two to four weeks of admission to inpatient rehabilitation (approximately six weeks post-injury)	Liaise with inpatient team regarding pre-vocational activity Identify relationship with pre-injury employer Identify motivations and future aspirations
	Within inpatient setting or as required	Exploration of vocational options, including retraining or returning to study
	One to six months post-injury	Career counselling
		Facilitate contact with or support to pre-injury employer
Explore vocational		Facilitate connections with peer support
options		Facilitate connections with disability liaison officers at education institutions
		Facilitate connections with community-based vocational rehabilitation providers
		Assist in navigation of entitlements and government benefits associated with returning to study, retraining, job-seeking and returning to work

Establish vocational goals, commence vocational pathway	Within inpatient or outpatient setting or as required	Provide expert advice and assistance with planning and give practical guidance relevant to individual's situation
	Two to twelve months post-injury	For example: If vocational goal involved returning to work or study, vocational rehabilitation professional to offer community-based support such as joint visit to workplace or education facility, meeting with human resource officer or disability liaison officer, environmental assessment of workplace or educational facility, or work with individual to identify and practice transport options.
	Within outpatient setting or as required	Workplace visit to assess both physical and social demands of the position and workgroup
Job support	When work-ready	Assessment/prescription of workplace equipment and/or modifications Assistance in navigation of entitlements and government benefits associated with job-seeking and returning to work Development (in coordination with both the patient/client and the putative supervisor) of a return to work plan Facilitating/supporting workplace trials or industry experience Provision of post-placement support to ex-patients and family members, as well as to workplace co-workers and supervisors
Service development role	No set time frames	Education of inpatient rehabilitation teams on importance of work in adjustment process and role of Early Intervention Vocational Rehabilitation program Education of co-workers and supervisors at the workplace Education of family and other relevant social supports and facilitation of family-based problem-solving and life planning

Referral to, consultation with and/or education of community-based vocational rehabilitation providers
Education of health professionals
Meeting with disability liaison officers at education institutions
Networking with local government, not-for-profit and private enterprises to establish possible employment links/opportunities
Education of funder

Note. Foundations for these practice guidelines were drawn from a document titled "Roles of vocational consultant working in spinal cord injury early intervention vocational rehabilitation", compiled by the Vocational Rehabilitation Discipline group in 2012, affiliated with Australian and New Zealand Spinal Cord Society (see Appendix B).

1.3.8 Summary

The overarching goal of SCI rehabilitation and community integration is to minimise the impacts of impairment and to maximise physical function and psychological capacity, along with participation in vocational, family and community roles (Bickenbach et al., 2013). The occupational therapist, as part of the multidisciplinary team, has a unique skillset to offer and plays a fundamental part in supporting people's return to productivity (K W Hammell, 2013). CMOP-E highlights how occupational therapists work to enable a person's full occupational potential (Polatajko et al., 2007a). However, while there is a clear need for vocational management as part of community integration, there remains a lack of supportive culture, prioritisation and specialist knowledge about SCI and vocational pathways within the health setting in general (Murphy, 2009; Ottomanelli et al., 2009), as well as among occupational therapists themselves (Leggat et al., 2007; Piccenna et al., 2015).

Identified gaps in service delivery gave rise to a new service called SCIS, which aimed to enhance community integration outcomes, particularly employment, for people following SCI. A predominant feature of the service was the recruitment of vocational rehabilitation professionals to deliver the EIVR program. The key principles utilised in the EIVR program focus on enhancing the return to work culture and setting early, positive expectations about work (Schonherr et al., 2004), underpinned by the concept of occupational performance. However, the effectiveness of this new service has not been demonstrated and research is required to identify if there have been changes in client outcomes. Furthermore, a deeper

understanding of individual experiences of returning to work could assist in shaping interventions and ultimately enhancing outcomes.

1.4 SUMMARY OF CHAPTER ONE

Chapter One has provided an overview of the complex and varied impacts of SCI on a person's physical, psychological and social wellbeing (Trieschmann, 1988). The importance of engaging in paid employment after SCI has been explored, as well as some of the reasons why returning to work is difficult (Lidal et al., 2007; Schonherr et al., 2004). The chapter has also discussed limitations with current vocational rehabilitation services and how these may be related to suboptimal vocational outcomes for people following SCI (Leggat et al., 2007; Murphy, 2009). In addition, it has provided definitions for key terms that will be used throughout this thesis. The ICF and CMOP-E have been introduced as frameworks that help to understand the complexity of impairments that may be experienced following SCI and how these impairments can impact on an individual's participation in the community, including their ability to seek and gain employment. The final section of Chapter One outlined recent changes to local services, many of which were informed by the ICF and CMOP-E frameworks, although it is still unclear whether or not these changes have helped overcome some of the barriers to employment for people post-SCI. A large body of literature exploring the barriers, facilitators and predictors of employment following SCI has been amassed over the past 30 years. This literature, together with emerging evidence with

regard to vocational rehabilitation approaches, the meaning of employment and key employment trajectories, will be reviewed and critiqued in Chapter Two.

CHAPTER TWO

2 LITERATURE REVIEW OF VOCATIONAL INTERVENTIONS AND FACTORS RELATED TO EMPLOYMENT AFTER SCI

2.1 OVERVIEW OF VOCATIONAL INTERVENTIONS AND FACTORS RELATED TO EMPLOYMENT AFTER SCI

The literature relevant to employment after SCI is diverse and includes epidemiological studies, identification of factors influencing employment outcome, and studies focusing on the effectiveness of specific vocational interventions. This chapter provides a summary of this literature. The chapter begins by reviewing literature that discusses the temporal variable in post-injury vocational pathways. It then offers a brief overview of literature relating to employment rate calculations, followed by a critique of vocational interventions that aim to enhance employment outcomes. A review of the literature relating to environmental and personal factors and their influence on employment after SCI follows. Using the CMOP-E as a framework, deliberation on literature covering the constructs of institutional, social and physical environment, as well as the cognitive, affective, physical and spiritual constructs of the person, and how they each impact on return to paid employment after SCI, closes the chapter.

2.2 VOCATIONAL PATHWAYS PRE- AND POST-SCI

The impact of time as a factor related to employment outcomes requires consideration in order to appreciate the potential for temporal influence on these outcomes. A consistent

finding in reports of employment outcome is that employment rates increase over the first 10–15 years post-injury (Ferdiana et al., 2014; Young & Murphy, 2009). Krause (2003) studied factors related to the length of time between the onset of SCI and the return to work post-injury in N = 259 people and suggested that it can take time for an individual to reach full vocational potential, particularly if an early window of opportunity is missed. In a modelling of the employment trajectory of a cohort of N = 176 with acute SCI, Ferdiana and colleagues (2014) identified three distinct pathways. The first encompassed no employment pre-injury and no employment for five years post-injury (called 'no employment'), the second included employment pre-injury and an increasing chance of employment in the five years post-injury (termed 'low employment'), and the third covered employment pre-injury and steady employment within five years post-injury (described as 'steady employment'). The study found that participants with secondary education were significantly more likely to gain steady employment outcomes versus low or no employment. This reinforces the value of vocational rehabilitation including components such as retraining and education early after injury to enhance opportunities for employment outcome, particularly for people with a likely trajectory of low or no employment. Before a further critique of the literature relating to vocational rehabilitation interventions, the next section outlines what is known about employment rates after SCI.

2.3 EMPLOYMENT RATES FOLLOWING SCI

The literature contains many studies that aim to calculate employment rates following SCI in order to compare outcomes and guide future research (Schonherr et al., 2004; Tomassen et al., 2000; Ville & Winance, 2006). There are difficulties in synthesising data about

employment rates because variables are often defined and measured differently (Ottomanelli & Lind, 2009). A typical discrepancy is recording a cumulative employment rate that includes work experience since injury versus employment status at the time of data collection. Despite these difficulties, there remains a general consensus that employment outcomes following SCI are low when compared to general labour force participation rates (Lidal et al., 2007; Ottomanelli et al., 2009; Ottomanelli & Lind, 2009). As described earlier, a review by Young and Murphy (2009) estimated the employment rate for people at least 12 months post-injury to be 35–40% in developed (high income) countries. The provision of vocational interventions is one way to increase employment rates (Lidal et al., 2007), therefore these interventions are reviewed in the following section.

2.4 VOCATIONAL INTERVENTIONS

Vocational interventions are collectively referred to as vocational rehabilitation in this thesis. As previously described, vocational rehabilitation is a multi-professional approach aiming to optimise work participation in people with health-related impairments, limitations or restrictions with work functioning (Escorpizo et al., 2011). In a systematic review investigating the effect of interventions that aimed to enhance employment outcomes in people with SCI, Roels and colleagues (Roels, Aertgeerts, Ramaekers, & Peers, 2016) reported on 15 studies, comprising one randomised controlled trial (Ottomanelli, Barnett, & Goetz, 2014) and 14 observational studies. The randomised controlled trial (Ottomanelli, Barnett, & Goetz, 2014) tested the use of evidence-based supported

employment (EBSE) with a group of military veterans with SCI in the United States. EBSE is a form of individual placement and support with demonstrated success in helping people with chronic intellectual disabilities and mental health issues find and maintain employment (Ottomanelli, Barnett, & Goetz, 2014). Ottomanelli et al. (2014), found that for the two years after the job-seeking intervention, those veterans receiving EBSE were significantly more likely to achieve employment (n = 81, 30.8%; 95% CI [21.8–41.6]), than those receiving treatment as usual (TAU) at the intervention sites (n = 76, 10.5%; 95% CI [5.2–19.7]; p < .001) or receiving TAU at the observational sites (n = 44, 2.3%; 95% CI [0.0–12.9]; p < .002). Treatment as usual included eligibility for a federally supported State Vocational Rehabilitation Program, which offers generic vocational rehabilitation and caters mainly to those who are work ready (Ottomanelli, Barnett, & Goetz, 2014).

At the time of enrolment in the study, the average duration of a participant's SCI was 12.4 (±11.2) years, with a proportion (35%) of the sample having experienced post-injury employment and 41% having received some form of vocational rehabilitation intervention. As veterans, all participants' care was managed under the same funding and benefits environment, as outlined in Tables 1 and 2, which also shows the differences in supports for non-veterans in the United States and other cohorts internationally. The exposure to vocational rehabilitation and employment prior to receiving the EBSE is a possible confounder to the study results. Likewise, a relatively high dropout rate of 48.8% by the end of the second year lessens the strength of this research. There may also be limited generalisation of these results to the broader SCI population, with 26.7% of the participants having a cervical injury of AIS A, B or C and 34.2% with an AIS D or E classification. These
proportions are lower and higher respectively of the available injury data relating to the non-veteran population internationally (Devivo, 2012; Jackson, Dijkers, DeVivo, & Poczatek, 2004; Norton, 2010). However, the apparent lack of literature describing the incidence, prevalence and aetiology of the veterans' SCI population makes this comparison difficult. The participants' neurological levels and extent of injury reported in Ottomanelli's study suggest greater functional independence than that described in other population-based studies (Cripps, 2009; Norton, 2010). These differences again raise questions about the ability to generalise study results to United States' non-veteran populations as well as Australian and other international samples. The delivery of the intervention at an average of 12.4 years after injury highlights a further gap in knowledge about earlier intervention post-SCI.

An observational study by Australian researchers Middleton et al. (2015), published while Roels et al.'s (2016) systematic review was in-press, investigated the effectiveness of early vocational rehabilitation in an acute and rehabilitation SCI setting on rates of employment within one year post-discharge. At case closure (median three weeks post-discharge), 34.5% had an employment outcome. This rate is similar to that quoted in aggregated research of 35–40% employment (Young & Murphy, 2009), however, this outcome was reached within a shorter timeframe post-injury (Middleton et al., 2015). Complementing Middleton et al's. (2015) observational study, Ramakrishnan, Johnston, Garth, Murphy, Middleton, & Cameron (2016), undertook a qualitative inquiry to examine the perspective of 13 participants who had received the early vocational rehabilitation intervention previously described (Middleton et al., 2015). Overall, Ramakrishnan et al. (2016) noted that

participants found vocational rehabilitation offered in the inpatient rehabilitation setting to be appropriate, effective and valuable. While Middleton has commenced the process of researching early vocational rehabilitation in Australia, similar programs delivered into New Zealand acute spinal units since 2000 have not been studied empirically. Hay-Smith et al. (2013) reported on Kaleidoscope, the New Zealand early intervention vocational rehabilitation service, and described its aim as nurturing positive expectations of future community participation after a SCI, which is an important precursor to employment outcomes (Schonherr et al., 2004). Employment rates for people with SCI have reportedly increased since Kaleidoscope's inception (Hay-Smith et al., 2013). The research work led by Ottomanelli (2014), Middleton, (2015) as well as Hay-Smith, (2013) all suggest that vocational rehabilitation delivered early post-SCI warrants further investigation, as does determination of whether vocational outcomes are sustained beyond 12 months.

2.5 ENVIRONMENTAL FACTORS AND EMPLOYMENT AFTER SCI

Vocational rehabilitation includes addressing issues related to the environment. A range of environmental factors are known to influence employment outcomes for people following SCI, including funding arrangements, social supports, and the social and physical environments where individuals live. The following subsections explore the literature using the CMOP-E framework of institutional, physical and social environments.

2.5.1 Literature relating to the institutional environment

The institutional environment as described in the CMOP-E, includes the political and social systems that affect opportunities for occupation (Polatajko et al., 2007a). Funding arrangements, inclusive of receipt of disability benefits or compensation, have been found to influence decisions about returning to work following SCI (Conroy & McKenna, 1999; Fadyl & McPherson, 2010; Ottomanelli & Lind, 2009; Paul et al., 2013; Phillips, Hunsaker, & Florence, 2012). However, the direction of influence is inconsistent across studies. Using grounded theory with a sample of 13 people within two years of SCI, (in a relatively homogeneous population in New Zealand in relation to access to funding; see Table 1), Fadyl and McPherson (2010) explored decisions relating to returning to work and identified four themes. The first three were the ability to work (given work demands and current resources); presence of responsibilities or pressures that compete with work; and access to a suitable job. The final theme of whether or not work was of enough benefit to the individual to be considered worth pursuing emerged in the context of multiple factors, such as financial considerations, others' perceptions, personal values and career status. Study numbers were small, however recruitment continued until themes were exhausted.

Chapin and Kewman (2001) also used grounded theory, but with a matched sample of employed and unemployed people, and similarly emphasised the challenges associated with the decision of giving up disability benefits to return to work. In a longitudinal study by Phillips et al. (2012) exploring the role of income and insurance on the return to productive activity, it was determined that being insured through the United States' system of public

insurance (Medicaid) significantly decreased the likelihood of returning to productive activity. In an Australian context, Conroy and McKenna (1999) observed financial disincentives to working, such as the perceived disadvantage of losing social security benefits (also called a disability support pension in Australia). In a no-fault compensation environment in New Zealand, return to work rates were higher (though not statistically significantly) in the insured group versus the uninsured (Paul et al., 2013). This is contrary to themes identified by Kilgour et al. (2015) in a systematic review of qualitative literature relating to injured workers with compensation. A consistent experience of the injured workers interviewed across the studies under review was that receiving compensation had negative consequences across mental health, social and vocational outcomes (Kilgour, Kosny, McKenzie, & Collie, 2015).

Due to the variation in government compensation schemes and insurance policy environments internationally, as documented in Table 1, the nature and extent of the relationship between receipt of disability benefits or compensation and the return to work following SCI remains unclear. Because of this uncertainty, it is important that any future studies in this area describe the funding arrangements in operation, as this environmental factor may play an important role in employment outcomes. The studies presented briefly in the previous paragraph provide varying information about the local funding arrangements. Similarly, methodology and participant demographics are diverse. Paul et al. (2013) gathered longitudinal data from 118 people with SCI in the two years following injury. There were higher return to work rates in the insured cohort versus people without insurance, however, the result was not statistically significant. While the authors conclude

that the results appear to be due to the high proportion of participants entitled to a no-fault compensation scheme, the study design does not control for the fact that an early intervention vocational rehabilitation service has been available across New Zealand since 2006 (Hay-Smith et al., 2013). The Kilgour et al. (2015) systematic review is methodologically robust, and while the authors do not specifically investigate the experiences of people with SCI, inferences can be drawn. The participants in the Phillips et al. (2012) longitudinal study were all working at the time of their injury, and hence the process and relationships examined in the study have unknown generalisability. Conroy and McKenna (1999) used a questionnaire to examine influences of vocational outcome in a north-eastern Australian population, although only a 38% return rate was achieved.

2.5.2 Literature relating to the physical environment

Social determinants of health, such as place of residence and how this supports work opportunities among the general population, are well understood (Marmot & Wilkinson, 2005). However, there is very limited research to identify how aspects of living environments such as local amenities and infrastructure may impact on the return to work for people with SCI. In the United States, Botticello and colleagues investigated local area economic characteristics and their relationship with participation in work in data extracted from the SCI Model Systems database (*N* = 1013) (Botticello, Chen, & Tulsky, 2012). The study found that people who lived in an urban area were more likely to be employed, and there was a strong correlation between urban dwelling and socioeconomic status. Similar to

the findings on funding arrangements, it is not clear whether it is possible to extrapolate these findings to other countries, given the vast differences in the provision of typical neighbourhood amenities and the policy environments that underpin these. However, it is feasible to expect, based on literature related to social determinants of health (Marmot & Wilkinson, 2005), that the place where person with a SCI lives and the availability of amenities such as health care and accessible public transport could influence opportunities for social participation, particularly in major life activities like employment.

2.5.3 Literature relating to the social environment

The impact of SCI on social participation has been frequently discussed in the literature (Craig et al., 2015; Whiteneck et al., 2004). Craig et al. (2015) found that the odds against being employed for an adult with poor social participation were 8.4 to 1. The specific relationship between social support and employment outcome has, however, been less well documented (Burns, Boyd, Hill, & Hough, 2010; Murphy, O'Hare, & Wallis, 2010) Social support is a multifaceted construct and can be broadly understood as being the perception and actuality that one is cared for and could obtain emotional or physical assistance if required from social networks such as family, friends or associates (Murphy et al., 2010). While research on social support is relatively limited in the SCI population, Murphy et al. (Murphy et al., 2010) found that practical social support was the most frequently reported contributing factor to enabling positive employment outcomes following SCI. This has been further supported by findings of Burns and colleagues (Burns et al., 2010), who established

that in a self-selected group of 83 men, greater perceived social support from significant others was related to higher employment outcomes. Hence, further research to investigate the impact of environmental features—such as financial security, where someone lives, and social support on employment outcomes achieved post-SCI—appears to be well warranted.

2.6 PERSONAL FACTORS AND EMPLOYMENT AFTER SCI

The SCI literature regularly addresses personal factors associated with employment outcomes for people with SCI. Findings consistently establish relationships between employment outcomes and level of education, pre-injury worker role (occupation type), psychological traits, and physical function (Krause & Pickelsimer, 2008; Lidal et al., 2007; Ottomanelli et al., 2009; Ottomanelli & Lind, 2009; F. P. Thomas et al., 2014). Less extensively explored are the personal factors around the process of returning to work after SCI, including the decision-making involved, an individual's hope for a future as a worker, and the meaning that employment holds for people. The following subsections of this chapter critique the literature in line with the concept of person, as presented in the CMOP-E. The CMOP-E (see Figure 1) portrays the person as having three performance components— affective, cognitive and physical—with spirituality at the core, and hence it offers a framework to relate back to the processes and experience of achieving employment after SCI.

2.6.1 Literature relating to affective factors

In examining psychological factors that differentiated people with SCI who returned to work from those who did not, Chapin and Kewman (2001) matched a sample of six people and used grounded theory to analyse interview responses. Participants were matched on demographics including age (ranging from 30–49), gender, level of injury and time since injury. The employed group were on average eight years post-injury, while the unemployed group were seven years post-injury. A useful aspect of this study in informing future research was the conceptualisation of the re-employment process that was provided through both narrative and diagrammatic forms. Key factors that were associated with employment were optimism, achievement orientation, self-esteem and role models. The most powerful moderating variable affecting the employment process was the difference in psychological functioning between people who were employed and people who were unemployed. The authors concluded that increasing optimism may promote employment outcomes. The majority of the small participant sample had a paraplegia level of injury and were not in a relationship, however, the matched design alleviates some bias associated with these limitations.

Researchers have known of a relationship between employment and adjustment in people with SCI for many years, while also recognising the difficulty in measuring adjustment accurately (Craig et al., 2015; Krause, 1990, 1992). In 1992, Krause used the Life Situation Questionnaire with 286 people with SCI to investigate the relationship between work history, biographical status and adjustment. Participants were on average 18.6 years post-

injury, and on completion of the survey they were then allocated to a predefined employment group. Krause (1992) found that the people in the 'current employment' group reported significantly better adjustment in many life areas. While the findings of Krause's work are limited due to the reliance on self-report, they gave a clear indication of the existence of the employment/adjustment relationship. More recently, following multidisciplinary efforts to develop the SCI adjustment model (Middleton & Craig, 2008), as described in section 1.3.3, Craig and colleagues (2015) have identified social participation as a measure of adjustment. The Impact on Participation and Autonomy Questionnaire has been identified as the measurement tool (Craig et al., 2015) in this regard. In a prospective longitudinal study with 88 participants recruited while completing inpatient rehabilitation for recently acquired SCI, Craig et al. (2015) found that at six months after discharge, just over half the sample population had difficulties with social participation. As previously stated, this study found that the odds against an adult with poor social participation being employed were 8.4 to 1. Further investigation of this over different settings and timeframes would contribute to knowledge about the complexity of adjustment following SCI and the relationship between employment and social participation.

2.6.2 Literature relating to cognitive factors

As outlined earlier in section 2.5.1, Fadyl and McPherson's (2010) study (based in New Zealand) used grounded theory to understand the role of decision-making in returning to work after SCI. It concluded that the process of returning to work was complex and

influenced by multiple related factors. The thirteen participants with a median age of 44 (ranging 22–48) were all within two years of injury (except one) and described tensions between expectations, abilities, benefits, limitations and implications associated with the return to work process. The authors proposed that future interventions could focus on balancing tensions by supporting the decision-making as early as possible after injury. Demographic information relating to ethnicity and pre-injury occupation was presented in the study, although the authors do not provide detail about pre-injury education levels. This limits the potential translation of the research, given that a person's level of education is a known predictor of employment outcome (Trenaman, Miller, Querée, & Escorpizo, 2015).

Bergmark et al. (2011) used a constant comparative method to explore expectations and experiences around paid work in eight young Swedish adults (aged 20–34) who were within one to five years of SCI. No participants were employed at the time of recruitment and none had gained tertiary level education. There were four main themes identified in the study. These were: finding a way to a life where work was possible, being at crossroads and working through expectations, dealing with the expectation that paid work is part of a desired future, and adopting the expectation to find solutions for oneself or with help from others. The participants described a lack of education, lack of work experience and perceived limitations due to the injury as major obstacles to employment. They wanted to work but expressed that time was needed first, in order to create new routines and identify possible solutions. This cohort would meet the criteria for the groups described as having no and low employment trajectories in the study by Ferdiana and colleagues (2014), (outlined in section 2.2). This suggests that Bergmark's cohort could particularly benefit

from specialised vocational rehabilitation to assist them with overcoming obstacles and building capacity for future employment.

2.6.3 Literature relating to physical factors

In a review of factors related to employment after SCI, Ottomanelli and Lind (2009) identify being able to drive or have independent transport as a frequently recognised characteristic that is associated with return to work after SCI. Similarly, a cross-sectional retrospective survey of the United States' SCI Model System database found the ability to drive a vehicle increased the odds of a person with SCI being employed by almost two times when compared with those not able to drive post-SCI (Norweg, Jette, Houlihan, Ni, & Boninger, 2011). While Norweg and colleagues do not provide detail about the length of time postinjury for the cases surveyed, their findings are consistent with other research by Ottomanelli and Lind (2009).

In the context of general physical factors and the return to work, information is available in the literature regarding the nature and extent of the relationship between employment outcomes and the level and severity of injury (Ottomanelli, Barnett, & Goetz, 2014; Trenaman et al., 2014). However, more specific physical impairments as a result of SCI, such as limited hand function, maintenance of skin integrity, bladder and bowel management, and pain control, are not addressed as comprehensively. In a guest editorial F. P. Thomas et al., (2014) comment on the array of physical conditions that can impact on vocational

reintegration for people with SCI, and then offers possible management strategies. The authors call for the development and implementation of clinical practice guidelines in vocational rehabilitation, as such guidelines do not currently exist. However, the research reported in the literature neglects to address the effectiveness of vocational interventions on employment outcomes post-SCI (Roels et al., 2016; Trenaman et al., 2014). Acknowledging that the physical factors influencing return to employment are multifaceted, a better understanding of what is known and undertaken at an individual level, such as the practical methods utilised by individuals to overcome occupational performance problems, would be useful to guide occupational therapists and other vocational rehabilitation professionals in providing support to people aiming to return to work after SCI. As previously discussed, further research is warranted to implement effective vocational rehabilitation to people with SCI.

2.6.4 Literature relating to spiritual factors

The CMOP-E refers to spirituality as the essence of the person (Polatajko et al., 2007a). In this thesis, spirituality is observed as it relates to a work context. While the relationship between work and a person's health, wellbeing and quality of life has been established, there has only been limited attention paid to the meaning that employment holds for people in the years after SCI. Hay-Smith et al. (2013) used an interpretive phenomenological analysis with a sample of 12 participants aged 23–57 from across New Zealand to explore the meaning of employment in the first two to three years following injury. At the time of

recruitment, four of the participants had achieved an employment outcome. In the research, the core identified meaning of employment was to live a normal life. An analogy of a jigsaw puzzle was presented to highlight the connection between the person, their supportive contexts and networks, and the work-related environment, in the pursuit of an employment outcome. The authors deduce that vocational rehabilitation may play a role in the reconstruction of employment identity, and this adaptation is part of the return to work process. While the study acknowledges the pre- and post-injury status of participants, it does not fully describe their vocational pathway inclusive of their education backgrounds. As in Fadyl and McPherson's (2010) work, this again limits the potential translation of research. The Hay-Smith et al. (2013) study gives a comprehensive picture of the meaning of employment in the potentially turbulent first two to three years following injury, including the advantages of social connectedness, a sense of self-worth, earning a living, and being occupied. However, a gap in knowledge is evident about the meaning and value of work for people beyond these very early years. Future research could build on this picture of the meaning of employment along the post-injury journey.

2.7 AIMS OF THE RESEARCH PROGRAM

Chapters One and Two of this thesis have reviewed a range of literature to illustrate some of the reasons why the process of seeking, gaining and maintaining employment after SCI is complex, and why achieving employment outcomes is difficult. Ultimately, in the translation of this research program into clinical practice, the end goal is to enhance employment

outcomes for people with traumatic spinal cord injury. In order to make a unique contribution in this field, four sequential but separate studies were undertaken. The aims of each of these studies are outlined below.

The first study aimed, through a systematic review of the literature, to:

1. identify the barriers and facilitators that influence people's experience of returning to work following SCI.

The second study, an audit of medical records, aimed to:

2. find and record data pertaining to employment outcomes and vocational pathways in the initial years following discharge from inpatient care for people admitted to Austin Health with a new SCI between July 2005 and December 2009. This study was undertaken to enable a baseline of employment outcomes prior to the introduction of the EIVR program.

The third study, using a longitudinal cohort design, aimed to:

3a. explore employment outcomes at three follow-up time points for people who received the EIVR program, implemented from the beginning of 2010

3b. explore the relationships between employment outcomes over time with aspects of functioning (physical and pain), activities and participation (psychological distress, social participation, relationships, pre-injury education, and pre-injury worker role) and contextual personal and environmental factors (emotional/wellbeing, social support, funding arrangements and where one lives)

3c. compare the employment outcomes for people following participation in the EIVR program with the rate of employment documented in the medical record audit from before the service changes.

The fourth and final study, using a mixed method approach incorporating interpretative phenomenological analysis, aimed to understand the experience and pathways of persons seeking and gaining paid employment outcomes after traumatic SCI in the state of Victoria, Australia, regardless of time since injury. Specifically this involved:

4a. identifying and allocating participants into three employment outcome groups of stable employed, unstable employed and without employment

4b. examining the nature and extent of relationships between employment outcomes and demographic variables, perceived satisfaction with life and dispositional optimism

4c. identifying pre- and post-injury pathways for participants in each of the groups, and

4d. exploring the experiences of people seeking, gaining and maintaining employment.

2.8 SUMMARY OF CHAPTER TWO

This chapter has provided an overview of research related to vocational pathways and employment rates. It has critiqued the literature pertaining to vocational interventions and explored the impact of various environmental and personal factors on employment after SCI. Overall, there is limited literature about the vocational interventions that are provided

to people with SCI to enhance their employment outcomes. This gap in the literature is particularly important given the sub-optimal employment rate post-SCI and the wellrecognised physical and emotional benefits of returning to the labour force (Manns & Chad, 2001; McKee-Ryan et al., 2005; Schonherr et al., 2004). Results from the small number of existing studies suggest that vocational interventions that provide dedicated, specialist vocational rehabilitation that is delivered early post-SCI warrant further investigation. The impact of environmental factors including social support, funding and compensation arrangements, and the area where an individual lives, also warrant future exploration. The participants in the studies critiqued within this chapter were predominantly two to five years post-SCI, and only a small proportion of them were actually employed (approximately one third). It is therefore questionable whether themes and factors associated with gaining and maintaining employment have been sufficiently explored. Further research is required to examine the experience and meaning of employment for people beyond three to five years post-injury, particularly with those who have actually achieved and maintained postinjury employment.

There is a growing recognition in the literature of the complexity of the return to work process following SCI and the array of contextual personal and environmental factors that can influence an individual's journey. An increase in understanding of the lived experience of the individual with SCI in seeking, gaining or maintaining employment will contribute positively to the future design and delivery of vocational interventions. With recognition of the existing strengths and gaps in the literature, the current research program was devised and its aims listed. The next chapter locates, appraises and thematically synthesises the

literature, focusing on the experience of participation in paid employment for people following SCI.

CHAPTER THREE

3 STUDY ONE: SYSTEMATIC REVIEW OF THE EXPERIENCE OF ATTEMPTING TO RETURN TO WORK AFTER SCI

A version of this chapter has been accepted for publication in the journal Disability and Rehabilitation. A co-author declaration and copy of the manuscript are provided in Appendices C and D.

Hilton, G. M., Unsworth, C. A., & Murphy, G. C. (2017). The experience of attempting to return to work following spinal cord injury: A systematic review of the qualitative literature. *Disability and Rehabilitation*. (April 11). DOI: 10.1080/09638288.2017.1312566

3.1 INTRODUCTION

The literature, as reviewed in the previous chapter, suggests that there are significant barriers for people in achieving employment following SCI. While there have been efforts to identify vocational interventions that may be effective in overcoming some of these barriers (Hilton, Unsworth, Browne, Murphy, & Olver, 2017; Middleton et al., 2015; Ottomanelli, Barnett, & Goetz, 2014), overall, as recognized in a systematic review undertaken by Roels et al., (2016) there remains a shortage of high quality studies about specific vocational interventions (Roels et al., 2016; Trenaman et al., 2014). In addition, intervention studies of robust design are inherently difficult to undertake with people with SCI, due to a small pool of potential participants, many of whom are subject to 'research fatigue'. Despite the lack of high quality studies, the employment-related literature increasingly recognises the complex influences of contextual personal and environmental factors on the return to work process following SCI (Lidal et al., 2007; Ottomanelli & Lind, 2009). Hence, a number of researchers have begun to explore this process using qualitative research designs in an effort to build a deeper and more comprehensive understanding of the dynamics, issues and challenges related to participation in paid employment after SCI, with a view to potentially informing future vocational interventions. Therefore, the aim of this study is to identify the barriers and facilitators that influence people's experience of returning to work following SCI.

3.2 METHODS

In seeking to answer the research question, this systematic review undertook three main steps. The first step involved a systematic search for studies focusing on the meaning for and experiences of people following spinal cord injury in seeking, gaining or maintaining paid employment in the open labour market. The second step conducted a critical appraisal of the identified literature, while the last step was a thematic synthesis of the results of the first two studies.

3.2.1 Review process

This review was performed in a systematic and comprehensive way and followed the process for review, appraisal and synthesis of qualitative literature, as documented by the Centre of Reviews and Dissemination (CRD) (Centre for Reviews and Dissemination, 2009) at the University of York, which is widely used in papers reporting a meta-synthesis of

qualitative studies (Sakellariou, Boniface, & Brown, 2013; J. Thomas & Harden, 2008). The review process and documentation were also informed by a framework identified by Tong et al. (2012) to enhance the reporting of synthesis of qualitative research (ENTREQ). The first author of the review (GH) developed the review protocol, performed literature searches and extracted and analysed data. GH and the second author, CU, critically discussed the review process and results, with CU cross-checking article selection and appraisal. GH completed the thematic synthesis of all eligible articles, with CU concurrently reviewing a sample. The two authors were in 95% agreement on synthesis results and discussed these until full consensus was reached. GH was responsible for writing all drafts including the final draft.

3.2.2 Selection criteria

Included articles were published between 1996 and 2016; used a research design that allowed exploration of individual experience from the perspective of the person with SCI; had results that reported the author's interpretation of the lived experience, meaning, decisions and/or values in relation to seeking, gaining or maintaining paid employment; were published in peer-reviewed journals accessible through electronic databases; and were written in English.

Articles where study participants were not primarily of workforce age (i.e., were <15 or >65 years old) or had significant co-morbidity of severe cognitive deficits, psychosis or other psychiatric illness were excluded from this review.

3.2.3 Databases

The search process for databases was pre-planned and sought to comprehensively identify all appropriate studies with the use of combined search terms. In order to ensure that the search was as explicit and reproducible as possible, only the electronic databases CINAHL Plus, MEDLINE, PsycInfo and Embase were used. It was believed that use of these four databases would capture all studies related to the topic. Searches were repeated in the databases between 26 June 2016 and 3 July 2016. Search terms used included spinal cord injury AND employment OR work OR jobs OR labor/labour force OR job tenure OR job retention OR sustain* employment OR maintain* employment OR return to work OR vocational rehabilitation AND meaning OR experience OR value OR employment identity. All search fields (title, keyword, abstract) were selected in all four databases. The search and selection process is presented in Figure 2.

Citations were exported into an online bibliography manager (EndNote), where duplicates were removed. Article titles, keywords or abstracts were then reviewed on the basis of the inclusion and exclusion criteria. Full text was obtained for articles that met the selection criteria. Following retrieval of full texts, articles were more closely reviewed against the selection criteria and reference lists were manually searched for additional appropriate articles. A further 15 articles were excluded on the basis of following a quantitative design or there being an insufficient focus on paid employment.



Figure 2. Search and selection process for Study One: Systematic review of the experience of attempting to return to work after SCI

3.2.4 Search strategy

3.2.4.1 Critical appraisal and data extraction

Articles that were retained and met the full selection criteria were critically appraised in order to assess their quality. The National Institute for Health and Clinical Excellence (NICE) (2006) guidelines (see Appendix E)—based on the broadly accepted principles that characterise qualitative research, such as focusing on process, letting themes emerge, and following a scientific method—were utilised to appraise the selected works. This was undertaken to establish the strengths and weaknesses of the studies, to ensure they were of sufficient quality for data synthesis. A summary of the appraisals is included in Table 4. Following the appraisal of the articles, J. Thomas and Harden's (2008) methods for developing a thematic synthesis were adopted, and data were extracted from the articles according to this method. For the purposes of this review, data were defined as the results obtained in each of the selected studies. The analysis and interpretations of the researcher, rather than individual participant quotes, were extracted from the results and discussion sections of each article and placed into a separate document, which was then uploaded to the qualitative analysis software, NVivo (NVivo for Windows, 2012).

3.2.4.2 Data analysis

As described by J. Thomas and Harden (2008), data analysis for the purposes of thematic synthesis has three main stages. The first involves coding the primary data (text) line by line; the second identifies descriptive themes that emerge from the coding; and the final stage draws out analytical themes. NVivo (2012) software was used to assist with data

management for the analytical process. An example of the coding and descriptive themes is provided in Figure 3.

Nod	les
*	Name
-0	a_pre - injury - the experiences, paradigms, personality that exist with individual pre-injury
	existing disability paradigm_social, attitudes, expectations, culture
Ð	individual personality traits optimism_pessimism, roles, identity,
	optimism_pessimism influencing
1	life experiences _ opportunities _ foundations for resilience
) b At injury_early adjustment (unknowns, identity confronted) comb w environmental (social, cultural, institutional) influences, comb with pre-mor
	Culture within SCI centre or facility_focus on physical vs roles, health, wellbeing
Contraction of the local division of the loc	facility focus on physical recovery or recognition of life roles
	supportive messages received from SCI facility during acute and rehabilitation about work
	Learning and re-creation process_identity
Ð	O Unknowns_lack of knowledge, understanding, information, sense of what possible and how
	- O fear of future related to lack of understanding about SCI
-0	c_life after injury_work value challenged by environmental factors (soc, inst, cult, phys) and personal factors (emotional, physical, spiritual)
	Balance
	Meaning of work and meaningful work_identity, roles
-	Social policy_system negotiations_insurance vs welfare
	Social supports_employer, family, personal care assistance, rehab profs
0	d_peer support_above challenged by peers, people w SCI who are living successfully with injury_show, inspire, challenge, motivate, educate, lead
- C	e_physical and environmental contextual factors_this is the known stuff

Figure 3. Example of coding and descriptive theme organization, managed with NVivo, in Study One: Systematic review of the experience of attempting to return to work after SCI

Typically, in employment-related research, the literature distinguishes between three groups of people: employed, unemployed but looking for work, and unemployed and not looking for work. This systematic review was ultimately concerned with facilitating effective and appropriate health care. To this end, results and discussion in this study were oriented to services and interventions that related to facilitating paid employment in the competitive workforce, as this is considered one of the optimal goals of SCI rehabilitation (Guttmann, 1954; Krause, 1990).

3.3 RESULTS

Critical appraisal of the nine studies that met the selection criteria found that all were of sound methodological rigour. Summaries of the nine studies are presented in Table 4. These studies were then included in the thematic synthesis, which reported on the experience of 114 people with SCI. The age range of people with SCI in the thematic synthesis was between 20 and 68 years, and the time since injury ranged from two months to 41 years.

Table 4

Summary of articles selected for review and appraisal for Study One: Systematic review of the experience of attempting to return to work after SCI

Authors	Year	Location	N	Age and time since injury	Aim	Design	Findings/recommendations	Discipline of primary researcher	Critical appraisal ¹
Hammel	1999	United States	16 people with SCI, unemployed at commencement of study	Age range 21–45 years, time since SCI 1–14 years	To explore the process of work re- entry and adjustment from perspective of individuals with SCI	Qualitative comparative case study	Individuals formed multiple 'strands' within role repertoires at any point in time. The metaphor of a Life Rope emerged as a useful conceptual framework for explaining life role development, including that of a worker.	Occupational therapist	Role of researcher not described; no report of ethics.
Chapin & Kewman	2001	United States	12 people with SCI, employed ² (<i>n</i> = 6), matched with unemployed (<i>n</i> = 6)	Age range 30–49 years, time since SCI 3–12 years	To examine factors that differentiated persons with SCI who returned to work from those who did not	Qualitative design using semi- structured interviews and grounded theory	Psychological factors associated with employment were: optimism, self-esteem, achievement orientation, and role models. Environmental factors were: monetary incentives and disincentives, access. and accommodation.	Discipline not clear, possibly psychology or social work	Role of researcher not described; no report of ethics
Ville	2005	France	17 people with SCI, employed (<i>n</i> = 9), unemployed (<i>n</i> = 7) and student (<i>n</i> = 1).	Age range 29–53 years, time since SCI 4–30 years	To analyse ways in which the question of returning to employment arises in relation to the biographical work of people with SCI	Qualitative design using semi- structured interviews and symbolic interactionism	A change of perspective is needed that encourages the biographical process. The primary objective of aiding people with SCI to return to work would therefore be to improve conditions around biographical work.	Discipline not stated	Role of researcher unclear; data analysis not rigorous nor reliability

reported;

Chan & Man	2005	Hong Kong, China	16 people with SCI, employed (<i>n</i> = 6) and unemployed (<i>n</i> = 10)	Age range 26–53 years, time since SCI 4–21 years	To explore and identify the barriers and important factors that might hinder people with SCI from seeking and sustaining jobs	Semi- structured focus group interview	Several modifications of existing rehabilitation intervention are necessary, as are further research directions.	Occupational therapist	Role of researcher unclear; data analysis not rigorous nor reliability reported; no report of ethics
Fadyl & McPherson	2010	New Zealand	13 people with SCI, including people who were currently working, employed but not working, and unemployed, although details were not provided, in order to protect the identity of participants	Age range 22–58 years, time since SCI 2 months to 10 years	To identify common influences contributing to decision-making about returning to work that would help to inform vocational rehabilitation practices	Symbolic interactionist approach informed by grounded theory	Ability to work (given demands and resources), presence of responsibilities or pressures that compete with work, access to a suitable job, and work being of enough benefit to be worth pursuing are all factors in the decision to return to work.	Discipline not stated	of ethics Role of researcher unclear
Bergmark et al.	2011	Sweden	8 people who had not yet returned to work	Age range 20–34 years, time since SCI 1–5 years	To explore the experience and expectations concerning paid work among young adults on sick leave after SCI	Qualitative design using semi- structured interviews and constant comparative method for analysis	Themes identified were: the possibility of finding a way to everyday life where work is possible; being at the crossroads of expectations about work through education; facing expectations of work as part of a desired future life; and accepting expectations of finding solutions	Occupational therapist	Role of researcher unclear; analysis reliability not reported

within oneself or with help from others.

Hay-Smith et al.	2013	New Zealand	12 people with SCI, employed (<i>n</i> = 4), looking for work (<i>n</i> = 3) and unemployed (<i>n</i> = 5)	Age range 23–57 years, time since SCI 2–3 years	To explore the experiences of vocational rehabilitation professionals and people with SCI who are pursuing a return to employment, in order to understand the meaning of employment, along with perceptions of barriers and facilitators to employment	Qualitative design using semi- structured interviews and interpretive phenomen- ological analysis	The core meaning of employment post-SCI was to live a normal life. Work advantages were: social connectedness, a sense of self- worth, earning a living, and being occupied. Employment was the zenith of rehabilitation but not the first priority post-SCI.	Discipline not stated	Nil issues
Leiulfsrud et al.	2014	Norway	31 people (28 with SCI and 3 with spina bifida), employed (<i>n</i> = 11), unemployed (<i>n</i> = 17) and student (<i>n</i> = 3), although specific employment status of people with SCI was not identified	Age range 23–68 years, time since SCI 3–41 years	To examine the value of employment for people living with SCI in Norway	Qualitative design using open-ended and follow-up questions, with analysis initially grounded theory then extended and updated to use symbolic interactionism	Value of employment described in terms of personal and social interaction with others as a hegemonic social norm and an obligation to contribute to society. The value of meaningful regular jobs—in contrast to government projects jobs or routine jobs—was emphasised by participants.	Occupational therapist	Nil issues
Wilbanks & Ivankova	2015	United State	4 people with SCI who were currently employed	Age range 42–57 years, time since SCI 24–37 years	To explore factors facilitating adults with SCI rejoining the workforce in an urban area, in order to identify items that may	Qualitative design using semi- structured interviews and	Motivation was the most common facilitator in returning to work. Family and rehabilitation professionals were extrinsic motivators, while other	Discipline not stated	Nil issues

be utilised in the phenomenrehabilitation process ological perceived benefits. approach to analysis.

Notes. ¹ NICE guidelines were used for critical appraisal.

² Participant characteristics were not always clearly described, however, they were taken as consistent with the definition of the Independent Labor Organization about labour force categories.

In keeping with J. Thomas and Harden's (2008) three stages of thematic synthesis, nineteen unique codes were initially identified across the nine studies. Line by line coding enabled the translation of concepts from one study to another (J. Thomas & Harden, 2008). In step two several descriptive themes inductively emerged from the coded primary data. These themes remained close to the data and were reflective of individual experiences of seeking or gaining employment post-SCI. The third step of the thematic synthesis involved going beyond the content of the original studies. Further interpretations were drawn from the descriptive themes to answer the review questions and consider clinical implications. Three broad, higher level analytical themes are identified (J. Thomas & Harden, 2008). The descriptive and analytical themes are shown in Table 5. The analytical themes are presented in the following sections. Data used in the representation of the analytical themes are derived from the author's interpretations of the primary data, not from participants' quotations. Table 5

Descriptive and analytical themes emerging from thematic synthesis

Descriptive themes

Pre-injury: The experiences, paradigms and personality that exist in individuals preinjury

At injury: Early adjustment (unknowns, identity confronted), combined with environmental (social, cultural, institutional) influences, combined with pre-injury experiences

Life after injury: Work value challenged by environmental factors (as above) and personal factors (emotional, physical, spiritual)

Peer support: Life after injury challenged by peers (that is, people living successfully with SCI) to show, inspire, challenge, motivate, educate, lead

Physical and environmental contextual factors: What is known

Analytical themes

A matrix of personal and environmental factors exists, requiring complex navigation in order to create possibilities and opportunities for achieving post-injury employment

The process of seeking or gaining post-injury employment shares a reciprocal relationship with the temporal nature of adjustment to SCI

There is an intrinsic need for occupational engagement through paid employment

3.3.1 Analytical theme: A matrix of personal and environmental factors exists, requiring complex navigation in order to create possibilities and opportunities for achieving post-injury employment

The experience of SCI is frequently described as complex in the context of the physical and psychological impacts of impairment (Lidal et al., 2007; Ottomanelli et al., 2009). The volition to work following SCI develops within a matrix of environmental dynamics and personal factors. The terms personal and environmental are used here as per the contextual factors in the World Health Organisation's (World Health Organization, 2002) International Classification of Functioning, Disability and Health. Different environmental contexts, such as the social, cultural or institutional environment, can present barriers and challenges to a successful return to work. Personal factors can include previous life experience, personality, and motivations. Effective navigation of these factors can allow opportunities and possibilities for employment outcomes.

In the studies investigated, the cultural environment within the SCI rehabilitation centre could sow the seed for a natural contemplation in people about work and the prospect of employment following injury (Hay-Smith et al., 2013). Conversely, people with SCI reported that the rehabilitation centre offered little emphasis on employment as a rehabilitation goal, with a focus instead on meeting "basic survival needs" (Hammel, 1999). People who experienced employment after SCI reported an explicit link to the extent of their social connectedness (Hay-Smith et al., 2013). This manifested as a positive relationship with their pre-injury employer, who supported a return to work, along with existing social contacts

who used their networks to offer opportunities for work and/or exposure to a peer mentor to challenge an individual's perspective of what might be possible in relation to employment (Chan & Man, 2005; Chapin & Kewman, 2001; Fadyl & McPherson, 2010; Hay-Smith et al., 2013).

Opinions of people with SCI varied about access to insurance or social welfare in relation to work, with both being described as a support but also a disincentive to employment (Bergmark, Westgren, & Asaba, 2011; Chan & Man, 2005; Chapin & Kewman, 2001; Hay-Smith et al., 2013). Given the extent of the physical and psychological impacts of SCI, while people expressed having an interest or desire to work (Chan & Man, 2005; Chapin & Kewman, 2001), it was often counteracted by the question of whether or not work was worth the effort (Hay-Smith et al., 2013). Similarly, an overriding wish for security (Bergmark et al., 2011), in the sense of having a stable income, influenced the decisions people made about work (Fadyl & McPherson, 2010). Where people could find a balance between different demands and expectations, employment became a possibility (Chapin & Kewman, 2001).

It was also found that people with SCI needed to negotiate cultural, social and institutional environmental factors, as mentioned earlier, to achieve employment after SCI. They did this intrinsically, drawing on personality traits, previous life experience and their sense of self. People who achieved employment after SCI were motivated and optimistic (Chan & Man, 2005; Chapin & Kewman, 2001; Wilbanks & Ivankova, 2015), had confidence in their ability to cope with challenges that arose, and had a determination to work against barriers (Fadyl

& McPherson, 2010). Conversely, people who were unemployed reported pessimism about finding a job, were anxious and fearful about working (Chan & Man, 2005), and had had negative experiences in relation to returning to work (Chapin & Kewman, 2001).

3.3.2 Analytical theme: The process of seeking or gaining post-injury employment shares a reciprocal relationship with the temporal nature of adjustment to SCI

Informed by Moss-Morris' (2013) theory of adaption to chronic illness, Craig et al. (2015) define adjustment following SCI as the rate of social participation of people living in the community following injury. Adjustment is impacted upon by multiple factors, including sociodemographic, injury-related, environmental and social relationships (Moss-Morris, 2013). These forces around adjustment are also evident in individual life trajectories, including the path to employment. This analytical theme therefore reflects the interrelationship between adjustment and employment that exists in people following SCI.

Pre- and post-injury exposure to social paradigms of disability appeared to be influential in adjustment and the return to employment. People with SCI described instances of discrimination and stigma (Chan & Man, 2005; Chapin & Kewman, 2001; Wilbanks & Ivankova, 2015), along with employer and others' misconceptions about their abilities, both physical and cognitive (Chapin & Kewman, 2001; Fadyl & McPherson, 2010; Hay-Smith et al., 2013; Leiulfsrud, Reinhardt, Ostermann, Ruoranen, & Post, 2014; Wilbanks & Ivankova, 2015). The reviewed studies suggest that in the initial two to three years after SCI, people

reported an initial focus on understanding their body, along with needing time to re-learn how to do daily activities and to create new routines (Bergmark et al., 2011; Ville, 2005). Personal resources were required to deal with emotional issues, particularly adaption to the physical and functional changes that resulted from injury, and also to manage people's concerns about supporting themselves and/or their families (Fadyl & McPherson, 2010). Some people with SCI reported a sense of disengagement from their worker role, and the longer this continued the less able they were to redevelop that connection (Hammel, 1999). While new life priorities and timelines were found, unresolved health issues continued to impact on adjustment (Hay-Smith et al., 2013).

In the years after injury, there was an increase in discussion about the benefits of employment while living with SCI. People who were engaged in paid work reported finding a sense of identity through employment (Chapin & Kewman, 2001; Hay-Smith et al., 2013), along with feelings of balance about the place of work in their lives (Wilbanks & Ivankova, 2015). This recognition of the value of work is reflected in the third analytical theme.

3.3.3 Analytical theme: There is an intrinsic need for occupational engagement through paid employment

People with SCI who were in employment reported feelings of satisfaction arising from the mental stimulation of work, social integration, a sense of purpose, and the opportunity for personal growth and independence (Chan & Man, 2005; Chapin & Kewman, 2001). Work

was perceived as being a sign of independence, proof of productivity, and a way of contributing to society (Chan & Man, 2005). The opportunity to contribute to society was reported by people who were employed as being crucial to their self-esteem, personal identity, pride and social value (Leiulfsrud et al., 2014; Wilbanks & Ivankova, 2015). Being a worker was part of the participants' identity and represented living a normal life, being socially connected, feeling confident, having a sense of worth, and earning a living (Hay-Smith et al., 2013). Finances were reported as being motivating to people but were not the main benefit of employment. Not working was unimaginable for many participants (Hay-Smith et al., 2013). However, people also reported that having meaningless work did not have same benefits as more purposeful employment (Hay-Smith et al., 2013) and that jobs obtained through welfare were considered inferior (Leiulfsrud et al., 2014). Where people had not achieved employment, they reported having little confidence (Leiulfsrud et al., 2014). Even younger people who had not yet regained employment after injury recognised the potential value of work. They had expectations of working and anticipated they would do well at work. They identified that participation in employment was valuable, and that it would be a way to express creativity and be good at something (Bergmark et al., 2011).

3.4 DISCUSSION

This discussion presents reflections on the analytical themes that emerged from the review and the implications of these for clinical practice. It also contains a summary of the strengths and weaknesses of the included studies, the limitations of this review and
suggestions for further research. The review highlights the variable and challenging nature of the return to work experience for people following SCI and also the positive impact that being a worker has on people's lives. Individual journeys are complex, influenced subtly or extensively by numerous personal and environmental factors. J. Thomas and Harden (2008, p. 45) state that the value of synthesising qualitative research in the evidence base is to facilitate "effective and appropriate health care". To this end, there are three main implications for clinical practice from this systematic review. These relate to the three analytical themes that emerged from the thematic synthesis. That is: there is a complex navigation of a matrix of personal and environmental factors to create possibilities and opportunities for employment; the experience of employment shares a reciprocal relationship with the temporal nature of adjustment to SCI; and there is an intrinsic need for occupational engagement through paid employment in people with SCI.

The first implication of this review is associated with the fundamentally difficult process of achieving employment after SCI. The complexity of the return to work process has been identified in previous literature (Lidal et al., 2007; Ottomanelli & Lind, 2009). Challenges and barriers are often unavoidable, but as the reviewed papers identify, intrinsic factors such as motivation, optimism, confidence and determination among participants were of assistance in overcoming barriers to gaining and maintaining employment (Chan & Man, 2005; Chapin & Kewman, 2001; Fadyl & McPherson, 2010; Wilbanks & Ivankova, 2015). The reviewed studies also demonstrate the utility of peer support, social connectedness and a positive institutional culture regarding return to work, and the importance of identifying and balancing economic goals in facilitating trajectories toward employment. From this, it can

be seen that it is critical that clinicians draw on and provide multiple strategies to support individuals in the navigation of the return-to-work process.

The second implication relates to the intertwined processes of adjustment and returning to work after SCI. This relationship is evident from the reviewed studies and further emphasised in other literature (Craig et al., 2015; Moss-Morris, 2013); (Krause, 1992). The clinical team can therefore play a sensitive yet pragmatic role in promoting employment outcomes with the person with SCI, while remaining cognisant to the personal motivations for being a worker and the individual adjustment process. They can do this by concurrently offering and linking to appropriate resources and benefits, being mindful of timing, and above all utilising a consistent and supportive framework and a culture of positivity about employment after SCI.

The third analytical theme of the intrinsic need for occupation guides the final implication of this review. Expressed in the findings of the reviewed papers is an overall drive from the participants to be engaged in productive activity, which is broadly termed occupation, regardless of whether people have achieved employment or not. This is well-documented in established theories of occupation, such as the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko et al., 2007a) and the Model of Human Occupation (MOHO) (Kielhofner, 2008), which hold that occupation is central to human existence. The findings from this review reinforce that, principally, the benefits of being in paid work outweigh the negative experiences encountered when seeking, gaining and maintaining employment. In the clinical environment, a focus on the value of employment

as occupation can be encouraged. Clinicians should ideally provide reassurance that employment is both possible and health-promoting. In doing so, they can offer a powerful and positive message about the future to people who are newly injured.

3.4.1 Strengths and weaknesses of the reviewed studies

The reviewed studies employed a variety of research designs. While the studies sought to answer different research questions, they all contributed to the understanding of the experience of returning to work for people with SCI. The studies were generally of very high quality with good methodological rigour. As such, all reviewed studies were included in the thematic synthesis, with no studies rejected on the basis of the weak methodology. Where studies scored lower in the critical appraisal according to the NICE guidelines (National Institute for Health and Clinical Excellence, 2006), the issues were similar, with several studies neglecting to document the relationship of the researcher to the participants or to describe how the research was explained to the participants. Only four studies provided details about the background discipline of the primary researcher. Clear and coherent reporting of ethics was also lacking in four studies, and three studies did not provide sufficient detail regarding how they ensured reliable analysis, such as using a second researcher to check themes and coding (see Table 4). Future research should describe the position of the researcher, provide detail regarding ethical considerations and undertake techniques to ensure analysis is reliable, in order to limit bias.

Challenges exist in accurately synthesising research from different countries, given their respective insurance and social welfare policy environments. For example, two papers were written in the context of a comprehensive no-fault accident social insurance system (including income support) in New Zealand, while three papers came from the United States of America, where rehabilitation and supports are largely driven by private health insurance policies. Similarly, studies had recruited participants from broad age ranges, with varying times since injury and disparate employment histories, thereby bringing varying perspectives and experiences to the research. Bergmark et al.'s (2011) study, for example, specifically recruited participants who were young adults, with no post-injury employment experience and all within five years of injury. In comparison, Wilbanks and Ivankova's (2015) work focused on participants who were all employed and more than 24 years post-injury. These are not necessarily weaknesses of the reviewed studies but an inherent challenge due to the high number of influencing variables to be considered with this population. It is equally appropriate to argue that a strength of the studies is that they cover a diversity of groups impacted by SCI.

3.4.2 Limitations and directions for further research

There are several limitations to this review. A publication bias exists, since studies were selected only from peer-reviewed journals across four databases, and only nine papers met the inclusion criteria for appraisal and synthesis. However, the nine papers combined data from several different methodological traditions, which added strength to the review

(Centre for Reviews and Dissemination, 2009). Researcher bias is also possible, as the first author is an experienced occupational therapist in SCI rehabilitation and service development. However, the pre-existing knowledge of this author provides a depth of understanding that can be considered a strength in synthesising and making sense of the issues and scenarios presented. The reviewed studies reflected a wide range of dates, from 1999 to 2015. As discussed with reference to the individual studies, the policy and practice landscape in relation to vocational rehabilitation specific interventions, the labour market and societal attitudes about SCI may have changed over this time. These factors may have impacted on individuals' experience and subsequent study results.

The varying contexts and sample populations included in this review highlight possible gaps in this body of literature about people's experiences of employment following SCI. Time since injury in the reviewed studies ranged from two months to 40 years, yet there was no particular acknowledgement of this by the researchers of the differing experiences. Earlier in this thesis, work by Ferdiana et al. (2014), Young and Murphy (2009) and Krause (2003) was introduced. All of these researchers acknowledge that without any specific intervention, employment rates will gradually increase over the first two decades following injury. Given this, the explicit exploration of employment experiences at different time ranges post-injury could be useful in producing data to guide the nature and extent of vocational interventions in clinical settings.

Some understanding has emerged from this synthesis of the nature and extent of the experiences and behaviours associated with different employment outcomes (notably being

employed versus unemployed). There is, however, scope for further exploration of these outcomes in relation to individual trajectories. The findings of this systematic review could also be used to demonstrate the importance of returning to work in the context of other health conditions—such as heart failure, organ transplant or limb amputation—for a person's overall health and wellbeing (Polatajko et al., 2007a). Indeed, in terms of occupational engagement, the views of people with SCI would seem to parallel those of the general population (Ezzy, 1993; Jahoda et al., 1971).

3.5 CONCLUSION

This review identified three analytical themes in response to the question 'What are the barriers and facilitators influencing people's experience of return to work following spinal cord injury?' The first of these themes is that seeking, gaining and maintaining employment for people after SCI involves a complex navigation of a matrix of personal and environmental factors that create possibilities and opportunities. The second theme is that the experience of employment shares a reciprocal relationship with the temporal nature of adjustment to SCI. Lastly, it is clear that there exists an intrinsic need for occupational engagement through paid employment in people following SCI. The implications of these findings are that clinicians need to draw on and provide multiple strategies to support individuals in the navigation of the return to work process, and they must also be cognisant of the adjustment process and the individual motivations for being a worker, while offering sensitive yet pragmatic support in promoting employment outcomes. Finally, clinicians need

to provide reassurance to people with SCI that employment is both possible and healthpromoting.

CHAPTER FOUR

4 STUDY TWO: MEDICAL RECORD AUDIT OF PEOPLE ADMITTED TO REHABILITATION WITH A TRAUMATIC SPINAL CORD INJURY PRIOR TO COMMENCEMENT OF AN EARLY INTERVENTION VOCATIONAL REHABILITATION SERVICE

4.1 INTRODUCTION

Chapter Three reviewed qualitative literature related to people's experience of achieving employment after SCI, which confirmed the need for additional research. As previously described in this thesis, returning to work is an important indicator of successful rehabilitation for people following traumatic spinal cord injury. Section 1.3.6 and 1.3.7 outlined the service changes that were implemented by the Victorian Spinal Cord Service in 2010, which included an increased focus on vocational rehabilitation interventions via the EIVR program. However, longer term employment outcomes for Victorians with SCI remain largely unknown both before and after these service changes. Therefore, a randomised controlled trial is ideally required to determine the effectiveness of the EIVR program. As is considered best practice, establishing a control group would have allowed a clear comparison of employment outcome both before and after service changes. However, conducting a randomised controlled trial or a study with a similarly robust design presented several insurmountable challenges in the Victorian clinical environment. There was only one recruitment site, a restricted time period and insufficient research resources to recruit an adequate sample size to power a randomised controlled trial. It was also considered unethical at the clinical site to restrict the provision of a new intervention to half the

inpatient client group or to waitlist people to receive services. Therefore, when originally designing the cohort study to explore the effectiveness of the EIVR program (presented in Chapter Five), the plan was to use an interstate comparison group who did not receive EIVR treatment. However, owing to different funding arrangements interstate with compensable and non-compensable clients, a suitable comparison group could not be located.

Ottomanelli and Lind (2009, p. 527) suggest that employment specific outcome data be reported in terms of "competitive employment rates, duration of employment" and instances of "job tenure", in order for studies of employment and vocational rehabilitation to be meaningfully interpreted.

This chapter presents a retrospective review of individual medical records from the period of July 2005 until December 2009, which is just prior to service changes in Victoria, to record data pertaining to employment outcomes and vocational pathway in the initial years following discharge from inpatient care. The purpose of this audit, therefore, was to provide an alternative method of establishing employment status outcomes among Victorians with SCI prior to service changes in 2010. In effect, the audit provides a baseline comparison for employment rates and other demographic data with those shown post-implementation of the EIVR program. The aim of the audit was therefore to: a) identify employment outcomes for people within approximately five years following admission for rehabilitation after traumatic SCI; and b) identify relationships between personal and environmental factors, and employment outcome for this cohort. Subsequent to this audit, Chapter Five presents the longitudinal employment outcomes for people following service changes in 2010 and

examines the differences in employment outcome for people with SCI before and after the service changes.

4.2 METHOD

4.2.1 Participants

A list of N = 118 people who were admitted to the Victorian Spinal Cord Service's (VSCS) Spinal Rehabilitation Facility between the years of 2005 and 2009 was obtained from VSCS records. Eligible admissions from 1 July 2005 until 31 December 2009 were identified until a consecutive sample of n = 100 records was obtained. This was a targeted sample size to make a direct comparison with the post-EIVR sample as reported in Chapter Five. Eligibility criteria included completing inpatient rehabilitation after traumatic spinal cord injury with the Spinal Rehabilitation Facility at Austin Health, being of working age (between 15 and 65 years) at time of injury, and residing in Victoria on discharge. The participants also needed to have experienced persisting neurological symptoms, as defined in Chapter One.

4.2.2 Instruments

An Excel spreadsheet was devised to collect the following demographic and injury data, where reported, from the patient record: gender, age, neurological level of lesion, AIS grade (classification of injury) on discharge from inpatient rehabilitation, pre-injury education level (highest achieved), pre-injury employment status, type of employment pre-injury

(professional, manual labour, etc.), compensation status, relationship status (at discharge), date SCI was sustained, and date of discharge from inpatient rehabilitation. For the purposes of this research, employment was defined as ≥ one hour work per week in which the person was paid. It was recorded as full-time (over 35 hours per week) or part-time, and also as a dichotomous variable as either 'in the labour force' or 'all others'. Data pertaining to employment outcomes and narrative relating to vocational pathway following SCI were also collected. Throughout this thesis, references to education level achieved and the type of work a person has been employed to do (also referred to as worker role or occupation type) relate to definitions available in the Australian Qualification Framework (Australian Qualifications Framework Council, N.D.) and the Australian Bureau of Statistics (2013) Classification of Occupation. These levels of education and occupation types are summarised in Tables 6 and 7.

Table 6

Education levels according to the Australian Qualification Framework

Levels of education

- 9 Postgraduate degree
- 8 Graduate diploma and graduate certificate
- 7 Bachelor degree
- 6 Advanced diploma and diploma
- 5 Certificate
- 4 Secondary education
- 3 Primary education
- 2 Pre-primary education
- 1 Other education

Table 7

Occupation type according to Australian Bureau of Statistics Classification of Occupation

Occupation type
Managers
Professionals
Technicians and Trades Workers
Community and Personal Service Workers
Clerical and Administrative Workers
Sales Workers
Machinery Operators and Drivers
Labourers

Obtaining data on from the medical record on pre-employment status, education history, relationship status and employment outcome required reviewing several sections of the record, including the medical discharge summary and the combined occupational therapy and physiotherapy discharge summary. Another section of the medical record reviewed was the surveillance clinic data. Following discharge from inpatient rehabilitation, all VSCS clients are invited to attend outpatient review clinics, referred to as surveillance clinics. These clinics use a set proforma for recording issues under headings such as bowel, skin, mobility, equipment or work. During the multidisciplinary consultation, each clinician will make a note under the relevant heading. An example of this under the heading of work (as depicted in Figure 4) could be: 'Engaged in graded return to work program with previous employer, currently working 3 days – 3 hours each day, nil issues', or 'Not interested in work at this stage'.

Correspondence records were also scanned for any details relating to vocational pathway and/or employment status. Details relating to employment status, including whether a person was in the labour force or not, their occupation type, the number of hours they worked, the date they returned to work, and so on, were recorded along with the date of the data entry. Any available narrative details related to the vocational pathway were also recorded: for example, 'wants to return to university this year'. Each piece of data was entered into an individual cell of the Excel spreadsheet. The narrative details provided an opportunity for cross-checking documented facts and dates, and was also used to deduce

employment outcome data, as suggested by Ottomanelli and Lind (2009). In addition, it was noted if no information relating to employment status was available for any given year following discharge. Figure 4 shows an example of the type of data extracted from individual medical records.

ID	Vocational related data reported - note date							
#4	DC 2/3/06; work ax to be completed today by VSCS OT and client	Outpatient OT note 3/3/06; worksite ax, recommendation initially 4 days, 4 hours each	DC 8/6/06; RTW full-time. Had outpatient OT assisting.	SC 1/5/08; not seen				
#26	SC 27/10/09; not working, leisure: watching TV, visiting friends	SC 20/11/08; comment about pre-inj. Then: nil issues, not keen to pursue work at present, suggested talk to private OT about this in future.	SC 1/2/2011; nil report	SC 30/10/2012; family business	SC 12/11/2013; gets out on good weather days	SC 13/11/2015; nil report	SC 2016; nil report	
#33	DC 9/8/2007; not feeling ready to return to work. Not wishing to be linked with vocational rehabilitation provider.	DC 11/10/2007; no plans for RTW. Focusing on physical issues.	DC 10/01/2008; reports being out a couple of times, better experience than expected. No plans for RTW, wants to concentrate on walking.	SC June 08 FTA	SC June 09 FTA			
#58	OT discharge summary; has been allocated RTW officer with company, plans RTW next year	DC 8/11/07; currently planning RTW in Feb. Deciding extent and type of work.	DC 14/2/08; planning RTW next month. Graded program.	DC 8/5/08; has returned to work. Has RTW coordinator.	SC 4/8/08; 3 hours on 3 days per week. Bench work at workshop/main- tenance.	SC 29/9/09; RTW after 11 months. Currently no longer working, laid off 2 months ago.	SC 28/09/10; no longer working	SC 20/9/11; nil report
	DC - Discharge Review Clinic	SC - Surveillance Clinic	RTW - Return to work	VSCS - Victorian Spinal Cord Service	FTA - Failed to attend	OT - Occupational therapy	Ax – Assess	ment

Figure 4. Example of data collected from medical record audit for Study Two: Audit of medical records prior to implementation of EIVR program

Upon completion of the collection, data were collated and managed into data analysis software (SPSS). Employment status data were organised into three time points at set intervals after injury, as described in the following dot points:

- Time point one corresponded with discharge from inpatient rehabilitation
- Time point two aligned with one year following discharge
- Time point three incorporated data collected between two and five years following discharge.

The last data entry available for any given client in relation to employment status was also collected. This could have been at a time as brief as one year following discharge, through to eleven years post-discharge. This is described as the final audit point. The length of time since injury was also noted for this audit point.

4.2.3 Procedure

Ethics approval for this audit LNR/15/Austin/478 was obtained from the relevant hospital human research ethics committees (see Appendix F). A memorandum of understanding was signed as part of the ethics application, between Austin Health and the university under which the candidate was enrolled (see Appendix G). Medical records for the identified sample population were then obtained. At the time a person presents to Austin Health for treatment, a unique identifier is allocated and a medical record (also referred to as patient history) is created. Prior to 2009, Austin Health maintained paper records for all patientrelated contact, such as presenting at emergency, being admitted as an inpatient, attending an outpatient consultation, or other patient-related correspondence. In 2009, following a directive from the Victorian Government's Health Department, Austin Health introduced a staged transition from paper records to electronic medical records, referred to locally as a scanned medical record. This audit ultimately spanned the time period of admissions from July 2005 through to December 2009, and therefore people's records were maintained both in paper (2005–2009) format and as a scanned medical record (2009–current). For example, a patient first admitted to the Austin Health in 2005 may have several volumes of paper record covering all activity from admission till the paper record was closed in 2009. All subsequent documentation for this person from 2009 onwards could then be found electronically in the scanned medical record.

4.2.4 Data analysis

Descriptive statistics (median, range) were used to summarise identification of employment outcome at all time points and key variables, such as gender, age group, injury type, AIS group, pre-injury education level, pre-injury occupation type, relationship status and compensation status. Chi-square analysis was used to test for differences between participants in and out of the labour force at time point three for the previously specified categorical variables, such as education history and relationship status. This audit data was also compared against data from Study Three, and the results of this analysis are fully described in Chapter Five.

4.3 RESULTS

Medical records, including all volumes of paper and electronic medical record, were obtained via the patient unique identifier for the 100 eligible cases. These admissions spanned the time period from 1 July 2005 until 17 December 2008. Paper records had between one and six volumes (approximately 600 pages per volume) and, when combined with a review of the electronic medical record, took an average of 20 minutes to audit. At a minimum, the audit included locating and reviewing the medical discharge summary, the occupational therapy and physiotherapy discharge summary, and surveillance clinic reports, which spanned a period from one to 11 years after inpatient discharge. Upon review, two cases at discharge had a classification of AIS E SCI (no persisting neurology) and were removed from the data set. Another four cases had deceased after discharge. Data for these cases were collated where it was available and otherwise treated as missing data. Subsequently, data relating to employment status were available for n = 98 at discharge from inpatient rehabilitation, n = 84 (85.7%) at 12 months post-discharge, and n = 69(70.4%) between two and five years following discharge. Outcome data were available for a further n = 55 (56.1%) beyond five years post-discharge. Figure 5 reports on the data available at each time point.



Figure 5. Flowchart for file selection in Study Two: Audit of medical records prior to

implementation of the EIVR program

Descriptive statistics for *N* = 98 cases are summarised in Table 8. The demographics of this cohort appear similar to the general population of people with traumatic SCI (Norton, 2010). The duration of initial care (DIC) for complete tetraplegia was a median of 260 days, with 150 days for complete paraplegia. The range (expressed as the 5th and 95th percentile) was 171–407 days for complete tetraplegia and 101–236 days for complete paraplegia. The median DIC for incomplete tetraplegia and paraplegia was 140 (ranging 32–428) days and 113 (73–192) days respectively.

The audit collected approximately 560 unique data entries. These were predominantly obtained from the surveillance clinics, and secondly from the correspondence section of the file (for example, a specialist letter or return to work report). Of the 560 data entry points, at least 100 did not include a report of employment status. That is, a person attended the clinic, but no notation was available in the surveillance clinic report in relation to employment. Examples of the type of data collected that related to employment status are shown in Figure 4.

Table 8

Descriptive statistics for N = 98 participants in Study Two: Audit of medical records prior to

implementation of EIVR program

Ν (SD) mean Age at injury (years) 98 32.74 (13.38) 0–15; 16–30; 31–45 78 46-60; 61-75; 76+ 20 n % Sex Male 83 84.7 Female 15 15.3 Severity of SCI neurology C1–C8 AIS¹ A, B or C 30 30.6 T1–S5 AIS A, B or C 45 45.9 AIS D any level 23.5 23 Injury type Tetraplegia 43 43.9 Paraplegia 55 56.1 Compensation status Insured 59.2 58 Public/uninsured 40 40.8

Demographic data (N = 98)

Relationship status at injury

52	53.1	
46	46.9	
19	19.4	
79	80.6	
76	77.6	
22	22.5	
11²	11.2	
22	22.5	
76	77.6	
	52 46 19 79 76 22 11 ² 22 76	 52 53.1 46 46.9 19 19.4 79 80.6 76 77.6 22 22.5 11² 11.2 22 22.5 76 77.6

*Notes.*¹ AIS American Spinal Injury Association Impairment Scale.

 2 n = 3 cases were in the labour force while also studying.

The data shows that at discharge, 3.1% (95% CI [0.6–8.7]) of cases were working (n = 3), while by one year post-discharge, 23.5% (95% CI [15.5–33.1]) had returned to or gained employment (n = 23). At the third time point of between two and five years after injury, 20.4% (95% CI [12.9–29.7]) of cases had reportedly returned to the labour force (n = 20). An additional twelve cases (12.2%) had experienced employment over the duration of the audit period, however, for a variety of reasons the employment was not sustained. Reasons that were clear in the data narrative included being 'laid off' or retiring. Other reasons were unclear or not reported. Five cases had returned to or commenced study following their SCI.

The median duration of SCI at the last data entry was six years post-injury (range 1–11 years). At this time, n = 27 (27.6%) of the original cohort (n = 98) were in paid employment, and 18 of these people (66.7%) had returned to work with their pre-injury employer. Of the people who had been in full-time employment prior to their SCI, n = 26 (34.2%) had returned to the labour force again. There was insufficient and at times ambiguous detail reported in the medical record about the type (role) of work and the number of hours people were employed per week, and therefore an accurate report of this level of information cannot be provided as part of this audit. Where there had been a report of returning to work over the duration of the audit, regardless of whether it was maintained or not (n = 34), this had occurred on average 1.93 years following onset of SCI.

Differences between all categorical variables and the primary outcome measure of employment status are presented in Table 9. At time point three, chi-square tests for independence shows that there were no significant differences between the group in the labour force and all others across all categorical variables, except for funding status χ^2 ((1, *n* = 69) = 3.9, *p* < 0.05, *phi* = -.273) and occupation type χ^2 ((1, *n* = 69) = 11.8, *p* < 0.05, *phi* = .45). Being in the labour force was correlated with having no compensation and having had a more professional occupation pre-injury.

Table 9

Comparison of demographic and injury data (n = 69) with labour force participation at time point three in Study Two: Audit of medical records prior to implementation of the EIVR program

	In labour force at time point three					
	yes		no			
	cases	0/	cases	0/	n valua	
Age at injury (years)	П	/0		/0	pvulue	
0–15; 16–30; 31–45	15	21.7	40	58	0.771	
46–60; 61–75; 76+	5	7.3	9	13		
Severity of SCI neurology ¹						
C1–C4 AIS ² A, B or C	0	0.0	4	5.8	-	
C5–C8 AIS A, B or C	2	2.9	16	23.2		
T1–S5 AIS A, B or C	12	17.4	22	31.9		
AIS D any level	6	8.7	7	10.1		
Injury type						
Paraplegia	14	20.3	25	36.2	0.240	
Tetraplegia	6	8.7	24	34.8		
Relationship status						
In relationship	12	17.4	26	37.7	0.796	
Single	8	11.6	23	33.3		
Compensation status						
Insured	8	11.6	34	49.3	0.046*	
Public/uninsured	12	17.4	15	21.7		

Education level pre-injury

Higher (tertiary)	7	10.1	7	10.1	0.107
Lower	13	18.8	42	60.9	
Occupation type pre-injury					
Professional	11	15.9	6	8.7	0.001*
Trade or unskilled	9	13	43	62.3	

Notes. * p < 0.05 (2-tailed) for chi-square.

¹No *p* value: violated assumption of minimum expected cell frequency.

² AIS: American Spinal Injury Association Impairment Scale.

4.4 DISCUSSION

This audit aimed to establish an employment outcome for all eligible cases that were admitted to Austin Health for rehabilitation following a traumatic SCI from July 2005 till December 2009. Findings from the audit are discussed in this section. Demographic and injury-related data was obtained for 98 cases, where admissions spanned from July 2005 until December 2008. Employment data was established for 69% of the study cohort at the third time point of between two and five years following discharge. The calculated rate of employment for all cases at this time was 20.4%, which is less than the commonly reported rate of 35–40% for people with SCI, as discussed in Chapter One (Trenaman et al., 2014; Young & Murphy, 2009). Two important findings included a relationship between employment status and funding status, and also a relationship between employment status and pre-injury occupation type. Limitations of the audit are also discussed in this section.

From the audit of medical records, a significant relationship was found between being in the labour force and an individual's compensation status, with comparatively more people

employed who were uninsured than insured. As described in section 2.5.1, the direction of influence around compensation and employment outcome is inconsistent across existing literature (Ottomanelli & Lind, 2009), and hence it is important to describe the funding arrangements that occur in various international environmental contexts. There is no prior published empirical data that explores the relationship between funding arrangement and employment outcome in Victoria, Australia. The findings from the records of the cohort in the present study are, however, consistent with anecdotal opinion (Leggat et al., 2007; Piccenna et al., 2015) about lower return to work rates for people who have access to compensation and associated income benefits.

A significant association was also found between having a higher level of professional occupation pre-injury and returning to the workforce following injury. This may have been related to the high proportion of people (14 of 20 at time point three) returning to their pre-injury employer. There was not an association, however, between employment and a higher education level, despite this being a common predictor of employment outcome (Ottomanelli & Lind, 2009) and being naturally associated with professional worker roles. The lack of statistical significance regarding education level may have been related to insufficient power in the sample size and the low (n = 20) actual numbers of people who did return to work.

4.4.1 Limitations

The audit was limited by several factors, including the number of individuals attending the surveillance clinics where data was collected, and the level of detail recorded by clinicians. The introduction of an occupational physician to meet/work with individuals was also a potential confounding of the data. The quality of data available was itself limited by the rate of individuals' attendance at the annual surveillance clinic. The availability of data postdischarge gradually reduced as a result of decreased attendance among individuals at the outpatient clinics, however, data for 69% of cases were still available at two to five years post-discharge. Reasons for attrition appeared to include personal choice not to attend or that the person had moved interstate or overseas. Completion of the work section of the clinic proforma was also variable, and when it was completed, the type and level of detail recorded was inconsistent. As described earlier, the purpose of the surveillance clinic is to monitor the health of the individual with SCI, as this has been demonstrated to be effective in the reduction of secondary complications (Bloemen-Vrencken, Post, Hendriks, De Reus, & De Witte, 2005; R. J. Cox, Amsters, & Pershouse, 2001). It may be that clinicians and/or the person attending the clinic do not recognise the importance and value of employment in relation to health and wellbeing, and therefore there is lower motivation to complete the section. Time pressures to finish the consultation may also result in the information being left out.

The latter years of the audit coincided with planning activity in relation to the proposed service changes, including discussion with the cohort about early provision of vocational

rehabilitation and the benefits of employment on health and wellbeing. Part of the cohort were also exposed to a 12 month pilot, which offered a consultation with an occupational physician early (within one month) in a person's inpatient rehabilitation. An occupational physician is a consultant specialist doctor who can advise on a range of services relating to the health of workers or employers (Pearson, 1980). The pilot ran for the 2008/2009 financial year and was only available for claimants of the state's transport accident insurance scheme, (known as the Transport Accident Commission). A total of seven cases were offered an occupational physician consult out of a total of n = 58 insurance claimants within the audit. It is possible that the audit results were influenced by a change in awareness about the importance of employment for wellbeing and by specific interventions encouraging return to work outcomes.

4.5 CONCLUSION AND IMPLICATIONS

Despite the study's limitations, data collected in the audit gives an indication of employment outcomes for people following traumatic SCI in the five years prior to the introduction of the EIVR program at Austin Health. Employment rates have been calculated as being at 20.4%, which is approximately 15–20% below commonly reported rates (Trenaman et al., 2014; Young & Murphy, 2009). This discrepancy may be due to the lack of individualised and systematic support to address a return to employment after SCI. The data from this audit can be compared with longitudinal outcomes for people who participated in the EIVR program after service changes. This will be explored in Chapter Five as a means of

gaining insights to the impact of the EIVR program on employment rates for people following SCI.

CHAPTER FIVE

5 STUDY THREE: LONGITUDINAL EMPLOYMENT OUTCOMES FROM AN EARLY INTERVENTION VOCATIONAL REHABILITATION PROGRAM FOR PEOPLE ADMITTED TO REHABILITATION WITH A TRAUMATIC SPINAL CORD INJURY

A version of this chapter has been accepted for publication in the journal Spinal Cord. A co-author declaration and copy of the manuscript are provided in Appendix H and Appendix I respectively.

Hilton, G. M., Unsworth, C. A, Browne, M., Murphy, G. C., & Olver, J. (2017).

Longitudinal employment outcomes of an early intervention vocational rehabilitation service for people admitted to rehabilitation with a traumatic spinal cord injury. *Spinal Cord*. (March 14), doi:10.1038/sc.2017.24

5.1 INTRODUCTION

For most people who experience a traumatic SCI, gaining or returning to durable employment is a significant achievement (Trenaman et al., 2015), and as previously described, it can be considered as a measure of rehabilitation success (Young & Murphy, 2009). Re-engagement in vocational roles has a positive influence on quality of life (Manns & Chad, 2001) and is held to be an important part of the adjustment process following injury (Boschen et al., 2003; Schonherr et al., 2004). The previous chapter identified longer term employment outcomes for people admitted with SCI to the Victorian Spinal Cord Service (VSCS) between 2005 and 2010. It was apparent, despite the health-promoting nature of work (McKee-Ryan et al., 2005) and the vocational potential of people with SCI (Young & Murphy, 2009), that employment rates after injury generally remain very low in this cohort (Schonherr et al., 2004). Earlier in this thesis, a rate of around 35–40% employment in developed nations for people with SCI was described (Trenaman et al., 2015; Young & Murphy, 2009), in cases involving no specific vocational intervention. Previous literature reporting post-injury vocational achievement has focused on calculating crude employment rates following SCI (Ottomanelli & Lind, 2009; Schonherr et al., 2004) and examining the personal factors relating to employment outcomes, such as the individual's level of education, pre-injury worker role, psychological traits and physical functioning (Ottomanelli & Lind, 2009). However, relatively little is known regarding change in employment outcomes over time or contextual factors that may influence the likelihood of individuals returning to work. These factors include access to social support, funding and compensation arrangements, the geographical area where the individual lives including amenities and infrastructure), and the use of vocational services (Trenaman et al., 2014).

Novel forms of vocational intervention are required to support people with SCI in returning to work. These should be accessible, individualised, flexible, and ultimately capable of meeting the multifaceted rehabilitation requirements of people with SCI (Roels et al., 2016). As outlined in Chapter Two, there is some evidence that supports the effectiveness of evidence-based supported employment (EBSE) for people with SCI (Ottomanelli, Barnett, & Goetz, 2014), but it is limited to the veteran population in the United States and people who have lived with SCI for several years. Early vocational rehabilitation interventions targeting individuals soon after injury have shown potential for enhancing post-injury labour force participation (Middleton et al., 2015). The potentially crucial role of an early vocational

service is also suggested by Krause (2003), who noted that it can take time for people to reach their vocational potential following SCI, particularly if an early window of opportunity is missed.

Therefore, the specific aims of this study were: 1) to explore employment outcomes at three follow-up time points for people who received the EIVR program at Austin Health between 2010 and 2013; and 2) to explore the relationships between employment outcomes over time with aspects of functioning (physical and pain), activities and participation (psychological distress, social participation, relationships, pre-injury education and pre-injury worker role), and contextual personal and environmental factors (emotional wellbeing, social support, funding arrangement and where one lives). A third aim was to compare the employment rate post-implementation of the EIVR program with the rate of employment documented from the medical record audit before the service changes, as reported in Chapter Four.

5.2 METHOD

5.2.1 Study design

The current study was a longitudinal cohort design, following a group of people who had received the EIVR program as part of the Spinal Community Integration Service (SCIS) attached to the Austin Health's SCI Rehabilitation Unit. The EIVR program was described in Chapter One.

5.2.2 Participants

Participants eligible for recruitment to the study had all sustained a new traumatic SCI, were residents of the state of Victoria, of working age at the time of injury (between 15 and 65 years), and admitted for inpatient rehabilitation with the VSCS between the years 2010-2013. Individuals were not eligible for the study if they had a comorbidity of significant brain injury or cognitive impairment or a lack of English that would limit their ability to participate. People also became ineligible for the study if they were discharged from SCIS to a high-level care facility or interstate destination. All consecutive admissions of people with SCI who met the inclusion criteria were approached to participate in the study. All of these potential participants accepted and were enrolled in the study (N = 97) early in their admission to inpatient rehabilitation. Baseline data (time point one) were collected for all participants at discharge from inpatient rehabilitation. Data were available for 74 (76.3%) people at the second time point (12 month following discharge) and for 60 (61.9%) people at the third and final time point (2+ years following discharge). Fourteen people (14.4%) declined to participate in data collection at the final time point, and n = 23 (23.7%) were unable to be contacted (two of whom were deceased). At least two individuals who declined to participate at this time point stated they were too busy, due to being in ongoing employment. Figure 6 reports on the sample sizes and data collection at different time points. Demographic data of the participant cohort is available in Table 8.



Figure 6. Flowchart for recruitment in Study Three: Longitudinal employment outcomes of

the EIVR program

Table 10

Demographic data for N = 97 participants in Study Three: Longitudinal employment

Ν mean SD Years since injury, mean (SD) 3.499 97 1.08 Age at injury (years) 97 35.1 -14.91 0–15; 16–30; 31–45 72 46-60; 61-75; 76+ 25 n % Gender Male 79 81.4 Female 18 18.6 Severity of SCI neurology C1–C8 AIS¹ A, B or C 33 34 T1–S5 AIS A, B or C 45 46.4 AIS D any level 19 19.6 Impairment level Tetraplegia 43 44.3 Paraplegia 54 55.7 Compensation status Insured 51 52.6 Public/uninsured 46 47.4

outcomes of the EIVR program

Education level pre-injury

Higher (tertiary)	16	16.7
Lower	80	83.3
Occupation type pre-injury		
Professional	27	34.6
Trade or unskilled	51	65.4

Note. ¹AIS American Spinal Injury Association Impairment Scale

5.2.3 Instruments

Data collection occurred at three time points: discharge from inpatient rehabilitation (time point one); 12 months following discharge (time point two); and at least two years following discharge (time point three). Basic demographic and injury data were collected at baseline. This included age, gender, relationship status, neurological level of lesion (including American Spinal Injury Association Impairment Scale (AIS) definitions), impairment type (tetraplegia, paraplegia), compensation availability, residential location, living arrangement, and estimates of care and support (hours of paid and unpaid care required in a typical day). Information about where someone lived was then converted to a geographical area, or Statistical Local Area (SLA), an Australian standard of geographical classification. SLA can be used in geographical information systems for analysis against other available government data, such as area remoteness, area economics, labour force activity and ease of access to amenities (Australian Urban Research Infrastructure Network, N.D.). For simplicity, geographical area was dichotomised into regional or metropolitan. On aggregation,
metropolitan areas have a lower level of remoteness and a higher level of socioeconomic status, labour force activity and ease of access to amenities.

Vocationally-related data included pre-injury education background (highest level achieved), type of occupation (professional, manual labour, etc.) and employment status. As before, employment was defined as ≥ one hour of paid work and was recorded from selfreport as full-time (over 35 hours per week), part-time variable, part-time fixed, and also as a dichotomous variable of being in the labour force versus all others. Any changes in demographic or injury data were noted at follow-up time points. (A copy of the data collection sheet is provided in Appendix J). Several self-rated standardised scales of psychosocial functioning were used as indices of rehabilitation progress at all three data collection points, as described below.

Numeric Pain Rating Scale: An 11-point numeric pain rating scale was used as a measure of pain intensity, where participants were asked to rate their experience of pain on a scale of 0–10, with 0 being no pain and 10 being the worst possible pain. Numeric pain scales have demonstrated their validity as measures of pain by their strong association with other measures of pain intensity, as well as by their responsivity to treatments known to impact pain (Jensen & Karoly, 1992). (See Appendix K.)

Hospital Anxiety and Depression Rating Scale (HADS): The HADS is a 14-question, four point, self-report rating scale designed to assess depressive and anxiety symptoms in patients with medical illnesses. Preliminary findings support the psychometric integrity of the HADS in an outpatient population with SCI (Woolrich, Kennedy, & Tasiemski, 2006). Separate subscale

scores ranging from 0 to 21 for depression (HADS-depression) and anxiety (HADS-anxiety) can be derived. Higher scores indicate greater psychological distress. (See Appendix L.)

The Personal Wellbeing Index (PWI): The PWI is a self-report scale developed as a measure for subjective wellbeing and holds high cross-cultural validity (Geyh, Fellinghauer, Kirchberger, & Post, 2010). Part One of the PWI can be used as a single-construct measure of Global Life Satisfaction, while Part Two is a multi-item Life Satisfaction Domain scale. The statements use an 11-point (0–10) end-defined response scale, addressing domains such as health, relationships, future security and personal achievement (International Wellbeing Group, 2013), to produce a final score of between 0 and 100. Higher scores indicate greater subjective wellbeing. (See Appendix M.)

Spinal Cord Independence Measure (SCIM): The SCIM measures self-care, respiration, sphincter management, and mobility. It consists of 16 questions with a final score ranging between 0 and 100 (SCIM-total). Higher scores indicate greater functional independence. SCIM has been shown to be a reliable and valid measure of functional status for people with SCI (Itzkovich et al., 2007). (See Appendix N.)

Impact on Participation and Autonomy Questionnaire (IPAQ): The IPAQ is a generic outcome measure designed for adults with a range of conditions. The English version (Kersten et al., 2007) contains 32 items that create five subscales: autonomy indoors, family roles, autonomy outdoors, social life and relationships, and work and education. Each subscale is averaged to produce a median score from 0–4. Additionally, a total 32-item score can be derived. A lower score on the IPAQ suggests greater perceived autonomy and participation.

The questionnaire takes approximately 20 minutes to complete and can be selfadministered. It has been found to be a reliable and valid instrument for assessing autonomy and participation for people with chronic disorders including SCI (Cardol, de Haan, de Jong, van den Bos, & de Groot, 2001). Since participants in this study were soon to be discharged inpatients at the time of the first data collection, the IPAQ was collected at the second and third time points only. (See Appendix O.)

5.2.4 Procedure

Ethical approval for this study HREC/14/Austin/256 was obtained from the hospital and university Human Research Ethics Committees (See Appendices P and Q). The researcher certifies that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

The SCIS program manager was responsible for screening eligible individuals for recruitment to the research and for obtaining their informed consent. This was done in close consultation with the inpatient treating team. If an individual chose not to participate in the research, they would still receive standard care. A member of the SCIS was responsible for collecting measures with the participants at the first and second time points, as documented above. At the second data collection (12 months following discharge from inpatient rehabilitation), formal involvement with the SCIS ceased. The thesis researcher then contacted participants by mail and telephone to complete a further follow-up at least two years after injury (time point three). Participants were offered a \$20 department store gift voucher to thank them for their time in completing the third round of data collection. Finally, an audit of medical records was undertaken as an alternative method of collecting basic data regarding the most recent report of employment status for people who did not complete the final data collection at 2+ years following discharge. This was reported in Chapter Four, and the analyses undertaken with this data are described below. A diagram depicting the recruitment period for Studies Two and Three is shown in Figure 7.



Figure 7. Visual representation of timeline for recruitment phases for Studies Two and Three, pre- and post-implementation of the EIVR program

5.2.5 Intervention

The EIVR program as part of SCIS was outlined in section 1.3.7, with further details provided in Appendix B. In summary, the EIVR program was initiated with eligible participants within two to four weeks of their admission to inpatient rehabilitation. The vocational rehabilitation professional remained involved with the participants, as per the EIVR program guidelines in Table 3, for up to one year following discharge.

5.2.6 Data analysis

Chi-square analysis was used was an initial test for systematic attrition bias. Differences between people who were included in the study but without 2+ year follow up and people who had 2+ year follow up were explored, on categorical variables of gender, age group, injury type, AIS group, pre-injury education level, pre-injury occupation type, compensation status and geographical area for time point one.

Descriptive statistics (means, *SD*) and comparison between the groups of 'in the labour force' and 'all others' were undertaken. This included summarising key variables such as age, gender, compensation status, neurological level of injury, education, pre-injury employment type, geographical area, function (SCIM-total score), perceived pain (Numeric Pain Rating Scale), psychological distress (HADS anxiety and depression), social participation (IPAQ subscales), and subjective wellbeing (PWI) at each time point, using means and standard deviations where applicable. In addressing this study's first research question about employment outcomes for people receiving the EIVR program, chi-square analysis was used to test for differences between participants in and out of the labour force preinjury and at the three time points post-injury for the categorical variables of gender, age group, injury type, AIS group, pre-injury education level, pre-injury occupation type, compensation status and geographical area (Statistical Local Area). A Mann-Whitney U Test was used to compare years since injury in participants in and out of the labour force at the final time point.

The second research question investigated in the current study related to the identification of relationships between employment outcomes and variables described according to the ICF. Aspects of functioning under consideration included injury characteristics, physical status (SCIM-total score) and pain (Numeric Pain Rating Scale). Variables relating to activities and participation included psychological distress (HADS anxiety and depression), social participation (IPAQ total), relationship status, pre-injury education, and pre-injury worker role. Variables measured as contextual personal and environmental factors included subjective wellbeing (PWI), social support (IPAQ subscale social life and relationships), funding arrangement, and geographical area (Statistical Local Area) over the three time points. Interdependence between the variables was determined with Spearman's correlation coefficient. As suggested by Craig et al., (2015) a dichotomised value for social participation was established using the mean IPAQ total score of the sample. That is, values equalling the mean score or less were indicative of high social participation, and values greater than the mean were indicative of low participation.

A regression analysis was undertaken to investigate possible predictors of employment status in recovering patients. Owing to the relatively low ratio of participants to independent variables (IVs), each IV was treated in a separate regression model. This approach was taken because the inclusion of all IVs and time point IV interactions would result in an unacceptably high number of degrees of freedom in the model. Therefore, reported beta coefficients do not reflect co-variation between predictors. Accordingly, a simultaneous multiple logistic regression was also conducted. Each model also included an effect for time (discharge, 12 months, 2+ years), and a time point IV interaction term.

Generalised linear mixed effects models (GLMEs) with a binomial error distribution and a log link (Bates, Machler, Bolker, & Walker, 2014) were employed, in order to manage the repeated measurements and the binary response. Apart from the fixed effects, each GLME also included a random intercept for participant. All analyses were conducted in the R statistical programming environment (R Development Core Team, 2008). Data collected in the audit of medical records were included in this analysis and the GLMEs.

The third aim of this study was to compare employment rates following the implementation of the EIVR program with the rate of employment that was drawn from the medical record audit in Study Two. The audit pertained to data obtained from medical records for admissions to the VSCS from July 2005 until late 2009. The findings of the audit were presented in Chapter Four. Descriptive statistics were used to compare the demographic and injury characteristics of the two cohorts: that is, cases reviewed in the medical record audit and participants in the EIVR program longitudinal study. Chi-square analysis was then used to test for differences in the employment rate between the two groups at equivalent time points. These time points, as before, were at discharge, 12 months after discharge and between two and five years following discharge.

5.3 RESULTS

The mean duration of SCI at the final time point was 3.50 (±1.08 years). Figure 6 demonstrates the sample sizes and data collection at different time points. Employment status was obtained for all of participants at time point three, either via self-report for study

participants (n = 60) or from audit for non-respondents (n = 37). At time point three, n = 32(33%, 95% CI [24%-42%]) of the total cohort (N = 97) were in paid employment. A chisquare test for independence to examine attrition bias indicated no significant differences between the demographic characteristics of study participants and non-respondents at the final time point, except for pre-injury education level χ^2 ((1, n = 96) = 6.5, p < 0.005). People with a lower pre-injury education level were less likely to respond. Twenty-five (78.1%) of the people employed at the final time point had been in full-time employment prior to their SCI, of whom 13 (40.6%) returned to full-time employment (n = 1 on leave), and 12 (37.5%) were in part-time employment. Of the three who were employed part-time pre-injury, one (3.1%) went into full-time employment post-injury and two (6.3%) remained in part-time employment post-injury. Four participants had not been employed prior to their injury and found part-time employment following discharge. Three participants re-engaged in employment following their injury, but for various reasons this was not maintained two to five years after discharge. One of these individuals sold their business once they were discharged from rehabilitation, and another two decided to cease their existing employment to investigate other career paths.

The duration of initial care (DIC) for complete tetraplegia for participants in Study Three was a median of 284 days, with 140 days median for complete paraplegia. The range (expressed as the 5th and 95th percentile) was 193–602 days for complete tetraplegia and 80–295 days for complete paraplegia. The median for incomplete tetraplegia and paraplegia was 217 (ranging 62–339) days and 112 (76–221) respectively.

Descriptive statistics and comparison between all categorical variables and the primary outcome measure of employment status are presented in Table 11. It shows that there were no significant differences between the groups 'in the labour force' and 'all others' across all categorical variables at the final time point, except for education level χ^2 ((1, n = 96) = 6.4, p < 0.01). A Mann-Whitney U Test revealed no significant difference in the years since injury for those people in the labour force (Md = 3.1, n = 32) and all others (Md = 3.8, n = 65), U = 889.5, z = -1.156, p = .248, r = -0.112.

Table 11

Comparison of demographic and injury data (N = 97) with labour force participation at time point three in Study Three: Longitudinal employment outcomes of the EIVR program

	In labour force at time point three							
	yes		no					
	cases		cases		p <i>value</i>			
Years since injury, mean (SD)	3.32	(1.16)	3.58	(1.04)				
	Ν	%	N	%				
Age at injury (years)								
0–15; 16–30; 31–45	24	24.7	48	49.5	1.00			
46–60; 61–75; 76+	8	8.3	17	17.5				
Severity of SCI neurology								
C1–C8 AIS ¹ A, B or C	11	11.3	22	22.7	0.43			

T1–S5 AIS A, B or C	17	17.5	28	28.9	
AIS D any level	4	4.1	15	15.5	
Compensation status					
Insured	14	14.4	37	38.1	0.32
Public/uninsured	18	18.6	28	28.9	
Education level pre-injury					
Higher (tertiary)	10	10.4	6	6.3	0.01*
Lower	21	21.9	59	61.5	
Occupation type pre-injury					
Professional	11	14.1	16	20.5	0.56
Trade or unskilled	16	20.5	35	44.9	

Notes. * p < 0.05 (2-tailed) for chi-square

¹AIS American Spinal Injury Association Impairment Scale

The relationship between personal characteristics at the different time points was investigated using Spearman's correlation coefficient. Correlations for all continuous and dichotomised categorical variables with the dichotomous variable of employment status ('in the labour force' versus 'all others') are shown for the final time point in Table 12.

In order to include the total IPAQ score in analysis as a measure of social participation, the mean score in the current study of 61.11 (*SD* 21.03) was used to dichotomise this variable. Therefore, scores of 61 or below were used to indicate high levels of social participation (n = 33), and scores above 61 were considered to represent low levels of social participation (n = 28).

Across the three times points, there were several strong, statistically significant correlations between variables. At time point three (2+ years post-injury), the dichotomised variable of social participation was positively associated with subjective wellbeing $r_s = .692$, n = 60, p <0.0005 and negatively associated with anxiety $r_s = -.522$, n = 61, p < 0.0005, depression $r_s = -.643$, n = 61, p < 0.0005 and pain $r_s = -.427$, n = 60, p < 0.0005. Higher levels of perceived participation and autonomy were correlated with high levels of subjective wellbeing, low anxiety and depression scores, and a low rating of pain. The full correlation matrix between variables at the final time point is presented in Table 12.

Table 13 shows odds ratios, beta coefficients and associated standard errors for the binomial GLMEs predicting employment status from covariates. Education status (p < 0.01), relationship status (p < 0.05), and total PWI score (p < 0.05) were reliably associated with being employed post-injury. No time-varying effects were significant at the p < 0.05 criterion. The most powerful predictor (holding a degree pre-injury) was associated with an eightfold increase in the odds of being employed at the final follow-up point. Being in a relationship at the time of injury was another strong predictor of returning to work, being associated with increased odds of being in employment of more than 350%. General health and wellbeing scores at the time of discharge were associated with a significant, but much smaller, increase in the odds of post-injury employment (OR = 1.8).

Based on the strength of their individual predictive ability, relationship status (at time point one), pre-injury education level and subjective wellbeing were entered into a logistic regression model over the different time points. The model for predicting a labour force

outcome at the third time point was statistically significant, being χ^2 (3, n = 79) = 11.663, p = .009. The model as a whole explained 13.7% (Cox and Snell R square; (D. R. Cox & Snell, 1989)) and 18.9% (Nagelkerke R squared; (Nagelkerke, 1991)) of the variance in employment status, and it correctly classified 68.4% of cases. When controlling for all other factors, the strongest and statistically significant predictor of being in the labour force in this model was being in a relationship, recording an odds ratio of 3.406 (95% CI [1.197–9.697]), p = 0.022.

Table 12

Spearman's rho correlations between measures of psychological, physical (injury data) and personal (age, education background, employment background) characteristics, functional status, subjective wellbeing, perceived pain and social participation at time point three (2+ years post-discharge), Study Three: Longitudinal employment outcomes of the EIVR program

Measure	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Age at injury	-	009	093	103	.223*	.178	050	.006	.577**	013	.126	286*	062	.147	161
2. Injury type (para/tetra)		-	.534**	108	113	048	.058	011	.027	.141	056	.366**	058	.305*	152
3. Neurological level (AIS)			-	017	141	072	.058	137	.037	.275*	077	.694**	110	.256*	045
4. Funding status				-	.019	.210	.008	.063	279*	.015	102	.241	.046	330*	.173
5. Pre-injury education level					-	.630**	.298	.181	.058	.080	.056	019	071	.071	162
6. Occupation type pre-injury						-	.172	.076	.082	.242	.167	.112	202	067	329*
7. Where living							-	.130	014	010	182	.222	.086	047	035
8. Employment status								-	.062	114	082	.096	.238	177	.010
9. Relationship status									-	.025	001	053	.108	005	.027
10. HADS Anxiety										-	.708**	.055	629**	.496**	522**
11. HADS Depression											-	292*	762**	.498**	643**
12. SCIM-total												-	.176	040	.217
13. Total PWI													-	485**	.692**
14. Numeric Pain Rating Scale														-	427**
15. Total IPAQ															-

Notes. * p < .05 (2-tailed).

** *p* < .001 (2-tailed).

Odds ratios, beta coefficients and associated standard errors for binomial GLMEs predicting employment status for groups 'in

			Ма	in Effect	Ti	Time Interaction				
		OR		<i>B</i> (SE)	OR	<i>B</i> (SE)	Nobs	N _{part}		
Occupation type (Professi	onal)	2.46		.90 (.64)	1.19	.17 (.49)	226	78		
Gender (Female)		0.78		25 (.77)	0.59	53 (.77)	281	97		
Age (46+)		2.12		.74 (.65)	0.48	53 (.60)	281	97		
Education (Tertiary)		8	**	2.08 (.77)	2.41	.88 (.59)	278	96		
Relationship Status (In relationship)		3.71	*	1.31 (.58)	0.33	-1.10 (.59)	268	95		
Location (Urban)		0.91		09 (.58)	1.38	.32 (.45)	281	97		
Finding Status (Uninsured)	2.27		.82 (.58)	1.55	.44 (.46)	281	97		
Injury Type (Paraplegia)		0.84		18 (.58)	0.76	28 (.45)	281	97		
Total PWI		1.8	*	.59 (.29)	1.31	.27 (.30)	204	89		
SCIM total		0.96		.45 (.32)	1.57	04 (.29)	210	89		
Total Care		0.89		12 (.26)	0.74	30 (.25)	198	87		
Numeric Pain Rating Scale	9	0.88		13 (.27)	0.73	32 (.29)	176	85		
HADS Anxiety		0.53		63 (.36)	0.92	08 (.29)	188	88		
HADS Depression		0.63		45 (.28_	0.96	.04 (.29)	188	88		
Neurological Level (AIS)	C1-C8	Ref		Ref	Ref	Ref				
	T1-S5 ABC	1.92		.65 (.68)	0.66	08 (.84)	281	97		
	AIS D	0.66		41 (.54)	0.59	65 (.67)	281	97		
Total IPAQ		3.49		1.25(.85)	0.32	-1.11 (1.05)	136	84		

the labour force' versus 'all others', Study Three: Longitudinal employment outcomes of the EIVR program

Notes: **P* < 0.05, **P < 0.01.

Each row in the table corresponds to a separate regression model

Demographic and injury characteristics between the audit group and study participants receiving the EIVR program were comparable and are shown in Table 14. The employment rate pre- and post-service changes at two to five years post discharge was 23% for the audit cases and 33% for the cohort who received the EIVR program. Chi-square testing for independence to examine differences between the two sets of participants before and after the EIVR program implementation indicated no significant differences, except for employment rate at time point one, χ^2 (1, n = 194) = 3.93, p < 0.05, phi = 0.16.

Table 14

Comparison of labour force participation, demographic and injury characteristics before

and after the EIVR program implementation

	Before (Audit)	After (EIVR)	p value
Employment status, time point one	N = 98	N = 96	
In labour force	3	11	0.047*
All other	95	85	
Employment status, time point two	n = 84	n = 94	
In labour force	23	19	0.343
All other	61	75	
Employment status, time point three	n = 69	n = 97	
In labour force	20	32	0.705
All other	49	65	
Gender	n	n	
Male	83	79	0.679
Female	15	18	
Age at injury (years)			
0-15; 16-45	78	72	0.472
46-60; 60+	20	25	
Severity of SCI neurology			
C1–C4 AIS ¹ A, B or C	5	10	0.547
C5–C8 AIS A, B or C	25	23	
T1–S5 AIS A, B or C	45	45	

AIS D any level	23	19	
Injury type			
Paraplegia	55	54	1.000
Tetraplegia	43	43	
Compensation status			
Insured	58	51	0.433
Public/uninsured	40	46	
Education level pre-injury			
Higher (tertiary)	19	16	0.760
Lower	79	80	
Relationship status at injury			
In relationship	52	46	0.724
Single	46	47	
Occupation type pre-injury			
Professional	22	27	0.105
Trade and unskilled	76	51	

Notes. * p < 0.05 (2-tailed) for chi-square

** p < 0.01 (2-tailed) for chi-square

¹AIS American Spinal Injuries Association Impairment Scale

5.4 DISCUSSION

This study described the development, implementation and results of the EIVR program that was delivered as part of a hospital-led Spinal Community Integration Service. It aimed to identify employment outcomes for the study cohort and explore the relationship between employment-related outcomes and various personal and environmental factors in the five years following injury. In this study, 33% of the cohort had returned to employment by time point three. This post-injury employment rate is comparable to that which has been reported in other studies, with the rate being slightly lower than that found Middleton et al. (Middleton et al., 2015) and slightly higher than that found by Ottomanelli et al. (Ottomanelli, Barnett, & Goetz, 2014). With respect to reliable predictors of post-discharge employment, three influential factors were identified: pre-injury education, relationship status at time of injury, and self-reported wellbeing.

The post-discharge employment rate observed from the current early intervention program is comparable to that reported from the observational study by Middleton et al. (Middleton et al., 2015), who recently reported the outcomes of the delivery of their early vocational rehabilitation in an Australian acute and rehabilitation SCI setting when post-injury employment was assessed within one year post-discharge. At case closure (median three weeks post-discharge), 34.5% of participants had an employment outcome. This rate is consistent with that quoted in aggregated research of 35–40% (Young & Murphy, 2009). However, Middleton et al.'s (2015) employment achievements were reached within a much shorter timeframe post-injury than is usually investigated. While Middleton has commenced the process of researching early vocational rehabilitation in Australia, similar programs delivered into New Zealand acute spinal units since 2000 have been described but not been studied empirically. Hay-Smith et al. (2013) reported on the New Zealand EIVR service, known as Kaleidoscope, and described its aim as nurturing positive expectations of future community participation after a SCI, which is believed to be an important precursor to employment outcomes (Schonherr et al., 2004). Employment rates for people with SCI in

New Zealand have reportedly increased since Kaleidoscope's inception (Hay-Smith et al., 2013), but little detail regarding these claimed increases has been reported. The research work by Ottomanelli et al. (Ottomanelli, Barnett, & Goetz, 2014), Middleton et al. (Middleton et al., 2015) as well as Hay-Smith et al. (Hay-Smith et al., 2013) all suggests that vocational rehabilitation delivered early post-SCI warrants further investigation, as does determination of whether vocational outcomes are sustained beyond 12 months.

In determining whether certain functions, activities, participation levels and contextual factors would increase the likelihood of achieving an employment outcome over the duration of this study, three independent variables of relationship status, pre-injury education level and subjective wellbeing were identified, from which some causality may be inferred. Of these three variables, relationship status and subjective wellbeing are the only 'modifiable' factors, and consideration therefore needs to be given to these during inpatient and outpatient rehabilitation, and attention paid to the potential role of both variables in influencing employment outcomes. For allied health and nursing staff, the finding with respect to relationship status has implications for the ways that patients' level of post-injury social support is monitored and, if need be, strengthened. In many areas of injury rehabilitation, social support has been shown to be associated with superior rehabilitation outcomes (see, for example, Murphy et al. (2010)). Services to enhance the subjective wellbeing of those living with SCI have been extensively researched by Kennedy (2008), who has described programs that reliably improve patients' ability to cope effectively. It seems worthwhile to strengthen both of these areas of service provision in any hospital-based rehabilitation program.

While research on social support is relatively limited in the SCI population, Murphy et al. (Murphy et al., 2010) found that practical social support was the most frequently reported contributing factor to enabling positive employment outcomes following SCI. This has been further supported by findings of Burns et al. (2010), who established that in a self-selected group of 83 men, greater perceived social support from significant others was related to higher employment outcomes. Hence, further research to investigate the impact of environmental features, such as financial as well as social support, on employment outcomes achieved post-SCI appears to be well warranted.

The finding in the present study that a higher level of pre-injury education was associated with a higher likelihood of achieving an employment outcome is consistent with previous research. The trajectory study undertaken by Ferdiana and colleagues (2014) and discussed in Chapter Two reported that participants with secondary education were significantly more likely to gain steady employment outcomes as opposed to having low or no employment. While pre-injury education level is not a modifiable factor, these results emphasise the potential contribution that retraining and further education could make to an individual's journey post-SCI. This would particularly be the case if that person is on a likely trajectory of low or no employment.

Finally, the impact of time as a factor related to employment outcomes must be considered. Previous literature has described how employment rates increase gradually over time (Ferdiana et al., 2014; Young & Murphy, 2009), and even suggest that this is particularly the case if vocational potential is not addressed soon after injury (Krause, 2003; Murphy, 2009).

This longitudinal cohort study has begun to explore the temporal nature of returning to employment after SCI, and like Middleton et al.'s (2015) study, it has seen an earlier return to work than has previously been reported. There is value in further investigation of time as a factor in return to work outcomes. Such research, particularly if undertaken with a qualitative methodology, could track unique or unexpected events, or illuminate certain experiences (Sofaer, 1999). The qualitative study presented in Chapter Six explores people's experience of seeking, gaining and maintaining employment following SCI, and it examines time as a factor in returning to employment after SCI.

While the early return to employment following SCI was associated with higher subjective wellbeing, there was no relationship with other psychosocial outcomes. A relationship did exist for these variables with social participation, where higher levels of social participation were associated with high levels of subjective wellbeing, low anxiety and depression scores, and a low rating of pain. Although social participation was not a primary focus of this study, this finding is of interest given the known relationship between this variable and employment (Marmot & Wilkinson, 2005), especially as Craig et al. (2015) posit that social participation is a measure of adjustment following SCI. The literature consistently reports that employment is health-promoting (McKee-Ryan et al., 2005), yet it might be that early return to work, while overall being a positive step, is still fundamentally very difficult. At a practical level, there are many personal and environmental factors to be considered and addressed in the return to work process. The current study may be capturing a period of change and uncertainty as a person returns to employment or gains post-injury work that initially counteracts the expected benefits of being a worker. It may be valuable to explore

more thoroughly this complex dynamic and to consider in future research the relationship between employment and social participation, as suggested by Craig et al. (2015).

The comparison of employment rates pre- and post-service changes indicates that there were no significant differences in outcomes between the audit group and the EIVR program cohort, except at the first time point. At discharge from inpatient rehabilitation, 11.5% (n = 11) of participants had returned to employment. While one participant did not stay in the labour force (due to selling their business), the rate of employment is still higher compared to the audit group. There were also several interesting differences between the two groups that did not meet the criteria for statistical significance, most likely due to the small sample size. For instance, the EIVR program cohort had twice the number of participants who had sustained a high level tetraplegia (n = 10, C1–C4 AIS ABC) than the audit group (n = 5). While these sample sizes are too small to demonstrate an effect empirically, in the clinical environment, this difference would be considered anecdotally as important. In a review of characteristics associated with return to work, Ottomanelli and Lind (2009) suggest that employability is affected by the severity of disability. The odds of being employed appear greater for people with paraplegia than tetraplegia, and it can take longer for a person with tetraplegia to achieve an employment outcome (Ottomanelli & Lind, 2009).

There were several participants in each group who gained employment following injury, but they were unable to maintain employment through to the third time point. The number of cases in this situation was higher in the audit group (n = 12) compared with the EIVR program cohort (n = 5). While there are no apparent reasons for this difference, the

outcome may have been influenced by the input of the EIVR program. As the audit and longitudinal cohort research only investigated employment status up to five years following discharge, a further point of interest is whether or not employment outcomes in both groups were maintained beyond the research period.

5.4.1 Limitations and directions for further research

The study had a clear limitation in lacking a control group. However, to the author's knowledge, this is the first study to examine longitudinally the predictors of employment outcome following participation in an intervention program aimed at vocational rehabilitation. The study was originally designed to include a comparison group that would receive treatment as usual. However, for practical reasons, owing to different funding arrangements with compensable and non-compensable clients, a suitable comparison group could not be assembled (as described in Chapter Four).

A drop-out rate of n = 37 (38.1% of participants) over the three time points was another limitation, as this resulted in a relatively small sample size by the final time point. This dropout rate is equivalent to that reported by other similar longitudinal studies investigating this population (Pollard & Kennedy, 2007). However, although 37 participants in this study were lost to follow-up at the third time point, their employment outcomes were still able to be obtained through an audit of their ongoing medical record. There was also a small proportion of people who declined to participate at time point three due to

being 'too busy' as a result of employment. These people may have been happy workers, but unfortunately this data has not been captured.

A further potential limitation to this study was the existing culture in the inpatient rehabilitation setting and a possible lack of willingness to embrace the new early vocational rehabilitation intervention. Education was provided to clinical staff in anticipation of this barrier, as historical experience has shown that vocational rehabilitation is not a priority focus in the inpatient rehabilitation setting. Murphy (2009) and Ottomanelli et al. (Ottomanelli et al., 2009) have previously recognised this same issue. Anecdotally, as staff in the rehabilitation unit became more familiar with the EIVR program and observed individuals achieving employment outcomes (which included some people returning to work while still participating in inpatient rehabilitation), the rehabilitation hospital culture became more positive and supportive. This cultural shift over the duration of the study may well account for some of the variance in outcomes across the three time points.

Despite many similarities in the traumatic spinal cord injured population throughout the world (Bickenbach et al., 2013), the differences in local policy and service delivery create challenges in comparing or translating findings across countries and jurisdictions. However, the introduction of an early intervention approach to vocational rehabilitation, such as the one under investigation here, could be applied to other settings and is worthy of further investigation.

An important follow-up to this research would be to interview individuals about their experiences of seeking and gaining employment. Exploring the concepts of timing and

adjustment in relation to returning to work, coupled with identifying influential environmental and personal factors, could deliver further insights into the complexity of returning to work for people following traumatic SCI. A mixed methods study examining individuals' experience of seeking and gaining employment is presented in the following chapter.

5.5 CONCLUSION

This study explored employment outcomes for people receiving the EIVR program at Austin Health and considered the relationship between these outcomes and personal and environmental factors in the first two to five years following injury. The EIVR program shows promise of delivering equivalent return to work rates to those that have been reported in similar intervention studies conducted earlier after injury, although it is premature to claim to have reliably demonstrated effectiveness of this intervention. Several factors were identified that appear to help facilitate employment outcomes, including relationship status, subjective wellbeing and pre-injury education. These, and the relationship between social participation and employment outcomes, are worthy of further investigation, particularly in relation to how they may support the return to and maintenance of employment in this population in the future. The findings of this study can inform clinical practice, particularly in relation to the importance of maintaining pre-injury relationships and cultivating subjective wellbeing, in order to promote positive employment outcomes.

CHAPTER SIX

6 STUDY FOUR: THE EXPERIENCE OF SEEKING, GAINING AND MAINTAINING EMPLOYMENT AFTER TRAUMATIC SPINAL CORD INJURY AND THE VOCATIONAL PATHWAYS INVOLVED

A version of this chapter has been accepted for publication in the journal Work. A coauthor declaration and copy of the submitted manuscript are provided in Appendices R and S.

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6.1 INTRODUCTION

The previous chapter explored employment outcomes for people receiving the EIVR program at Austin Health and investigated the relationships between these outcomes and personal and environmental factors. An important follow-up to this longitudinal study was to interview people about their experience of seeking, gaining and maintaining employment post-SCI. Gaining durable employment is one of the most important indices of community re-integration following SCI (Schonherr et al., 2004). The benefits of returning to employment have been well documented and include financial independence and security. physical and psychological health and wellbeing, and improved self-efficacy and self-esteem (Clifton, 2014; Leiulfsrud, Ruoranen, Ostermann, & Reinhardt, 2016; Schonherr et al., 2004; Tomassen et al., 2000; Ville & Winance, 2006). It is also widely recognised, however, that achieving durable—that is, stable and permanent (International Labour Organization, 2013)—employment after SCI is difficult and involves the extensive navigation of multiple personal and environmental factors (as described in Chapter Five). As a result, durable employment rates remain low post-SCI (Trenaman et al., 2014; Young & Murphy, 2009) and the vocational potential of many people remains unrealised (Young & Murphy, 2009). While literature focused on gaining employment after SCI is extensive (Lidal et al., 2007; Ottomanelli et al., 2009; Ottomanelli & Lind, 2009; Trenaman et al., 2014; Yasuda, Wehman, Targett, Cifu, & West, 2002; Young & Murphy, 2009), there is a relatively limited amount of robust and rigorous qualitative research that can contribute to our understanding of this complex community integration goal. The systematic review of the literature presented in Chapter Three of this thesis focused on what we know of the experience of returning to work after SCI. It recommended further exploration of employment experiences across different environmental contexts, at varying time periods post-injury, and with respect to individual vocational pathways.

As discussed in Chapter Two, gaining employment involves the navigation of environmental factors, such as social policy and funding arrangements as well as the physical environment and societal attitudes, all of which can vary significantly across different countries and jurisdictions (K W Hammell, 2007). SCI management across environmental contexts can also differ, as demonstrated in Tables 1 and 2 in Chapter One. This potentially influences the individual experience of seeking, gaining or maintaining employment. Opinions in the literature vary regarding the access to and impact of insurance or social welfare on employment outcomes (Conroy & McKenna, 1999; Leiulfsrud et al., 2016; Paul et al., 2013). Chapin and Kewman (Chapin & Kewman, 2001) suggest that finding a balance between

different life demands and personal expectations helps to alleviate the influences of funding arrangements on decisions around returning to work. Further in-depth exploration of the impact of environmental factors across different countries and jurisdictions, as well as clear descriptions of the relevant insurance and social welfare policies, may draw a more comprehensive understanding of the phenomena around pathways to employment after SCI.

Existing qualitative literature on this topic has begun to expose the differing traits and experiences of people who have participated in employment following SCI compared with people who are unemployed (Bergmark et al., 2011; Chapin & Kewman, 2001; Fadyl & McPherson, 2010). Few studies, however, have explored the different pathways or trajectories that people have taken to get to these outcomes and the factors that may influence these. A study by Ferdiana et al. (2014) modelled employment trajectories, as discussed in Chapter Two. However, there was no explorative component to this study to help contextualise and understand the different contributing factors and experiences associated with certain outcomes. Chapin and Kewman's (2001) work (also covered in Chapter Two) used semi-structured interviews and a grounded theory approach to analysis, with a matched sample of employed and unemployed people, to examine factors affecting employment after injury. While the authors did not explore pathways per se, they did conceptualise re-employment as a process that included job consideration or exploration, job seeking or offer and return to work, job maintenance and advancement, and perceived advantages of working.

A widely studied personality trait, dispositional optimism, has been found to be a robust predictor of functional health status following SCI (Vassend, Quale, Røise, & Schanke, 2011), and it is a characteristic of the resilience required to protect the individual against long-term sequelae of severe physical injury (Monden et al., 2014; Vassend et al., 2011). However, additional empirical efforts to explore the relationship between optimism and other key rehabilitation outcomes such as participation in employment appear to be limited. Better understood is the relationship between life satisfaction and employment following injury. In an expost facto design with N = 61 participants, Chapin and Holbert (2010) explored the characteristics associated with being employed and consistently found higher life satisfaction for employed people in comparison with people who had not achieved employment (Chapin & Holbert, 2010). Further exploration and understanding of the relationship between life satisfaction and dispositional optimism with different employment outcomes may assist in the provision of vocational counselling within the EIVR program and similar vocational interventions, to prepare people for employment participation following SCI.

The purpose of this research was to understand the experience and pathway of persons seeking and gaining paid employment outcome after traumatic SCI in Victoria, Australia. Specifically this involved: identifying and allocating participants into three employment outcome groups of stable employed, unstable employed and without employment; exploring relationships between demographic variables and employment outcomes; identifying pre- and post-injury pathways for participants in each of the groups; and exploring the experiences of people seeking, gaining and maintaining employment.

6.2 METHOD

6.2.1 Study design

This study used a mixed methods convergent design, merging concurrently collected quantitative and qualitative data to address the study aims (Klassen, Creswell, Plano Clark, Smith, & Meissner, 2012). It is increasingly recognised that a triangulated approach, where both quantitative and qualitative data are collected, provides a better understanding of research problems than collecting either data type in isolation (Creswell & Plano Clark, 2006). Interpretive phenomenological analysis (IPA) (Hycner, 1985; Smith, 2015) was used to understand the qualitative data obtained through interviews, while quantitative data were explored using descriptive statistics, correlations and pathway mapping. The findings from the analysis of each dataset were then compared, with interpretations presented in the discussion section of this chapter (Klassen et al., 2012). IPA is founded in phenomenology, hermeneutics and idiography. In this study, the phenomenological component refers to the lived experience of people following traumatic SCI, and the idiographic refers to seeking, gaining and maintaining paid employment in Victoria, Australia. Hermeneutics is the understanding that was sought through the analysis and the interpretation of what people said in participant interviews (Smith, Flowers, & Larkin, 2009).

6.2.2 Participants

Determining the sample size for a mixed methods study requires consideration of both the quantitative and qualitative components (Onwuegbuzie & Collins, 2007). The purpose of this study was to understand the experience and pathway of individuals with SCI in relation to employment, in order to contribute to a knowledge base. The three groups-stable, unstable and no employment—were chosen and defined in order to explore a variety of vocational pathways. It was believed that key differences or patterns would emerge across the groups that could be used to inform implications for future policy and practice. Purposive sampling of approximately 30 participants was deemed appropriate to address both the qualitative and quantitative components of the study aim (Onwuegbuzie & Collins, 2007). In this method of sampling, participants are selected because they hold characteristics of interest to the phenomenon being studied. The intention in this research was to recruit at least 10 participants to each group, where Group A had outcomes of stable employment, Group B had outcomes of unstable employment, and Group C were without employment. Individuals with each of these outcomes were drawn from the spinal cord injured population living in the community. Based on previous interview studies undertaken with this population, this sample size was considered appropriate to capture variance in client situations and enable observation of a likely plateau in the production of novel response elements (Murphy & Young, 2006). Ethical approval for this study H2013-05011 was obtained from the hospital and university Human Research Ethics Committees (see Appendices T and U).

People eligible to be recruited to the study had sustained a traumatic spinal cord injury with persistent neurology, were of workforce age at time of recruitment (15–65) and had sufficient English language to participate in an interview. No constraints were placed on the time since injury or the level of impairment. If a potential participant had a comorbidity of severe brain injury or cognitive impairment that would limit their ability to return to employment (assessed by their ability to live independently and engage in and complete the consenting process), they were excluded from recruitment into the study. Criteria for the outcome groups are described below. On allocation to a group, participants were assigned a code. For example, the code SA07 refers to a client, where S means subject, A, B or C refers to their employment outcome group, and the number is their participant number.

Group A: Stable employment was defined to align with the Australian Bureau of Statistics (ABS) (July 2014) definition of employment as having permanent employment for at least six months, of at least one hour per week of paid work. This could include an apprenticeship or steady self-employment.

Group B: Unstable employment was defined as work arrangements being precarious, temporary, casual, or contract-based. This included fragile self-employment or sole trading, or where the employment had been non-durable; that is, the person had gone back to work and then withdrawn from it in the six months prior to interview.

Group C: Participants who had not had any form of paid work for at least six months were allocated to Group C. This group included people who were unemployed, whether they

were actively seeking and available for work or not looking, demotivated, not available, or retired.

6.2.3 Instruments

Basic demographic and injury data were collected. Semi-structured interviews with openended questions were used to seek information regarding an individual's vocational pathway before and after injury, including employment and education history, timelines, health services utilised, vocational services utilised, entitlements and interventions received, and stakeholders involved. Questions were also posed to elicit responses about the experience of seeking, gaining or maintaining employment in relation to the aforementioned factors and perceived enabling elements or complications, difficulties, or challenges encountered. Members of the research team were experienced in the field of SCI rehabilitation, with both clinical and academic experience. Development of the interview questions was informed by findings from existing literature (Murphy, 2009) and the prior knowledge and experience of the research team. The interview outline for the three groups is provided in Appendix V.

Towards the end of each interview, a measure of satisfaction with the individual's current situation was ascertained, and two formal psychosocial measures were completed: the Satisfaction with Life Scale (SWLS) (Diener, Emmons, Larsen, & Griffin, 1985) and the revised Life Orientation Test (LOT-R) (Scheier, Carver, & Bridges, 1994). The Satisfaction with Life

Scale was developed by Diener and colleagues in 1985. It is a five-statement, self-report scale measuring global life satisfaction. Statements such as 'In most ways my life is close to my ideal' are responded to on a Likert scale ranging from 1 (strongly disagree) through to 7 (strongly agree). Total score ranges from 5–35, with higher scores indicating greater perceived life satisfaction. (See Appendix X.) The revised Life Orientation Test is a measure of dispositional optimism (Scheier et al., 1994). Ten statements are scored on a five-point Likert scale, with responses to questions such as 'Overall, I expect more good things to happen to me than bad' ranging from 0 (strongly disagree) to 4 (strongly agree). Six of the 10 items contribute to an optimism score, with four questions (2, 5, 6 and 8) being filler items. Three of the six scored items (3, 7 and 9) are negatively worded and need to be reverse-scored before calculating. The final score could range from 0 to 24. (See Appendix Y.)

6.2.4 Procedure

The study was advertised and promoted via the local state spinal cord injury service and a member-based community support organisation, as well as on websites, newsletters and notice boards. Interested persons either telephoned or emailed the researchers for further information. Once contacted, and if able to participate, the potential participants were assessed by the researchers to ensure they met the selection criteria and were then allocated to the relevant subgroup. If there were concerns about correct allocation to a subgroup based on the characteristics of the participant, the first author sought a second

opinion from the research team and decisions were agreed. Interviews were arranged at a place and time that were convenient to the participant. All the interviews were conducted by the thesis researcher, who is an occupational therapist experienced in in spinal cord injury rehabilitation. This expertise was made known to participants, and the researcher remained reflective of the concepts, values and preconceptions that could be brought to the process of analysis (Smith et al., 2009). For example, as an occupational therapist, the researcher views employment through an occupational therapy lens. Employment is viewed as one of many potentially valued occupations an individual engages in, among others that include self-care and leisure occupations. Occupational therapists are concerned with the relationships between engagement in these occupations and a person's overall health and wellbeing. Their focus is to facilitate individuals with health-related problems to reach their potential through participation in occupations. Once at least 10 cases for each group had been identified, recruitment ceased.

Informed consent was obtained at the commencement of each interview. The interview schedule was expected to take between 45–90 minutes and began by obtaining a detailed history of the person's education and employment history, pre- and post-SCI. Interviews were recorded and subsequently transcribed verbatim. Each transcription was allocated a code as an identifier that reflected the participant's employment outcome group. Transcriptions were then uploaded into NVivo qualitative data analysis software (NVivo for Windows, 2012). This software allows for the sorting of data under sources and nodes, so that each employment outcome group as well as individual participants could be coded
separately. Quantitative data obtained from the Satisfaction with Life Scale and revised Life Orientation Test were managed with statistical software SPSS.

6.2.5 Data analysis

For analysis of the quantitative data, descriptive statistics were completed and vocational pathways were identified for each participant including education (e.g., secondary, trade, tertiary, etc.) and employment (e.g., part-time, casual, etc.). These pathways were mapped in relation to when the person sustained their SCI. Factors such as compensation status, personal care requirements and age were incorporated into the map. For each employment group, similarities and differences in employment trajectories were observed and noted. Demographic and injury data were entered into statistical software package SPSS. Spearman's correlation coefficients were undertaken to explore relationships between employment outcomes, participant characteristics, and demographic and injury data, and pathways were drawn to visually inspect differences between outcomes for the three employment outcome groups (A, B and C).

Data from the Satisfaction with Life Scale (SWLS) and the revised Life Orientation Test (LOT-R) were also analysed quantitatively after being entered into the statistical software package SPSS. Initially, descriptive statistics were used to describe the participants' data from the two scales. Means and standard deviations were calculated for the entire data set, as well as for the three groups for each scale. A range of chi-square, correlation and ANOVA

tests were undertaken to examine relationships between employment outcomes, demographic and injury data, and emotional characteristics (reported satisfaction with life and dispositional optimism), as well as to explore differences between outcomes for the three employment outcome groups (A, B, and C).

For the qualitative data, IPA was used to explore in detail how participants made sense of their personal and social world in the context of their lived experience of seeking, gaining and maintaining employment after SCI (Smith, 2015). The key features of IPA are phenomenology, hermeneutics and idiography. Phenomenology is the philosophical study of 'being' and/or experience, while hermeneutics is the study, methodology and practice of interpretation. Idiography prioritises a focus on a particular individual event or process. Overall, IPA requires the researcher to become highly familiar with interview transcripts in order to engage in an interpretive relationship with the data (Smith, 2015).

Analysis of interview data initially followed a three-step process for each individual transcript that was consistent with guidelines documented by Smith and colleagues (Smith et al., 2009). First, the researcher engaged in 'free' or open coding, becoming very familiar with a single transcript by reading and re-reading it, and reflecting against any preconceptions. The second step involved phenomenological coding of the transcript line-by-line, noting descriptive, linguistic and conceptual comments in the data. Thirdly, interpretative coding was undertaken to identify emerging patterns and commonalities as themes. Once this had been completed, the three steps were repeated with the next transcript, and so on until all cases had been analysed. Following individual case analysis,

the researcher looked for patterns across the cases, including within employment outcome groups. This allowed for the identification of superordinate themes (Smith, 2015). A second researcher then reviewed and analysed a sample of interview transcripts using the same process. Where there were any discrepancies or disagreements, they were discussed and resolved. On completion of analysis, member checking was undertaken, as is usual in qualitative research (Letts et al., 2007). Through this checking, participants were invited to read and provide feedback on a summary of the analysis. This process was followed so as to promote credibility and achieve trustworthiness (Smith et al., 2009).

Findings from IPA and the quantitative mapping exercise were considered together in order to identify additional themes or reinforce existing ones, while considering the experiences within different employment outcome groups. This triangulation strengthened the analysis, enabling deeper understanding of the data.

6.3 RESULTS

The results of this study are presented in four sections related to the study aims. Sections 6.3.1, 6.2.2 and 6.2.3 relate to quantitative data, including identification of participant demographics, group characteristics, relationships between variables, emotional characteristics and results from the pathway analysis. Section 6.3.4 presents the results of the qualitative IPA findings.

6.3.1 Participant demographics, group characteristics and relationships between variables

Thirty-one participants (N = 31) were successfully recruited to the study. Of these participants at the time of the interview, Group A were in stable employment (n = 12), Group B were in unstable employment (n = 10), and Group C were without employment (n =9). Table 15 shows the demographic characteristics of the study population. On initial recruitment, one participant was allocated to Group C. However, it transpired that this participant had only recently retired after being in the labour force for over 35 years, and therefore it was more appropriate to allocate this person to Group A: Stable employment.

Table 15

Demographic data compared across employment outcome groups in Study Four:

Experience of employment after SCI and pathways involved

Group	Fu	ll Sample	Stable Employment		Unstable Employment		No Employment	
	mean	(SD)	mean	(SD)	mean	(SD)	mean	(SD)
Age at injury	33.32	(12)	29.25	(11.16)	36.7	(13.35)	35	(11.20)
	n	%	п	%	n	%	n	%
Gender								
Male	25	80.60	9	75.00	8	80.00	8	88.90
Female	6	19.40	3	25.00	2	20.00	1	11.10
Location								
Metropolitan	24	77.40	12	100.00	7	70.00	5	55.60
Regional	7	22.60	0	0.00	3	30.00	4	44.40
Compensation status								
Insured	18	58.10	4	33.30	6	60.00	8	88.90
Non-insured	13	41.90	8	66.70	4	40.00	1	11.10
Time since injury								
≥ 10 yrs post SCI	13	41.90	8	66.70	3	30.00	2	22.20
< 10yrs post SCI	18	58.10	4	33.30	7	70.00	7	77.80
Level of injury								
Tetraplegia	15	48.40	8	66.70	3	30.00	4	44.40
Paraplegia	16	51.60	4	33.30	7	70.00	5	55.60
Level of impairment								
C1–C8 AIS ABC	13	41.90	8	66.70	2	20.00	3	33.30
T1–S5 AIS ABC	15	48.40	3	25.00	7	70.00	5	55.60
AIS D any level	3	9.70	1	8.30	1	10.00	1	11.10
Education level pre-injury ¹								
Yr 10 High school	5	16.13	1	8.33	2	20.00	2	22.22
Yr 12 High school	2	6.45	1	8.33			1	11.11
College/University incomplete	8	25.81	5	41.67	2	20.00	1	11.11
College/University complete*	16	51.61	5	41.67	6	60.00	5	55.56
Postgraduate complete	0							
Occupation at injury ²								
Manager	4	12.90	2	16.67	1	10.00	1	11.11
Professional	6	19.35	2	16.67	3	30.00	1	11.11
Community/service worker	1	3.23			1	10.00		
Sales worker	2	6.45	1	8.33			1	11.11
Clerical/administration	1	3.23	1	8.33				
Technician/trades worker	11	35.48	1	8.33	4	40.00	6	66.67
Machinist/driver	0							
Labourer	1	3.23	1	8.33				
Student	5	16.13	4	33.33	1	10.00		

Notes. *includes trade qualification

¹Australian Qualifications Framework Council (N.D.)

²Australian Bureau of Statistics (2013)

Spearman's correlation coefficients showed there were no significant differences in individual nor group demographics and employment outcome, except for funding status. There was a moderate, positive correlation between funding status and employment status, $r_s = .400$, N = 31, p < .05, where being uninsured or non-compensated was associated with being in the labour force.

6.3.2 Employment, satisfaction with life and dispositional optimism

When exploring the relationship between the emotional characteristics, demographic and injury data, and employment outcome using chi-square and ANOVA tests, there were no statistically significant findings. Using Spearman's correlation coefficient, there was a moderate positive correlation between the two variables Satisfaction With Life Scale (SWLS) and revised Life Orientation Test (LOT-R), $r_s = .477$, N = 31, p < .01, where reported satisfaction with life was associated with dispositional optimism. Overall, this lack of statistical significance in results may be related to the relatively small sample size. A correlation matrix for all the findings relevant to sections 6.3.1 and 6.3.2 is available in Table 16.

Table 16

Correlation matrix for all demographic and injury data, emotional characteristics and employment status data used in Study

Four: Experience of employment after SCI and pathways involved

Measure	1	2	3	4	5	6	7	8	9
1. Gender	-	0.251	0.02	0.148	0.133	-0.265	0.08	0.133	0.169
2. Time since injury		-	-0.308	-0.11	0.3	-0.026	0.134	0.307	0.278
3. Neurological level (AIS)			-	.712**	-0.106	-0.201	0.065	-0.082	-0.199
4. Injury type (para/tetra)				-	-0.05	-0.095	-0.224	-0.116	-0.166
5. Employment status					-	-0.334	.400*	0.346	0.327
6. Living location						-	-0.146	0.207	0.022
7. Funding status							-	0.286	-0.022
8. Satisfaction with life (total scor	e)							-	.477**
9. Life orientation (total score)									-

Notes. * Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

6.3.3 Vocational pathways pre- and post-SCI

A visual map was developed to demonstrate the similarities and differences in pathways taken by participants across the three groups (see Table 17 and Figures 8–10). Key findings from the pathway analysis are summarised below. These pathways are further explored in the discussion section of this chapter, in the context of the four superordinate themes identified through the IPA.

Table 17

Employment pathway and demographic data of participants (N = 31) in Study Four: Experience of employment after SCI and

pathways involved

Employment Pathways					Demographics					
Participant	Pr	e-SCI	SCI		Post-SCI	Age sustained SCI	Comorb.	Insured under TAC/WSV ¹	Req. assist. with personal care	
GROUP A: Stable employment										
SA02	Study	Full-time		Full-time		47	No	No	No	
SA03	Study*	Full-time		Full-time		40	No	Yes#	No	
SA04	Study	Full-time		Full-time		24	No	No	No	
SA09	Study**	Full-time		Part-time		48	No	Yes	Yes	
SA10	Study	Full-time		Part-time		27	No	Yes	Yes	
SA11	Study*	Part-time		Full-time		20	No	No	No	
SA08	Study	Full-time		Study	Part-time	39	No	Yes#	Yes	
SC02		Full-time		Study	Full-time (recently retired)	25	No	No	Yes	
SA01		Study		Study	Full-time	21	No	No	Yes	
SA06		Study		Study*	Full-time	20	No	No	Yes	
SA05		Study		Study	Full-time	16	No	No	Yes	
SA07		Study		Study	Part-time	24	Yes	No	Yes	
GROUP B: Unstable employment										
SB01	Study*	Full-time		Part-time casual		56	Yes	No	No	
SB04	Study*	Full-time		Part-time casual		28	Yes	Yes	Yes	
SB06	Study	Full-time		Part-time temp.		43	Yes	No	No	
SB07	Study*	Full-time		Part-time casual		33	Yes	Yes	No	
SB08	Study	Full-time		Part-time casual		34	No	Yes	Yes	

SB10	Study	Self-emp.		Self-emp. part-		57	No	Yes	Yes
SB05	Study	Full-time		Retrenched (looking	g)	46	No	No	No
SB09		Study		Study/Part-time cas	17	No	Yes	No	
SB02	Study	Full-time		Study	Study/Part-time casual	27	No	No	No
SB03	Study**	Full-time		Volunteer	Part-time temp	26	Yes	Yes	No
GROUP C – Without employment									
SC10	Study	Full-time		Part-time	Study/not working/looking	27	No	Yes #	No
SC04	Study**	Full-time		Full-time temp	Study/not working/looking	47	No	Yes	No
SC05	Study	Full-time		Part-time casual	Study/not working/looking	21	No	No	No
SC07	Study**	Full-time		Full-time	Study/not working/looking	23	Yes	Yes	No
SC09		Full-time		Study	Part-time temp./not working/recently retired	42	No	Yes	Yes
SC06		Full-time		Part-time casual	Not working/looking	24	Yes	Yes #	Yes
SC01	Study**	Full-time		Study*	Not working/not looking	49	Yes	Yes	Yes
SC03		Full-time		Not working	Not looking	38	Yes	Yes	No
SC08	Study**	Full-time		Not working		44	Yes	Yes	Yes

Notes. Different shades in this table aim to demonstrate the various pathways within each outcome group.

Unless otherwise indicated, employment is permanent.

* Studies were not completed

** Studies include trade qualification

Not eligible for loss of earning benefit (or equivalent), given lump sum payment

¹ TAC/WSV are abbreviations for Transport Accident Commission and WorkSafe Victoria

6.3.3.1 Group A: Stable employment outcome

In Group A: Stable employment, there were two main pathways: (a) from study pre-injury to study and then employment post-injury (40%) and (b) from study and employment preinjury and returning back into the same or similar role post-injury (50%). People in stable employment were on average younger (29.3, SD = 11.16) at the time of their injury than participants in the other groups. Forty per cent of participants in this group were students (in either secondary or tertiary education) at the time of injury. Participants' preemployment skills were less physically-oriented, with only one participant having a trade background. Of the group, 70% held at least a university degree. Two participants in this group did not actually complete their pre-injury studies, and therefore had no formal qualifications. However, due to prior sufficient work experience, they had remained secure in their employment through on-the-job training programs. Four of the people in Group A were insured under Victoria's no-fault accident compensation system. Two (16.7%) of these were eligible for and had accessed a loss of earning benefit or equivalent, while the other two (16.7%) had received a lump sum payment in the past. Seventy per cent of the group required assistance with aspects of personal care. Fifty per cent had an AIS classification of A and a cervical lesion (that is, complete tetraplegia). A figure to depict these pathways is provided below in Figure 8.



Figure 8. Pathways and characteristics of Group A: Stable employment

6.3.3.2 Group B: Unstable employment

There was one main pathway for 70% of the participants in the unstable employment group. This was having studied and worked pre-injury followed by achieving unstable employment post-injury. Only one participant (10%) was in similar employment post-injury to that of their pre-injury role. All participants in Group B had studied prior to their injury. Seventy per cent of these had completed their qualifications, and of them less than half were at degree level or above. The pathway to employment following injury for this group appeared less clear and was potentially complicated by major comorbidities, such as pain or skin issues, and/or additional life responsibilities, such as being the primary carer for a child. Twenty per cent of the group identified experiencing mental health issues. Sixty per cent of the group had insurance under a personal accident scheme, and all received a loss of earning benefit or equivalent. Sixty per cent of the group had a classification of AIS A and a thoracic lesion (that is, complete paraplegia). Thirty per cent of the group required assistance with personal care. The pathway for this group is presented in Figure 9.



Figure 9. Pathways and characteristics of Group B: Unstable employment outcome

6.3.3.3 Group C: Without employment

Group C participants had variable outcomes. Eighty per cent of this group had achieved some level of employment at some stage post-injury, however, at the time of interview all were without employment. Forty per cent had trade backgrounds. Twenty per cent of the group had a qualification of degree or above. Significant mental health issues were reported by 50% of the group. Eighty per cent of the group were insured under a personal accident scheme, with 60% receiving a loss of earning benefit or equivalent. Half of the group required some assistance with personal care, and 40% of the group had a classification of AIS A and a thoracic lesion (that is, complete paraplegia). The remaining 60% varied in both AIS and level of injury. The pathway for the group without employment is presented in Figure 10.



Figure 10. Pathways and characteristics of Group C: Without employment outcome

6.3.4 Lived experience of seeking, gaining and maintaining employment after SCI

Superordinate themes from the interpretive phenomenological analysis are presented below. These provide insights into the personalities of the participants and the experiences that may have contributed toward the employment outcomes they achieved. These themes are supported with quotes from participants, coded to maintain anonymity. Words that have been added to the original quotation to clarify meaning or provide a brief explanation are enclosed in square brackets.

6.3.4.1 Expectations about employment after SCI

Participants in Group A provided a consistent message that paid employment was an accepted part of the journey for them post-SCI. Only one participant reported questioning (at a very early stage) whether returning to employment would be possible. Participants were focused on achieving or maintaining employment and were motivated by financial and social reasons, as well as by gaining or maintaining a sense of purpose and meaning through the worker role. In particular, one participant emphasised that employment was an accepted part of the future after SCI.

[At the start] I had so many people tell me, like, just focus on your disability and learn about that first ... I already knew what the deal was ... It's like, well, a job's not going to take away 24 hours of your day. You can still research, learn your disability (SA07).

Opportunities had arisen for people in Group A following their SCI, and due to their positive expectation of work, they had actively pursued them, with the result that these opportunities often led to an employment outcome.

I got an opportunity ... I had people vouching for me that were high up in the company ... I was very well supported to begin. I didn't need that support so much once I started working, because I was confident with what I could do and, you know, [had] the runs on the board (SA05).

These opportunities were often synonymous with having a supportive employer.

[They've given] me the opportunity to step back into the role, they've been hugely supportive as a company (SA09).

This highlighted the importance of remaining in contact with pre-injury employers through the rehabilitation process.

So I was in contact with them [the company previously worked for] and they basically said to me, 'Okay look, you know what? When you're ready, give us a yell, we'll see if we can help you out.' When I finished my rehab, I started there three days a week (SA11).

Participants in Group B and C held a strong motivation and desire to work. While opportunities had emerged for these participants, as they had done for people in Group A, it appeared that the pathways to stable employment were less clear, with competing life demands being raised as a common concern.

I'm a full-time parent, so all my work needs to fit in within school hours usually, you know (SB07).

The medical stuff, you know, it's– I really hate letting people down, I really hate ringing up and saying, 'Look I know I'd said I'd do it, but I can't', and that really bugs me (SB07).

You know, if I'm not fighting all the battles that I've had to fight over the years against [insurance company] or my ex-wife or whoever, then that opens up a whole lot of extra time. And also you need some sanity time as well, because sometimes I'm just not in the mood for [work] (SB08).

At times, pre-injury workplace limitations also prevented a return to the pre-injury employer. While two participants in Group C had returned to work successfully in their preinjury role within one month of their discharge from rehabilitation, organisational demands had ultimately forced those workers to cease employment.

[*I*] just couldn't have gone back to the corporate ... job. It was really, really hard parttime (SC10).

Both of these participants have gone through or were in the process of reskilling and seeking new employment.

So teaching was always something that I'd wanted to do ... I think the school holidays and things like [that] will work in my favour, that I can rest and the days are short (SC10).

At an individual level, people who achieved employment also demonstrated a motivation and willingness to problem-solve and successfully deal with adversity. It wasn't so much

that those who were not employed did not have these attributes, but more that people in employment had 'seen it through'. The inherent bias in a self-selecting sample must be noted here, as this potentially gives a skewed picture of personality traits and the ability to deal with adversity. Indeed the vast majority of participants interviewed presented themselves in a positive manner, regardless of their present employment circumstances.

6.3.4.2 Comprehension and navigation of systems and rights

The majority of participants in Group A had an understanding of their rights as employees and an awareness of legislation and regulations. A common understanding in the maintenance of employment was having open and effective communication with the employer. Appropriate support for the person to do their job was reliably provided for people in this group, particularly when the employee helped the employer to understand the implications of SCI. In contrast, several participants in Group B did not appear to have a comprehensive understanding of their regulatory-based rights, whether as insurance claimants or within the broader welfare systems. Participants in this group expressed difficulty in obtaining information that was relevant and useful to their situation. This difficulty was often exacerbated by a concern with 'doing the wrong thing' or fear of their income or financial support being affected.

You know ... they don't tell you that from the [insurance company], and there were people that I had heard about that had got caught out by that [pre-safety net] and couldn't get their benefits again, and you know, they tried everything to get back to work and then are punished basically ... They get tricked, they feel like they got tricked

(SB04).

One participant had heard of the possibility that working more hours could impact on his loss of earning benefit (insurance payment). He noted that when he spoke to the insurance agency: *even then I had to go through a few different levels before I found the right information. Because I really didn't want to be disadvantaged in any way* (SB03).

Across the full sample four participants with no-fault personal injury insurance described receiving a lump sum payment following their injury, and the remaining participants were eligible for a loss of earnings benefit or equivalent. Those receiving this form of compensation commonly described an uncertainty about how to navigate these systems if they were to return to work or increase their hours. It was apparent across all three groups that unclear or poor quality information had caused anxiety or confusion about entitlements and/or the security of payments related to a person's injury. People described difficulty finding correct information that was relevant to them and their situation, based on which they could make reliable decisions about the financial implications of gaining or losing employment.

Participants who were insured also recognised the financial security that compensation brought to their lives and how this in turn provided opportunity for choice.

Well, the fact that I had an accident at work is a blessing; I mean without that, I think my life would be completely different. In other words, being funded without that, I would just shudder to— I don't know if a marriage would survive, family would survive,

you know. It just brings a whole lot of other pressures to bear, so that's been a huge godsend, huge benefit for all of us in my family (SA03).

I guess what that ... [having compensation] did for me was it provided me some security, it's given me some time, a chance to do some different things and work out what I want to do (SB09).

While several uninsured participants received payments under the federally funded social security system, there was not the same level of uncertainty about how much they could work, or indeed how the system would monitor their work involvement. Participants who were uninsured generally described additional pressures or expectations on finances to manage day-by-day and reported struggling with issues such as funding for equipment or care. However, this need appeared in itself to be another motivator for employment. While this scenario for non-insured people would not be specific to participants in this research, there was a general awareness that life in general was tougher for people not covered by one of the jurisdiction's no-fault accident compensation schemes (including the Transport Accident Commission and WorkSafe Victoria).

For the majority of participants, there was a clear sense of preference to be fully or partially independent of service systems. The process of negotiating with service systems such as accident compensation schemes was commonly described as enormously time- and energyconsuming, complex and bureaucratic. When it was possible to remove the reliance on welfare or loss of earning (or equivalent) payments, people described having greater choice, freedom and control over their lives.

But yeah, I'm really looking forward to not getting the loss of earnings from [the insurance company]. I want to– I'd love to just be a [worker] and just do that rather than having to have a– get these payments from [the insurance company] (SB09).

6.3.4.3 The impact of worker identity on motivating employment

While some frustrations were expressed in relation to service systems and resources, participants in Group A were motivated by employment goals to overcome these barriers. It was apparent that some participants had actively contributed to the occupational roles they held so as to overcome certain physical or environmental limitations. This was often achieved through open and effective communication with their employer.

Managers and people are usually pretty good. Part of the job— my first job was, I could do on call support, but that's not really an option, you can't get up during the night and get a laptop and a phone and start handling issues and things, but they accommodate, they said, 'Look, you know, you don't need to do on call support' (SA01).

People were highly resourceful in their ability to problem-solve through the potential barriers to maintaining employment. This resourcefulness, and the confidence gained in achieving independence, would likely infiltrate other areas of life.

[I use] 1.5 litre leg bags and that gets me through the day ... I had to find them [by myself] ... Without those leg bags I would have huge problems, because you know you need to keep your fluids up and ... there's a disabled toilet on my floor [at work] but I can't lock it, and I can't have people walking in on me ... If I didn't have these leg bags I

would effectively ... need one of those crappy one hour [personal care] shifts at lunchtime, which are hard to fill, for someone to empty the leg bag (SA05).

Participants reflected on the shift in validation they felt upon returning to work post-injury and how this, in itself, helped them to recognise their own self-worth.

And then you go home on the weekends and you can't look after the house and you can't do things with your kids and can't do this and can't do that, so it's harder to then find ... that validation for the role you're playing ... that you were used to ... But at least during the week ... even if your role is totally different, even if you were a plumber and now ... you're in a role counselling people to help them ... but if that's your job now and you are getting paid for it, they're paying you, they're validating your ... worth (SA02).

Due to a perceived inability or lack of interest among participants in Group B about returning to their pre-injury career or employment, a recurring theme in this group was that of finding and/or creating a new worker identity. Participants described a process of exploration and trialling different things, followed by a sense of satisfaction when they discovered a skill or role that suited them. This process could take some time and varied between each individual.

Yeah, I want to do something useful and productive but I just don't know what to do, and now I've figured out what I want to do, so it's good ... It's about sort of meeting people and spending time with people. I don't want to sit at home by myself all day and

only ever see [my partner], you know. You need to have relationships with other people and I'm missing that. I've been missing that for too long. It's huge (SB04).

Another participant in Group B reflected on their time in rehabilitation and spoke about thinking ... what am I going to do? I don't want to work in a call centre ... It was all of my horrible nightmares come true ... Sitting at a desk is not the kind of work I do. I just don't thrive (SB07). This participant then spoke with elation of the day they realised they could do something different and be good at it.

I was at [hospital] one day and bumped into [a friend] ... She thought that because I'd talked a lot, apparently, it [job opportunity] would be good for me ... And that was the start of my new employment (SB07).

Three participants in Group C identified their ongoing struggle with not being able to physically do and achieve what they could pre-injury. There was a sense of loss—and grieving at times—for the physical person that they once were, along with either a lack of hope for future possibilities or a despondence about overcoming barriers. This was in direct contrast to scenarios described by participants in Groups A and B.

I just can't stand the thought of people seeing me like this, because it's just not the way I was. I was six foot tall, super fit ... But no, I just don't want people seeing me like this (SC01).

I suppose the work I did was very much hands-on, you know, and probably very physically demanding, and so that's out, can't come back to that obviously. So I've got

to look at a whole new occupation, completely (SC03).

Participant SC03 grappled with how to manage pain effectively so that work could become a possibility again: One particular day I did feel good, and when I feel that good, I feel like I'm ready to tackle the world, so I went in and met them [previous employer] and had a good conversation with them, but two days later I felt like absolutely shit at the end, back to square one.

Three others in Group C described a similar stage of grieving, however, they had—with time and appropriate supports—been able to adjust, and they spoke positively about the new identity, skills and roles they were creating for themselves.

Yeah, it was just switch flicked when I had a [serious] pressure sore ... and I thought 'I can't keep doing this to myself.' I couldn't push myself up a ramp to get in the house. I had to like get some help ... I want to be—not the breadwinner—but I want to show [my partner] that [they] can come home and be with the family and I can go to work (SC06).

Perceptions of self featured regularly in participants' discussions about avocational activities and roles, as well as directly in relation to identity gained through employment. For example, many people described the value and role of leisure in helping to establish a sense of self-worth and ability, either by adding to a level of confidence in other life areas (such as relationships or employment) or by providing motivation to be a worker.

Playing rugby with the boys has taught me a lot ... [Player name] works, plays rugby, has a family ... There's other blokes out there that do it ... That really motivates me even more (SC06).

Conversely, others, particularly earlier after injury, appeared conflicted by their self-image and described a hope for a different future.

I went down to [peer support organisation] one day, and I met with [peer support workers]. So we're going across the road to the pub for lunch and ... I just wanted to turn around and get into my car and just go home. This is not for me ... So I just don't like being around people (SC03).

I know I'll never have my old life back ... and to be honest with you, my old life was 150 miles an hour ... It was too fast ... But I know that I'll never have that back, but if I got it back to 14 miles as hour, I'd be happy with that life for now, and I think that's what keeps me going, just the thought of... getting myself back into some sort of managing again (SC03).

6.3.4.4 The importance of social supports and their contribution to employment outcomes Social support, which is a critical component of social participation, is a multifaceted construct and can be broadly understood as the perception and actuality that one is cared for and could obtain emotional or physical assistance if required from social networks such as family, friends or associates (Murphy et al., 2010). An important component of social

support in relation to achieving employment is having access to appropriate and adequate formal support for assistance with personal care.

Several people described having inadequate support, usually around accessing hours and/or staff for personal care. Of participants currently employed, at least nine people (predominantly from Group A) described having to modify their work arrangement and/or lifestyle in order to maintain their worker role.

The main problem is its accessing care ... Luckily I've got just enough, but I had to fight for ages and ages to get enough care hours to live independently (SA07).

I'd love to live in places like [inner city suburb] ... but getting carers in places like that would be really difficult ... Because most of my carers come from the lower socioeconomic areas ... you've got to live within cooee of them (SA05).

For others, however, their physical limitations combined with inadequate personal care resources meant that they could not sustain employment, despite a desire to be working.

I've only got three [carers] at the moment. I'm supposed to have 14 hours of care a day. Yeah, I can't get skilled people locally (SC08).

Participants also described a wide variety of interventions, services and entitlements that may have assisted in individual cases, but no one single resource stood out, possibly due to the fact that participants experienced their accidents over several decades, and therefore their experiences of different systems and processes were varied.

One recurring theme, however, across the three groups, regardless of time since injury, was that if an individual had access to a person or persons who had an understanding of SCI, as well as a knowledge of the local insurance and support systems and what was possible in terms of outcome, this appeared to assist the individual in navigating the journey towards an employment outcome. An example of this was the phenomenon of peer support, which is described in this context as people with lived experience of SCI who are willing to offer their support and knowledge to other people who are recently injured or needing assistance with a particular life domain. Several participants described the value of the peer support relationship in providing a sense of community, which in turn helped to build confidence and foster independence, while also being a source of motivation.

So that's when we started wheelchair rugby ... and from then you get to meet other people in chairs, and also there's another element of your life that's opened up. So that's when you can start to see the acceptance come in. You start to meet people who accept people in chairs, so that's another environment altogether. So again, that sort of progressed another area of my life of acceptance. And that's where confidence starts to build in (SA11).

Playing rugby with the boys has taught me a lot ... like knowing that there's other blokes out there in the same position that do it [work]. Yeah, really that motivates me even more (SC06).

I still see him [peer mentor] regularly. We have the same injury and he's a walker, so we're– we're called walkers ... Yeah, so I catch up with him and he actually goes to [the

same university] to study as well, so we just catch up after classes, and yeah, he's probably– he's a really good help because he knows exactly how it feels, you know. People who [haven't] had an injury ... can only understand to a point. Same with people who are in wheelchairs. They can't really relate to someone who's walking with a disability because we're really, really, we're such a minority (SC05).

Where participants needed specific knowledge about gaining employment after SCI, they might seek out peer connections for assistance.

I'm looking for anything I can do. Admin, sales, yeah, I had a chat to [person's name]. Actually we're close mates, and he said get into HR and I've got no idea what that would entail, so I've got to rack his brain a little bit more because he's in that sort of field (SC06).

Similarly, people with employment experience were willing to share what they had learnt, whether it be with other workers or with people with SCI who were looking to work. As participant SA11 said, *We're professionals in chairs, [let's] get together, let's share some ideas, let's share travel, let's share career [aspirations]* (SA11).

6.4 DISCUSSION

This is the first study in an Australian context to explore people's experience of returning to work following SCI. It is also the first study to document the vocational pathways of people from pre-identified groups of employment outcome. With the use of survey data, Krause

(Krause, 1992) allocated research participants into three employment groups to explore relationships with adjustment. In research by Ferdiana and colleagues (2014), three distinct trajectories towards employment were identified for a group of people, all within five years of sustaining SCI. The current study, in comparison, purposively selected people according to their employment outcome and then collected data about their individual experiences. Similar to the Dutch experiences presented by Ferdiana et al. (2014), the results of this study reinforce the value of education in facilitating post-injury employment and echo the research by Krause (Krause, 1992) that highlights the contribution of employment to people's sense of wellbeing. The current study also provides additional insights through four superordinate themes that were drawn from interview data. These themes highlight the influence of social and institutional environments, system navigation, worker identity, and social supports on a person's experience of seeking, gaining and maintaining employment following SCI. The implications of these themes for clinical practice both locally and internationally are discussed in this section. Study limitations and priorities for future research are also presented.

6.4.1 Implications for clinical practice

Despite many similarities in the traumatic spinal cord injured population throughout the world (Bickenbach et al., 2013), differences in local policy and service delivery can create challenges when comparing or translating findings across countries and jurisdictions. While there were individual perspectives in this study that are possibly unique to Australia, the

majority of themes and pathways identified are both congruent with previous international research and largely translatable to other countries with developed welfare regimes, such as Sweden, Canada, the United Kingdom and New Zealand. Analysis of interview data identified cultural change, system navigation, worker identity and social supports as important considerations in the context of emerging pathways to employment. Research from Sweden and New Zealand (Bergmark et al., 2011; Hay-Smith et al., 2013) has previously recognised the role and contribution of social supports in promoting employment, and the importance of nurturing worker identity is a consistent finding in studies from New Zealand, Norway and Sweden. The implications of the four themes for clinical practice is considered below.

6.4.1.1 Social and institutional cultural change

Participants in this research who had gained stable employment after sustaining a SCI had from the outset largely optimistic expectations of paid employment being part of their lives after injury. Conversely, for people who were in unstable or no employment, achieving work was more complicated and difficult, with attitudes being more pessimistic about reaching a stable employment outcome. Participants' experiences and previous research in this area suggest that the typical culture of social and institutional environments, including spinal rehabilitation centres and workplaces, has not been predominantly supportive of and positive about people returning to work after SCI (Murphy, 2009; Ottomanelli et al., 2009; Ottomanelli & Lind, 2009). This was also found in research by Hammel (1999), where it was noted that spinal rehabilitation centres offered limited information and support concerning the resumption of employment after injury. Ottomanelli and colleagues (Ottomanelli et al.,

2009) suggest there are potentially negative consequences for employment outcomes for people who undergo rehabilitation in spinal centres that do not have a culture of supporting vocational goals after injury. The EIVR program has been in place since 2010 at the spinal centre where the participants in this study received services (the details of which were outlined in Chapters One and Five). However, the majority of participants in the research received rehabilitation prior to this service commencing, at a time when there was very little emphasis on the benefits of employment after injury, and there was still a strong traditional focus on physical recovery.

Other factors that may have also limited the employment outlook for people in the unstable or no employment groups may have included fears and unknowns for the individual about living with SCI, community misconceptions of disability, and the perception that social stigma existed in the workplace about people's capacity to maintain job roles. Other qualitative literature exploring employment after SCI has reported negative perceptions of disability and resulting discrimination as a common issue (Chan & Man, 2005; Hay-Smith et al., 2013; Leiulfsrud et al., 2014; Wilbanks & Ivankova, 2015). The inpatient rehabilitation environment, social networks and workplaces can all have a role, however, in providing positive messages about returning to employment and backing that with practical support. In New Zealand, for example, people have described the spinal rehabilitation centre as 'sowing the seed' to contemplating employment after SCI (Hay-Smith et al., 2013). This demonstrates the constructive influence that the social or institutional environment can have in regards to employment after rijury.

The lack of a supportive culture about employment after injury that was identified by participants also appeared to have manifested as misinformation or difficulty with information dissemination or comprehension. This was frequently reported to cause anxiety or confusion about entitlements and/or the security of welfare or payments related to a person's injury. People often found it difficult to find information relevant to their situation and the stage of their post-injury pathway. This is not a scenario unique to the setting for this research, and as a result, opinions vary across settings as to the value of entitlements and benefits (Bergmark et al., 2011; Chan & Man, 2005; Chapin & Kewman, 2001; Hay-Smith et al., 2013). Therefore, it is essential to ensure access is provided to correct and clear information about entitlements, benefits and resources, in order to assist in nurturing a culture that is positive and supportive about the possibility of employment after SCI.

6.4.1.2 System navigation

The state of Victoria, Australia, has established systems of welfare and accident insurance (for motor transport or work-related injuries) that can support spinal injured persons and provide a sense of security in times of need. However, characteristics of these current service systems have been described in this research as consuming enormous amounts of time and energy, as they are large, complex and bureaucratic. It was consistently evident from the experiences of study participants that if it were possible to remove the reliance on welfare or loss of earning (or equivalent) payments, people with SCI would have greater choice, freedom and control over their lives. This was also reflected in the findings from the correlation analysis, where being uninsured or non-compensated was associated with being in the labour force. Insurance bodies and welfare programs should therefore consider

innovative approaches to promote system flexibility that would in turn promote opportunities for employment and independence from the systems. An example may be giving people the opportunity to trial employment without any fear of impact on their benefit entitlements.

The research found that people's knowledge of systems and the supports that were available to them was very limited. This was particularly so for people in the unstable or without employment groups. Similarly, the pathways for people in this group were not straightforward, and these participants often experienced major comorbidities or complications with their injury. This highlights the need to remind funders and service providers that any vocational intervention offered must be holistic and individualised in its approach, in order to adequately meet the highly variable needs of service users.

6.4.1.3 Worker identity

There is a strong evidence base to suggest that, if a person can, it is definitely better to work than not (McKee-Ryan et al., 2005; Murphy & Athanasou, 1999). This was reinforced in this research with consistently positive messages from participants about the value of being in paid employment and about how this contributed to their sense and strength of identity. People in employment identified benefits such as being financially better off, having greater social connectedness, and having an improved sense of purpose, worth, meaning and wellbeing. These people also described receiving validation through their employment and having greater opportunities to contribute to their society or community. These experiences echo the survey data of retrospectively-defined employment groups by Krause (Krause,

1992). That research found that people in the 'current employment group' reported significantly better adjustment in many life areas. Furthermore, in a paper called "Spinal cord injury and the joy of work", Shane Clifton (2014), who himself lives with a cervical level of spinal cord injury, reflects on the ambiguity of work and happiness. He describes our fundamental need to participate in all elements of society and how our contribution to the world through work supports our overall happiness and wellbeing. Clifton's (2014) experiences and observations further augment the value of employment after SCI to a person's identity.

Explorative research in the New Zealand setting by Hay-Smith and colleagues (Hay-Smith et al., 2013) recognised the significance of the modification of employment identity in the return to work process. This was also prevalent for participants in this research, particularly those in the unstable and without employment groups. As previously discussed, the pathway back to work for those in the stable employment group was reasonably clear. For others in the unstable and without employment groups, there was often a process of rethinking, recreating and potentially retraining for an employment role that could be achieved. Given the additional challenges people experience in relation to medical comorbidities and extra life responsibilities, there is clear rationale for promoting and encouraging the development of skills in people for alternative or flexible worker roles. This may include scenarios such as self-employment.
6.4.1.4 Social supports

The importance of social supports and the role these played in contributing to employment outcomes was clearly evident in the findings of this research. This mostly manifested in the form of ensuring access to adequate hours and staff for personal care, but also related to having open and effective communication with potential or current employers, and utilising peer support networks. Connection with peers helped to alleviate some of the fears and 'unknowns' around returning to work, provide possible motivation to become a worker, and assist with modelling employment opportunities, such as exploring flexible work arrangements. The value of social connectedness, peer networks and open communication with employers has also been identified in several other studies as facilitators to employment (Bergmark et al., 2011; Chan & Man, 2005; Chapin & Kewman, 2001; Hay-Smith et al., 2013). Clinicians and service providers can support people's employment goals by promoting peer connections, encouraging effective communication with employers, and, where possible, guide funding arrangements or problem-solve flexible solutions for work arrangements.

6.4.2 Translation of research findings into practice

In order to facilitate the translation of these research findings into practice, a series of six key messages were drawn and developed from the participant's experiences and are presented in Table 18. These messages are specific to people with SCI in the Victorian context, however, the underlying principles could be applied internationally.

Table 18

Key messages supporting translation of research findings into practice, drawn from Study Four: Experience of employment after SCI and pathways involved

• Research and individual experiences consistently show that people are happier and healthier at work.

If people can, it is definitely better for them to work than not. Other research and individual experiences consistently show that people are happier and healthier at work (McKee-Ryan et al., 2005; Murphy & Athanasou, 1999). The many reasons for this include: being financially better off; having better social connectedness; experiencing an improved sense of purpose, meaning and wellbeing; having more opportunity to contribute to the society/community; feeling a more developed sense of worth, etc.

• The pathway back to work may be reasonably clear or incredibly complex.

For some people, the pathway back to work may be reasonably clear, though not necessarily easy, because of their skills and employment history prior to their SCI. For others, there may need to be a process of rethinking, recreating and retraining for a work role that can be achieved. That path is much less clear and can be very difficult to navigate. Large-scale cohort studies are needed to reliably establish the relative proportions of persons in this and other groups.

• When they do not need to rely on welfare or loss of earning benefits, people describe having greater choice and control over their lives.

Victorians have systems of welfare or accident insurance (if an injury is motor transport or work-related) that can support injured persons and provide a sense of security in times of need. However, characteristics of current service systems have

been reliably shown to consume enormous amounts of time and energy, as they are big, complex and bureaucratic. If it is possible to remove the reliance on welfare or loss of earning (or equivalent) payments, people describe having greater choice, freedom and control over their lives.

• Dissemination of inaccurate information or difficulty with comprehension of information is a common experience.

Unreliability of information dissemination or comprehension was frequently reported to cause anxiety or confusion about entitlements and the security of welfare or payments related to a person's injury. It is often difficult to find correct information that is relevant to an individual's situation. It may be that a person wants to work but does not know what to do, is in the process of returning to work, or is working and worried about being able to maintain a job. An easy place to start in guiding a person through this process is the website SpinalHub.com.au, particularly the pages providing information about work.

• Resources are available to assist with return to work.

There are resources available to help overcome obstacles that exist in returning to or seeking employment, regardless of whether a person is insured or not. An example in the Victorian context would be the Employment Assistance Fund through JobAccess, which can provide funding for equipment or modifications that are required in order for a worker with a disability to do a job. If a person is covered under no-fault accident schemes such as Transport Accident Commission (TAC) or WorkSafe Victoria (WSV), they can access vocational guidance and job seeking or job retention support after speaking with relevant claims staff. These systems are not always straightforward to negotiate, which is one of the reasons that many people with SCI do not return to work after their injury. However, examples from current study participants indicate that with persistence and a willingness to problem-solve, it can be done.

• Open communication with employers is crucial.

Achieving successful employment is not just about finding or having the right job. There is so much more to consider and negotiate, from finding independent transport options to making flexible work arrangements that will fit in around personal care requirements. Open communication with one's employer or potential employer and talking to employees who have a SCI can be a useful place to start and can make a difference in achieving or maintaining post-SCI employment.

6.4.3 Limitations of study

The findings of this study shed light on people's experience of returning to work and their employment pathways. These findings can be used to guide future experimental research and also be applied to strategic policy development. However, a number of factors relating to the recruitment of participants in this research potentially undermine comparisons between individual or group experiences in relation to services received.

Eligibility criteria for this study were broad, and the length of time since injury varied between 18 months and 33 years. The policy and practice landscape in relation to specific vocational rehabilitation intervention and the labour market has changed over the period 1975–2012, and therefore participants have been exposed to a range of different services, resources and employment opportunities. The sample size was selected to compliment the aims of the study, with 10 participants in each group believed to be sufficient to produce a stable correlational analysis and enable data saturation in the qualitative analysis. While saturation was achieved in relation to the IPA analysis, it is not clear that 10 participants in each group was adequate for the correlational analyses undertaken. A lack of statistical

significance in the quantitative results may have been related to the relatively small sample size. Despite this, the triangulation of results achieved through the use of mixed methods, has itself enhanced and validated the findings (Klassen et al., 2012).

A further limitation relates to the classification of the groups. The definition for Group C: Without employment had been set prior to participant recruitment and group allocation. Participants met the criteria for the group if, at the time of interview, they had been without employment for a continuous period of at least six months. Of the 10 participants recruited to this group, the majority had experienced some post-injury employment, with only three participants having no post-injury work experience at all. As a result, there was variability observed in the group's pathways and experiences. Upon reflection, the definition for this group needed to be 'no post-injury employment at all', in order to have a cohesive group and provide a clearer contrast between this group and participants in Group B.

The final limitation is not related to participant recruitment. Researcher bias is possible as the first author is an experienced occupational therapist in SCI rehabilitation and service development. As previously described, this information was shared with the participants, and the researcher remained cognisant to this potential bias throughout the data collection and analyses. Occupational therapists work within frameworks such as the CMOP-E to support clients in achieving the goals that are important to them across the domains of selfcare, leisure and productivity (Polatajko et al., 2007a), and they may be biased towards assuming that other health professionals and the client all want to achieve goals in these

domains. Although this potential bias and the pre-existing knowledge of the first author may be considered as a limitation, it also provides a depth of understanding that becomes a strength for interpreting and making sense of the issues and scenarios presented.

6.4.4 Priorities for further investigation

The findings of this study showed that a relationship existed between the measures of satisfaction with life and dispositional optimism, yet neither variable showed a statistically significant relationship with employment status. As described earlier, this may have been related to the sample sizes available. Both of these factors have been associated in previous research with finding or maintaining employment. For example, Chapin and Kewman (2001) identified optimism to be associated with employment, and satisfaction with life as measured by subjective wellbeing was identified in Study Three of this thesis as being predictive of employment outcome. Given the potential utility of this in implications for practice, further exploration of these relationships is encouraged in future studies.

Other recommended priorities for further research include comprehensive tracking of individual employment outcomes over several years post-SCI, and research using a multicentre experimental design to test the effectiveness of different vocational rehabilitation interventions. Also worthy of investigation would be trials of innovative programs designed to build skills in achieving alternative or flexible work arrangements, such as selfemployment, or in navigating service systems related to employment. In addition, the

employment outcome groups and pathways identified for people with traumatic SCI defined in this study could be used for future comparative research.

6.5 CONCLUSION

This research highlights the complex dynamics involved in seeking, gaining or maintaining employment after SCI. Results of this research will assist hospital clinicians, communitybased rehabilitation professionals and funders (both private and public) to reflect on optimal practice to support employment outcomes, regardless of setting and health care or funding systems. The findings provide a greater understanding of the perspective of the service user and yield a number of recommendations to funders of research, system designers and policy makers. Included in the implications of this research is a better recognition of the importance and role of further education to increase skills in appropriate work and hence strengthen opportunities for post-injury employment. People with SCI also need access to accurate and clear information about entitlements, benefits and resources. This access can in turn empower people to negotiate the often extensive environmental factors that can exist as barriers in organisations and service systems, in order to achieve and maintain employment. Adequate and appropriate social supports—such as personal care, employer connections and peer networks—are also critical in facilitating pathways to employment. Finally, of further importance to employment outcomes are the personal drivers. Efforts must be therefore made to encourage positive motivators, including the process of re-establishing worker identity following traumatic spinal cord injury.

CHAPTER SEVEN

7 DISCUSSION

7.1 INTRODUCTION

Extensive clinical experience of local issues, together with limitations in the existing international literature that reports on the challenges people face when seeking, gaining and maintaining employment following traumatic SCI, have led the author to this field of study. Society recognises the fundamental role of employment in people's lives, and the importance of this role is not lessened when an individual sustains a SCI (Clifton, 2014). Despite the recognised vocational potential in individuals who are living with SCI (Young & Murphy, 2009), barriers to employment frequently exist, and the labour force participation rate post-injury often remains substantially lower than the equivalent rate in the general population (Australian Bureau of Statistics, July 2014; Lidal et al., 2007; Ottomanelli et al., 2009; Ottomanelli & Lind, 2009).

This thesis has explored the multiple factors that surround employment outcomes for people following SCI in Victoria, Australia. An innovative approach to vocational rehabilitation, the EIVR program, has been investigated, with the aim of identifying strategies that could facilitate individuals into positive pathways to employment after SCI. In-depth exploration of the experience for the person in attempting to return to work after injury has also been a focus of this work. This research has included investigating the influence of institutional settings (including workplace and rehabilitation facility) and

individual factors that may provide insights to inform practice and potentially be translatable across different settings and environmental contexts.

In achieving these objectives, the thesis has contributed to a deeper understanding of the individual experience of seeking, gaining and maintaining employment following SCI. It has also explored successful vocational pathways taken, along with the contributions of personal and environmental contextual factors in the return to work process and how the introduction of the EIVR program at Austin Health may have influenced employment outcomes. Ultimately, it is hoped that this increased knowledge will inform practice to maintain and enhance employment rates for people following SCI. The thesis aims, and the four studies through which these were achieved, are presented below.

Study One, involving a systematic review, aimed to:

1. appraise and synthesise the peer-reviewed literature to identify the barriers and facilitators influencing people's experience of return to work following spinal cord injury

The second study, an audit of the medical record, aimed to:

2. locate and extract data pertaining to employment outcomes and vocational pathway in the initial years following discharge from inpatient care, for people admitted to Austin Health with a new SCI between July 2005 and December 2009.

The third study, using a longitudinal cohort design, aimed to:

3a. explore employment outcomes at three follow-up time points for people who received the EIVR program, implemented at the beginning of 2010

3b. explore the relationships between employment outcomes over time with aspects of functioning (physical and pain), activities and participation (psychological distress, social participation, relationships, pre-injury education, and pre-injury worker role) and contextual personal and environmental factors (emotional wellbeing, social support, funding arrangement and where one lives)

3c. compare the employment rate after the EIVR program implementation for participants in Study Three with the rate of employment documented from people included in Study Two: Audit of medical records prior to implementation of the EIVR program.

The fourth and final study, using a mixed method approach incorporating interpretative phenomenological analysis, aimed to understand the experience and pathway of persons seeking and gaining paid employment after traumatic SCI in the state of Victoria, Australia, regardless of time since injury. Specifically this involved:

4a. identifying and allocating participants into three employment outcome groups of stable employed, unstable employed and without employment

4b. examining the nature and extent of relationships between employment outcomes, demographic variables, perceived satisfaction with life and dispositional optimism

4c. identifying pre- and post-injury pathways for participants in each of the groups

4d. exploring the experiences of people in seeking, gaining and maintaining employment.

The use of mixed methods across the four different studies included in this thesis allowed for the investigation of diverse research questions in the most appropriate way. Mixed methods provide a richer understanding of research problems, and through triangulation of the results, they provide enhanced and validated research findings (Creswell & Plano Clark, 2006).

In this discussion chapter, the main findings of the thesis are presented and discussed in relation to the aims and the methods used. The findings are also considered with regard to relevant literature—as reviewed in Chapters One, Two and Three—and to the theoretical models of ICF (World Health Organization, 2002) and CMOP-E (Polatajko et al., 2007a) that were used to underpin the research program. Implications of the research findings will be discussed in relation to service delivery, such as possible changes to funding and SCI service models, and to clinical practice. Study limitations from across the research program will be acknowledged, and these, along with the implications identified, inform recommendations for further research.

7.2 FINDINGS

The main findings of this thesis provide the organising structure for this discussion. These findings include:

- The Early Intervention Vocational Rehabilitation program shows promise in enhancing and maintaining positive employment outcomes for people following traumatic SCI.
- The concept of worker identity includes the process of becoming a worker after SCI, as well as the meaning and value of being a worker post-injury.
- Secure relationships, social supports, and the presence of an institutional culture and social environments that are positive about the possibility of achieving employment appear to facilitate labour force participation.
- People with access to loss of earning benefits or equivalent are less likely to return to the labour force.
- Having a higher level of pre-injury education is positively related with participation in the labour force.
- 6. Higher levels of subjective wellbeing are predictive of labour force participation and are positively associated with higher levels of social participation.

A visual figure has also been provided to encapsulate each of these main findings in the relevant section.

7.2.1 The Early Intervention Vocational Rehabilitation program shows promise in enhancing and maintaining employment outcomes for people following traumatic SCI

The EIVR program was implemented as part of SCIS in early 2010. The program focused on enhancing the return to work culture within the rehabilitation setting by encouraging early and positive expectations about work (Schonherr et al., 2004), and through providing vocational interventions to encourage and facilitate vocational pathways and employment outcomes. Figure 11 shows the key inputs of the EIVR program by vocational rehabilitation professionals and acknowledges the steps that a person with SCI would experience in navigating the commencement of or return to employment. The utility of the EIVR program was explored in Studies Two and Three through the comparison of the employment rate two to five years following injury for a group that received the EIVR program and a group that did not. An audit of the medical record of 98 cases of people with traumatic SCI admitted to SCIS between 2005 and December 2009 established an employment rate of 20.4% (95% CI [12.9–29.7]) at two to five years post-injury. A cohort of N = 97 people admitted to the spinal rehabilitation unit between 2010 and 2013 received the EIVR program and were then investigated via a longitudinal study. The employment rate at two to five years post-injury for this group was 33% (95% CI [24%–42%]). In addition to the different employment rates, maintenance of employment appeared stronger in the EIVR program cohort. In the audit group, 12 people commenced employment following injury and then ceased again within five years post-injury. Comparatively, in the EIVR program group, five people commenced employment post-injury and then ceased within five years.

While the sample sizes in these studies are small, and the differences for gaining and maintaining employment were not statistically significant between the two groups, the results are nevertheless encouraging for the use of the EIVR program.



Figure 11. Visual representation of the research findings related to the EIVR program

As identified earlier in section 2.4 in Chapter Two of this thesis, there is a limited evidence base for the effectiveness of vocational rehabilitation interventions for people with SCI (Roels et al., 2016). Ottomanelli and colleagues' (Ottomanelli, Barnett, & Goetz, 2014) study investigated the use of evidence-based supported employment (EBSE) and is the only randomised controlled trial examining the effectiveness of vocational interventions with people with SCI. As previously discussed, however, there are limitations with extrapolating the findings of that trial outside of the US, and difficulties exist in implementing EBSE in different jurisdictions. For example, EBSE has most commonly been used in populations with severe and persistent mental illness, but this approach is not widely available nor understood in Australia (Waghorn & Hielscher, 2014) (Waghorn & Hielscher, 2014). Coupled with this, supported employment has historically been delivered in Australia in specialist supported work environments (Australian Disability Enterprises, N.D.). This is not mainstream employment and not comparable to the open labour market. There are, however, elements of the EBSE approach which may offer some utility in Australian SCI rehabilitation settings. Ottomanelli et al. (Ottomanelli, Barnett, & Goetz, 2014) propose that vocational rehabilitation interventions are more valuable if they are integrated into the SCI rehabilitation setting, engage in an individualised approach and remain involved with the client as required, and are not time-limited. These views resonate with the philosophy and practice behind the EIVR program that was implemented in this research program.

As promoted by Ottomanelli et al. (2014), Middleton et al.'s (2015) study, which was outlined in section 2.4, also utilises an individualised vocational rehabilitation approach and integrates it early into the SCI rehabilitation setting. The employment rate of 34.5%

achieved at six month post-discharge by participants in Middleton et al.'s (2015) research appears very promising, and the authors have proposed a longitudinal follow-up study to ascertain if the employment rate is maintained beyond this first time point.

Many of the formative features of the EIVR program, such as setting positive expectations and early support with decision-making, were manifest in the findings of this research program. In the analysis of vocational pathways in Study Four, of the 31 people interviewed, only five had a clear pathway to employment after injury. These people appeared to have a positive expectation about work and a supportive employer. Additional considerations such as workplace modification, physical requirements or other life demands did not become barriers to employment for those people. In contrast, all other participants identified difficulties such as decision-making, balancing other life demands or physical issues, or having an unsupportive employer as factors that complicated their vocational pathway. A recurring theme in Studies One and Four was the need to nurture a sense of hope and possibility in individuals for their future as workers. Dorsett (2008) undertook a ten year longitudinal cohort study with 46 people to explore the role of hope in coping and adjustment to SCI. The findings suggest that life roles such as employment provide positive motivation and can support a person's ability to cope with significant life changes (Dorsett, 2010). Furthermore, early access to vocational rehabilitation in another Australian SCI rehabilitation setting, also nurtured feelings of hope (early after injury) among several participants in a qualitative inquiry (Ramakrishnan et al., 2016).

Hope and possibility are also central to the spiritual domain of the CMOP-E. Spirituality sits at the 'heart' of the CMOP-E (see Figure 1), which provides further context for clinical practice. The vocational rehabilitation professional, working alongside occupational therapists in SCIS, aimed to support hope and possibility in the individual for a future as a worker, while also encouraging cultural change within the rehabilitation facility. Bergmark and colleagues' (2011) study with young adults who had recently sustained a SCI further supports the relevance of early discussion and intervention. It was deemed essential by the participants in that study to consider a future as a worker. Early, positive expectation setting and support with decision-making were also recognised as important by Fadyl and McPherson (Fadyl & McPherson, 2010), who proposed a model incorporating four identified themes (see section 2.5.1) to guide practice in the SCI rehabilitation setting to assist people in making informed decisions about their employment after SCI.

While providing an opportunity to reflect on and re-engage with a person's vocational identity, the EIVR program aims to assist an individual in navigating the process of seeking or returning to work. This can include providing education to employers about SCI and accessing funding for assistive technology to support a return to work. The results of the thematic synthesis in the systematic review of Study One, together with the IPA and pathway analysis of participants interviewed in Study Four, re-emphasise that the process of seeking, gaining and maintaining employment following SCI is incredibly complex. However, the literature consistently demonstrates that gaining employment following SCI is a positive outcome for people (Hay-Smith et al., 2013; McKee-Ryan et al., 2005) and that regardless of their level and severity of injury, people have an intrinsic need for

occupational engagement through paid employment (K W Hammell, 2013). This is also reflected in the CMOP-E, where productivity is treated as a core component of occupational performance (Polatajko et al., 2007a). One of the findings from the IPA of interviews with participants in Study Four was that having access to someone who could help to navigate the return to work journey appeared to assist people in achieving an employment outcome. In New Zealand, early vocational rehabilitation has been incorporated into the spinal injury rehabilitation program since 2000. Hay-Smith and colleagues (2013) explored the meaning of employment in this setting, from the perspectives of persons with SCI and the vocational rehabilitation professionals employed alongside them. The authors suggest that people with SCI need support and understanding to allow for a process of employment identity modification. Furthermore, they believe that vocational rehabilitation professionals have a role in facilitating return to employment by supporting clients to find work opportunities congruent with employment identity (Hay-Smith et al., 2013).

In summary, all studies undertaken in this research contributed to the finding that the EIVR program shows promise in enhancing and maintaining employment outcomes following SCI. While a true comparative design was not achieved in Study Three, and therefore causation cannot be inferred, the results of the medical record audit and longitudinal study are still of interest. This limitations and directions for future work regarding this finding are explored later in this chapter.

7.2.2 The concept of worker identity includes the process of becoming a worker after SCI, as well as the meaning and value of being a worker post-injury

Findings around the concept of worker identity were particularly prevalent in the thematic synthesis of the literature completed in Study One and in the IPA of interview data undertaken in Study Four. As depicted in Figure 12, the concept of worker identity appears to be interrelated with the process of or motivation for becoming a worker and the meaning and value of being a worker. Pre-injury worker identity also appears to influence the relationship between the process of becoming a worker and value of being one. While a research aim was not developed to explore the concept of worker identity in Studies Two and Three, the importance of recognising vocational identity in people with a recently sustained SCI is a documented step of the EIVR program guidelines, and therefore emerged as a key finding.



Figure 12. Visual representation of the research findings related to worker identity

In Study One, the analytical theme that there is an intrinsic need for occupational engagement through paid employment was drawn from descriptive concepts across several appraised papers. As discussed under the previous finding about the EIVR program, this need for occupational engagement is also reflected in the CMOP-E, which notes that productivity such as in paid employment is core to occupational performance (Polatajko et al., 2007a). In all papers included in Study One, the value and meaning of being a worker was highly visible and was often described in association with worker identity. The CMOP-E provides a spiritual context for value, meaning and identity to be expressed as the essence of the person. The participants in Study One and Four presented consistently positive messages about the value of being in paid employment and highlighted how this also contributed to their sense and strength of identity. People described employment as a source of mental stimulation and an opportunity for personal growth and independence (Chan & Man, 2005; Chapin & Kewman, 2001), and furthermore it was part of their identity and represented "living a normal life" (Hay-Smith et al., 2013). Given the established association between experiencing SCI and a subsequent loss of identity (K W Hammell, 2007; Levi et al., 1996) the findings from this research reaffirm the significance of seeking, gaining and maintaining employment after SCI as a way of reconnecting individuals with a sense of identity post-injury.

The interpretative phenomenological analysis of participants' interview data in Study Four also revealed experiences relating to the process of becoming, as well as being, a worker. Combined with the analysis of the vocational pathway, this led to a theme of the impact of worker identity on motivating employment. The re-establishment of worker identity appeared to be a positive motivator for many participants and was observed in examples of problem-solving to overcome environmental barriers and appreciation of role validation in the workplace. Finding a worker identity again could also be complicated, however, by changes to physical identity or life roles that were associated with the pre-injury worker identity. This was also identified in the literature analysed in Study One. Adjustment to SCI appears to be a highly personal journey. Study One suggests that as individuals reflect on the loss of their pre-injury worker identity, it can take time for them to find meaning and

identity again in employment, particularly early after injury (Bergmark et al., 2011). Personal resources were required to deal with emotional issues (Fadyl & McPherson, 2010) and disengagement from the worker role (Hammel, 1999). These personal resources referred to the emotional energy required to adapt to physical and social changes, along with financial concerns, following SCI.

While the concept of worker identity is often described in the literature, these studies rarely reflect on the multiple components relating to the process and meaning of worker identity. In studies by Leiulfsrud et al. (2014), and Wilbanks and Ivankova (2015), the focus is on the contribution of being a worker to a person's sense of worth, self-esteem, social value and confidence. Consistent with findings from Murphy et al. (2014), these studies affirm that being employed helped people to have a feeling of place in society (Leiulfsrud et al., 2014; Wilbanks & Ivankova, 2015). Hay-Smith et al. (2014) also recognised the process and meaning involved with worker identity. These authors observed the concept of employment identity and its role in returning to employment. When a person had been employed pre-injury, the authors described a process of 'identity modification' as part of the experience of pursuing post-injury employment (Hay-Smith et al., 2013).

The qualitative analyses conducted through thematic analysis in Study One and through interviews conducted with people who have experienced SCI in Study Four were the most useful in recognising and drawing out the concept of worker identity and the relationship of this with processes and outcomes. The findings highlight the importance of addressing worker identity, as outlined in the interventions described in Study Three. The second step

of the EIVR program (see guidelines in Table 3) is to acknowledge the vocational identity of the individual. The EIVR staff then proceed with exploring vocational options, assisting the person to form a vocational plan, and tailoring interventions to suit their goals and situation. (For more detail, see Chapter 1 and Appendix B).

As described earlier, the meaning and value associated with worker identity is also reflected in the spiritual and affect components of the CMOP-E (Polatajko et al., 2007a). Rosenbloom and Williams (2010) illustrate this in relation to the various impacts of trauma. At the spiritual level, there can be a loss of hope and greater meaning in the world following SCI. In an affective sense there can be fear, grief and loss of self-esteem (Rosenbloom & Williams, 2010). The current research demonstrates that finding a positive worker identity can help to counteract these challenging experiences. It is therefore vital that individuals are supported in navigating the return to work process and nurturing their worker identity. As Hammell (2013) observes, employment as 'occupation' is essential in redefining or creating identity.

7.2.3 Secure relationships, social supports, and the existence of culture in institutional and social environments that are positive about the possibility of achieving employment appear to facilitate labour force participation

The overlapping nature of the factors that appear facilitatory of labour force participation are depicted in Figure 13 and were drawn from across the four studies in the current research program. Having secure relationships appeared to be positively associated with participation in the labour force post-injury. Study Three found that participants who were

in a relationship at discharge had significantly increased odds of gaining employment after SCI. In addition, through thematic synthesis of literature in Study One (Chan & Man, 2005; Hay-Smith et al., 2013) and thematic analysis of participant interviews in Study Four, it was observed that opportunities for employment were enhanced through the existence of social support. An explicit link between social connectedness—such as the use of social networks to link to possible work, or exposure to a peer who was active in the labour force (Hay-Smith et al., 2013)—and employment outcome was evident in Study One. Furthermore, sufficient practical support to manage personal care was a key form of social support that was identified by participants in Study Four as being essential to achieving a stable employment outcome. Similarly, the IPA of participant interview data in Study Four identified that exposure to the phenomenon of peer support fostered independence and helped to build motivation and confidence in individuals. Previous studies further augment the value of social support, suggesting that it can contribute to positive employment outcomes (Burns et al., 2010; Murphy et al., 2010). This finding has direct implications for clinical practice, most specifically the way in which allied health and nursing staff monitor, and if need be strengthen, a person's level of post-injury social support.



Figure 13. Visual representation of the findings related to culture and social supports

The culture in institutional and social environments has been included in this finding due to the apparently overlapping nature of culture and social support. The existence of 'culture' in institutional and social environments was not explicitly explored or measured in any of the four studies, yet findings across this research program refer to aspects of culture and the possible influence of it on people's experiences and employment outcomes. The cultural environment is also recognised in both the CMOP-E and ICF. Even so, the experience of culture can be intangible and subjective and therefore potentially difficult to measure (Mohr & Rawlings, 2012). It is possible that this is the reason there is little recognition across the SCI literature about why culture is important in relation to supporting a return to work (Murphy, 2009; Ottomanelli et al., 2009). As depicted in Figure 13, the institutional environment refers to culture in the workplace and the SCI rehabilitation facility, while the social culture includes the social environment, societal attitudes and social support (Mohr & Rawlings, 2012).

In Study One of this research program, the first analytical theme was that a matrix of personal and environmental factors exist, requiring complex navigation in order to create possibilities and opportunities for achieving post-injury employment. The theme refers to examples in the literature about accessing peer support, the attitude of social networks, and supportive institutional cultures. Positive cases of peers who had returned to work (Chapin & Kewman, 2001), a social network that recognised the value and importance of work (Hay-Smith et al., 2013), and/or a rehabilitation environment that encouraged the exploration of work possibilities and incorporated these goals into the rehabilitation plan (Fadyl & McPherson, 2010) were all examples of culture that appeared to promote postinjury employment. Conversely, there were also examples in the literature where people had been exposed to instances of discrimination and perceived social stigma in the workplace (Chan & Man, 2005; Chapin & Kewman, 2001; Wilbanks & Ivankova, 2015). This manifested as misconceptions about an individual's physical and cognitive abilities following injury (Chapin & Kewman, 2001; Fadyl & McPherson, 2010; Leiulfsrud et al., 2014; Wilbanks & Ivankova, 2015). Contrary to these examples, (Murphy, Middleton, Quirk, De Wolf, &

Cameron, 2009) undertook an exploratory analysis of participation and environmental factors in predicting post-discharge employment for 72 people following SCI. As defined by the ICF, the environmental factors included the physical, social and attitudinal environments in which a person lives their life. The authors reported that an individual's sense of belonging in their community, as evaluated by the Community Integration Measure (McColl, Davies, Carlson, Johnston, & Minnes, 2001), appeared to be predictive of postinjury employment success. All of these examples provide insights into the underlying importance of a supportive culture in the return to work process and also emphasise the relevance of effective communication and education in the workplace to alleviate misconceptions and misunderstanding about SCI.

In the audit of data pertaining to the employment status of individuals in Study Two and the longitudinal employment outcomes collected in Study Three, aspects of the institutional rehabilitation culture—or the lack thereof—emerge in the narrative around the results. There were sparse details concerning work in the medical record. Rarely did it appear that vocational exploration between the person with SCI and the clinician occurred. Conversely, the EIVR program delivered as part of Study Three deliberately engaged strategies to enhance the rehabilitation culture with positive messages about work being possible and important for people after SCI. A potential shift in culture was anecdotally observed in the rehabilitation setting longitudinally following the implementation of the EIVR program, but this was not empirically tested. In exploring participants' experiences in Study Four, an historical lack of supportive culture about employment in the rehabilitation setting was reported. This also appeared to manifest as misinformation or difficulty in the dissemination

or comprehension of information. In contrast, however, a supportive workplace, encouraging peers, and positive messages regarding the importance and possibility of work helped to promote aspirations of future employment.

As described in Chapter One and further emphasised in section 6.4.1.1 of Chapter Six, existing literature suggests that the culture of social and institutional environments, including spinal rehabilitation centres and workplaces, have not typically been predominantly supportive and positive about people's ability to return to work after SCI (Hammel, 1999; Murphy, 2009; Ottomanelli & Lind, 2009). It is a limitation of this research that culture was not explicitly measured, as it appears to be a concept that is worthy of further exploration. Reflection on the various aspects of relationships, social support and culture in relation to employment after SCI can lead to the identification of implications for practice. These implications will be addressed later in this chapter.

7.2.4 People with access to loss of earning benefits or equivalent are less likely to return to the labour force

Each study in this thesis deliberated, to some extent, the relationship between labour force participation and the funding or compensation status of the individual. The first finding of interest from a broader international context came from the systematic review, and it is poignant in any setting. This finding noted that once a person had found a balance between different financial demands and expectations of life post-injury, employment could become a possibility (Chapin & Kewman, 2001). The findings from Studies Two, Three and Four were

all drawn from the Victorian service system, and are therefore related more specifically to an Australian context. Drawing on the findings across all studies, Figure 14 depicts the various factors related to funding status or compensation, that require practical consideration before employment itself may be a possibility following SCI.



Figure 14. Visual representation of the findings related to funding status and practical considerations

In the audit of medical records conducted in Study Two, people who achieved an employment outcome at two to five years post-injury were more likely not to have access to a loss of earning benefit or equivalent. Similarly, in the quantitative component of Study Four, participants with loss of earning benefit or equivalent were statistically more likely not to be in paid employment. That study also made an observation from a qualitative perspective, however, that if it is possible to remove the reliance on welfare or loss of earning or equivalent payments, people described having greater choice, freedom and control over their lives. This reinforced the finding from Study One about the importance of finding balance between financial demands and lifestyle expectations (Chapin & Kewman, 2001). These observations also broadly align with the findings of Kilgour et al.'s (2015) systematic review of interactions between injured workers (all injuries) and insurers in systems with workers compensation. While it does not appear that any of the worker injury types included in the review were SCI, the findings still offer valuable insights into the experiences of insurance claimants and the potentially negative impact of these on their mental health, social and vocational outcomes (Kilgour et al., 2015).

No significant relationship was found between funding status and labour force participation for participants in Study Three. This suggests that more people in this study with access to compensation chose to return to the labour force than is indicated in rates reported in other research. It is possible, therefore, that the EIVR program promotes positive expectations about work, beyond the financial benefits, and actively supports people in exploring the return to work. This requires further investigation.

It is believed that this is the first empirical investigation of employment outcomes and funding status for people with SCI in Victoria. The findings vary across Studies Two, Three and Four, but the principles influencing outcomes are often the same, and echo those identified through the thematic synthesis in Study One and the interpretative phenomenological analysis of participant interview data in Study Four. As outlined

previously, opinions vary about funding scenarios across jurisdictions. In a study of a sample of people with SCI in Queensland, Australia, social security benefits in the form of disability pension were deemed a financial disincentive to employment (Conroy & McKenna, 1999), and with a cohort post-SCI in the United States, public insurance was also deemed to negatively influence a return to the labour force (Phillips et al., 2012). In contrast, (Paul et al., 2013) observed higher employment rates (although these were not statistically significant) for people with SCI who were eligible for insurance, however, this was in the context of a no-fault accident insurance scheme (Accident Compensation Corporation) and an established early vocational rehabilitation intervention program. The findings of this current research and the variations in context and findings of existing research, combined with the knowledge that people will make choices in relation to financial security and stability (Fadyl & McPherson, 2010), highlight the importance for the individual of regaining financial control. Where possible at a policy or practice level, changes should be considered to reduce concerns about loss of entitlement, to ensure that opportunities for work are available to people without fear of failure and associated financial risk.

7.2.5 Having a higher level of pre-injury education is positively related with participation in the labour force

The findings from this research program are consistent with the literature in terms of higher pre-injury education being a known facilitator of post-injury employment (Ottomanelli & Lind, 2009; Trenaman et al., 2015). In the longitudinal cohort study of people receiving the

EIVR post-SCI (Study Three), a generalised linear mixed effect model predicted employment status from covariates. Holding a degree level of education or above pre-injury was the most powerful predictor of employment outcome and was associated with an eightfold increase in the odds of being employed at two to five years post-injury. Similarly, the pathway analysis conducted in Study Four showed a distinct difference in employment outcomes between people who had completed tertiary level education and those who had not. For example, almost three quarters of the participants in the stable employment group had undertaken tertiary studies, whereas only one fifth had done so in the group without employment. Of the people who returned to study or retrained post-injury, the majority were able to achieve stable employment following cessation of their studies.

In the audit of medical records in Study Two, there was no statistically significant relationship between pre-injury education and employment outcome. A significant correlation did exist, however, between pre-injury occupation type and employment outcome, with more professional-level positions being associated with participation in the labour force by two to five years post-injury. While this discrepancy may have occurred due to the small sample size or inaccurate recording of primary data, as detailed in the limitations section of Chapter Four, the finding is reflective of earlier research with another Australian cohort (Murphy et al., 2009). In that study, Murphy and colleagues (2009) found that a highly skilled pre-injury occupation was predictive of employment success at one year following discharge. Visual representation of the different variables related to education level is provided in Figure 15. The darker shades relate to higher employment outcomes.



Figure 15. Visual representation of the findings related to education level

Empirical reviews of factors associated with employment outcome across numerous studies consistently find that a higher level of pre-injury education is positively associated with post-injury employment (Ottomanelli & Lind, 2009; Trenaman et al., 2015). Post-injury education has been less frequently explored, but nonetheless, studies also consistently recommend the potential scope of post-injury vocational pathway facilitation through retraining or further education (Krause & Reed, 2009; Murphy, Brown, Athanasou, Foreman, & Young, 1997; Tomassen et al., 2000). Ferdiana and colleagues (2014) acknowledged this in more recent work and particularly promoted education and training to people who may be on a low or no employment trajectory. This work was described in detail in section 2.2 of Chapter Two.

Resources exist in Australia to facilitate participation in educational opportunities after the acquisition of disability. For example, some compensation systems (such as the Transport Accident Commission in Victoria) will cover the "reasonable cost of vocational retraining and prevocational activity to enable clients to resume and maintain employment" (Transport Accident Commission, 2005). Tertiary education facilities in Australia usually employ "disability practitioners" (often known as liaison officers), whose role is to support the participation of people with disability in the "education environment" (Australian Disability Clearing House on Education and Training, N.D.). The efficacy of these resources in assisting people with SCI are currently unknown. It would seem appropriate that these types of resources be further explored regarding their contribution to post-injury employment outcomes.

7.2.6 Higher levels of subjective wellbeing are predictive of labour force participation and are positively associated with higher levels of social participation

Subjective wellbeing, understood in lay terms as 'happiness' or 'life satisfaction' (Diener, Oishi, & Lucas, 2003), was found in this research to have a relationship with employment and social participation (as depicted in Figure 16). Subjective wellbeing was measured in the participants of Study Three by the Personal Wellbeing Index (International Wellbeing Group, 2013), and the cognitive component of subjective wellbeing was measured in the
participants of Study Four using the Satisfaction With Life Scale (Diener et al., 1985). The mixed method study designs across this thesis again provided the opportunity to triangulate results from the different study methodologies to enhance and validate the research findings. The qualitative components of Studies One and Four provide additional insights regarding adjustment and identity that were also discussed in the finding related to worker identity (see section 7.2.2).



Figure 16. Visual representation of the findings related to subjective wellbeing

Study Three aimed to examine the relationship between personal factors and employment outcome. A regression model found that a higher level of subjective wellbeing in participants at discharge from the SCI inpatient rehabilitation unit was predictive of participation in the labour force at two to five years post-discharge. Diener and colleagues (2003) define subjective wellbeing as a person's cognitive and affective evaluations of his or her life. The cognitive element refers to what people think about life satisfaction in global and domain—such as work—terms. The affective element includes emotions, moods and feelings, which can be positive or negative (Diener et al., 2003). The finding of this study is supported by other research, where benefits of employment on personal health and wellbeing have been identified. Employment gives people an opportunity to contribute to society, subsequently providing them with life purpose (Schonherr et al., 2005; Tomassen et al., 2000; Ville, 2005). The relationship between employment and subjective wellbeing is also suggested by Chapin and Holbert (2010). In an expost facto design with N = 61participants, Chapin and Holbert (2010) explored the characteristics associated with being employed and consistently found higher life satisfaction in employed people when compared with people who had not achieved employment.

There was no significant relationship found between global life satisfaction (the cognitive component of subjective wellbeing and measured by SWLS) and employment in Study Four. This may have been because the study was cross-sectional and the time since injury for participants ranged from between 18 months and 35 years. There were, however, themes identified in the interpretative phenomenological analysis of the interviews in this study that consistently represented a sense of control and satisfaction, strength in identity, and

role validation in being a worker, especially for people in the stable employment group. As previously mentioned, this finding about subjective wellbeing overlaps somewhat with the finding in Study One about adjustment. It was beyond the scope of this thesis to explore the psychological aspects of the adjustment process following SCI. However, it is acknowledged that adjustment is a personal journey (Middleton & Craig, 2008) and that employment appears to play an important role in the adjustment process (Craig et al., 2015).

The second part of this finding about subjective wellbeing, as found in Study Three and depicted in Figure 16, was that higher levels of subjective wellbeing were positively associated with higher levels of social participation. The data analysis undertaken in Study Three showed that high levels of social participation were positively related to lower ratings of pain, as well as lower scores of anxiety and depression. It is pertinent to reflect again (see also Chapter Five) that, as shown in Figure 16, there was a lack of significant findings between social participation and employment in this research program, despite this relationship being found in similar cohort and sample size in another Australian study (Craig et al., 2015). Craig's study (2015), however, measured post-discharge outcomes at six months. This is compared to outcomes at 12 months following discharge for the participants in Study Three of this research program. It is also not clear in Craig's (2015) study if being employed only referred to paid employment. Despite these limitations, further investigation of the relationship between employment and social participation is warranted.

7.3 STUDY LIMITATIONS

While the limitations associated with each study were addressed in the relevant chapters, this section summarises the main methodological limitations across the research program. The review process, documentation of data, appraisal and synthesis undertaken in the systematic review in Study One were guided by the ENTREQ statement (enhancing transparency in reporting the synthesis of qualitative research; (Tong, Flemming, McInnes, Oliver, & Craig, 2012). However, the main limitation associated with the review was restricting the search process to four electronic databases and to peer-reviewed literature. It may have been that expanding the search process beyond peer-reviewed databases and using reference list checks to include 'grey' literature may have identified additional studies. Even so, it is unlikely that any additional papers identified this way would have met the methodological standards required to be included in the synthesis.

Study Two involved an audit of medical records. The quality and quantity of data obtained through the audit were limited due to missing information. This was either due to client non-attendance at outpatient appointments or insufficient detail recorded by scribes over the duration of the record. It is possible that the results obtained in this study provide a biased picture of employment outcome, as missing data was treated as constituting 'no employment outcome'.

As has been previously discussed, the methodology of Study Three was compromised by the lack of a control group and was therefore limited in its ability to test the efficacy of the EIVR program. The sample size of N = 97 was insufficient to support regression modelling, and

this issue was exacerbated by the occasional absence of data at different time points and for different measures. It is therefore possible that statistically or clinically significant results between variables were not revealed.

The sample size of N = 31 for Study Four was sufficient for the qualitative data used in the IPA but provided inadequate power for statistical testing of the quantitative data collected from participants. With a larger sample size, a significant relationship between optimism, life satisfaction and employment may have been identified. A further limitation of Study Four was the accuracy of the definitions used for the three employment groups. It is possible that the characteristics between Group C: Without employment and the two other groups were too similar, and therefore the differences between the groups were not substantial enough to show an effect.

In summary, the limitations of this research program predominantly related to small sample size and the need to achieve a randomised control trial design to test the effectiveness of the EIVR program. The small size of the SCI population in Australia, along with difficulties in withholding interventions in clinical environments, reduces the opportunity to overcome these limitations.

7.4 IMPLICATIONS FOR PRACTICE

This program of research has offered many insights into the experience and pathway of seeking, gaining and maintaining employment after SCI. Findings have also strengthened knowledge of potential interventions and strategies that may better support people with

SCI to achieve employment outcomes. In this section, implications for practice have been summarised in relation to areas of service delivery (funding models and SCI services) and the clinical practices of health professionals such as occupational therapists, medical staff and nurses.

The findings from this research program create several opportunities to explore and potentially strengthen how both funders—in the public health, welfare and insurance sectors—and employers develop policy and provide support and resources to people with SCI through different service delivery models. These opportunities could include:

- Exploring changes to policies that relate to human resource management in order to trial supported and flexible structures in the workplace. This might involve the trial and implementation of programs such as a sick-leave bank, working remotely, sick leave at half pay, and flexible work hours that allow workers to maintain employment while having access to adequate leave for sickness and recreation.
- Exploring changes to welfare and insurance policies to allow trials of paid employment for a set period of time without any change to or fear of impact on benefit entitlements. This could include providing further education and awareness about existing safety nets that promote a return to work but are designed to accommodate changes in capacity.
- Accommodating changes to work arrangements, such as offering reduced working hours combined with access to disability superannuation or other income support, to allow workers to maintain employment in an appropriate capacity.

- Creating or exploring funding models, such as shared care, that provide adequate personal care provisions to allow individuals to fully participate as workers.
- Offering additional retraining and/or further education to promote and encourage the development of skills in people to allow for alternative or flexible worker roles. This may include scenarios such as self-employment or upskilling to enhance employment opportunities.

Service providers in SCI management could consider the following opportunities to enhance practice and facilitate optimal employment outcomes for people with SCI:

- Implementing or continuing the provision of the EIVR program as early as possible within acute and rehabilitation SCI services in Australia
- Partnering with advocacy groups to provide education to employers and workplaces in order to promote corporate social responsibility and policy level strategies, as described earlier, to support people's ability to maintain employment.

Finally, health professionals working with people with SCI have the opportunity to:

- Be trained in the EIVR program (see Table 3)
- Recognise the value of employment as occupation for an individual's identity and life meaning
- Acknowledge the value that peer connections can add to a person's rehabilitation experience, and utilise these positive role models in practical settings to support the encouragement of hope and possibility after SCI.

7.5 DIRECTIONS FOR FURTHER RESEARCH

The aim of this research program was to extend knowledge and understanding of people's experience of seeking, gaining and maintaining employment after SCI. This involved investigating the pathways taken to achieve this and examining how the EIVR program may influence employment outcomes. The findings of this research have enabled the provision of recommendations that will further enhance policy and practice and promote positive employment outcomes for people following SCI. At the same time, the research findings have produced a new set of questions that are beyond the scope of this current research. Some of these questions have arisen from the limitations that existed across the studies. Others have been prompted by the desire to understand even further the complexity of seeking, gaining and maintaining employment after SCI. These questions guide directions for further research.

Further research is required to explore the effectiveness of the Early Intervention Vocational Rehabilitation program and its application in other national and international settings. It is recommended that this be done using a randomised control trial design, in conjunction with comprehensive tracking of individual employment outcomes over several years post-SCI. Ideally, this would be undertaken across multiple centres. Trials of innovative programs designed to build skills in achieving alternative or flexible work arrangements, such as self-employment, or of innovative approaches to promote system flexibility that will support opportunities for employment and independence from systems,

also require further study. These possibilities were identified in section 7.4 and require empirical exploration. The value of peer mentors was referred to on several occasions throughout this thesis and formed part of the overarching themes identified in Studies One and Four. Research to explore the role and value of peers, and how this resource can best be utilised in rehabilitation and community settings, is also worthy of investigation.

Several environmental contextual factors were raised over the course of this thesis in relation to employment outcomes and these may be useful to investigate further. Some of the participants in Study Four reflected on the challenges of accessing sufficient personal care in order to allow for participation in a worker role. This included making considered choices about where one lived in order to have access to a stable carer workforce. Such choices needed to be made in conjunction with decisions about access to independent transport and proximity to employment opportunities. Study Three used information about where people lived (converted to SLA) to explore if there was a relationship between people's employability and factors of area remoteness, area economics, labour force activity and ease of access to amenities. While no relationship was found in this regard, it is recommended that SLA be explored further with a larger sample, or indeed with people from different impairment groups. Independent transport was not explicitly investigated in any of the current studies, however, it did emerge in the thematic synthesis in Study One and the thematic analysis in Study Four as another important consideration in the return to work process that has previously been recognised in the literature (Lidal et al., 2007). Further exploration of these potentially modifiable environmental factors could provide

additional valuable insights around barriers and facilitators to gaining and maintaining employment.

Future research could also investigate strategies that support people in gaining employment. Several participants in Study Four described difficulties in finding or getting a job. While this challenge is common in the general population, some aspects of job seeking can be unique for people with SCI, such as whether or not to disclose extent of impairment and how to alleviate misinformation about SCI with potential employers. Support around this could be a role for the vocational rehabilitation professional or be included as part of job seeking services offered by community-based vocational rehabilitation providers. Young and colleagues (1996) trialled a 'job club approach' based on Azrin's behaviourally-based job club methodology (in (Young, Murphy, & Athanasou, 1996) with ten people with SCI who wanted to work. The results were encouraging, but the service did not continue. It may be timely to revisit such interventions or strategies, particularly in the community setting, and investigate their ongoing value.

Findings from this program of research identified individual attributes and skills in people that appeared facilitatory of employment success after SCI. These have included people's level of motivation, having strong social support, and the ability to seek out positive role models. Future research should consider investigating other specific psychological characteristics or protective factors—such as a person's coping style, their level of resilience and skills in appraisal—and the relationship between these characteristics and employment. Attempts were made in Study Three to explore the relationship between social participation

(as a measure of adjustment), optimism and employment outcomes. However, significant findings were not obtained. Based on the experiences of some participants in this study and that which is described in other research (Chapin & Kewman, 2001; Craig et al., 2015; Dorsett, 2010; Kennedy, Evans, & Sandhu, 2009; Krause, 1992), further exploration in this area is warranted.

One additional area of potential research would be an examination of the relevance of the findings presented here to the Australian National Disability Insurance Scheme (NDIS). In July 2012, following a Productivity Commission report and years of discussion about the need for a major reform to disability services, the Council of Australian Governments committed to the implementation of a National Disability Insurance Scheme (NDIS). The NDIS provides supports to people with disability using a very different model to previous disability services. The purpose of the NDIS is support people with disability to build their skills and capability so they can participate more fully in the community and in employment (National Disability Insurance Agency, 2016). From 1 July 2016, the NDIS has been introduced in stages around Australia. It will continue to be introduced over three years to ensure it is successful and sustainable (National Disability Insurance Agency, 2016). The NDIS is constantly evolving, and it is difficult to know exactly what the future with a fully implemented NDIS will look like. However, the changes to funding for non-compensable clients should be monitored carefully, and research should investigate the effect of these funding changes and the model of care in general on employment opportunities for people with SCI.

7.6 SUMMARY

The main findings from across the four studies carried out in this thesis have been discussed in detail in this chapter and reflected against findings both from existing literature and the theoretical models of the ICF and CMOP-E. These findings have led to the identification of implications for practice across funding environments, SCI service provision, and the delivery of clinical practice by health professionals. Limitations of the studies have been considered and presented. Finally, directions for future research, in order to further enhance opportunities for people to achieve and maintain employment outcomes after SCI, have been described. The next chapter summarises and concludes the thesis.

CHAPTER EIGHT

8 SUMMARY AND CONCLUSION

This research program comprised four studies that aimed to: further understanding of the complexity of seeking, gaining and maintaining employment after traumatic SCI; explore changes to practice that have attempted to improve opportunities for people for employment following SCI; identify vocational pathways that can lead to employment success; and recognise different personal and environmental contextual factors that can contribute to people achieving employment outcomes post-SCI.

Chapter One provided the background rationale for this research. It outlined the functional and structural components of SCI from the ICF framework and introduced the key impacts of SCI, in terms of activity limitations and participation restrictions. Also described in that chapter was how the systems of SCI management in Victoria, Australia, operate to assist people with SCI to live as fully and independently as possible. This included an outline of the Early Intervention Vocational Rehabilitation program, which was implemented in 2010 in response to several identified issues that were negatively impacting on people's ability to optimally reintegrate to their communities post-SCI. Literature concerning what is known about the experience of people attempting to gain or return to employment after SCI and the current vocational rehabilitation service system in Victoria were reviewed in Chapter One. A selection of environmental factors that influence SCI management, along with vocational rehabilitation provisions, were presented for several countries and jurisdictions. Chapter One also introduced two frameworks—the ICF and CMOP-E—which were chosen to assist in understanding the complexity of problems arising from SCI and how these impairments impact on a person's ability to effectively reintegrate into their community, including seeking and gaining employment.

In Chapter Two, a critique of the literature in relation to vocational interventions, vocational pathways, employment rates and factors related to employment after SCI was completed. Literature pertaining to environmental and personal factors associated with SCI was presented in relation to the CMOP-E domains. The critique of the literature identified several areas requiring further exploration, which ultimately assisted in the identification of research aims. Broadly, this thesis aimed to: establish what is known in the qualitative literature about barriers and facilitators influencing people's experience of return to work following SCI; identify employment outcomes for eligible persons with SCI admitted to Austin Health in the five years preceding the implementation of the EIVR program; explore the longitudinal outcomes for people who received the EIVR program and examine the nature and extent of relationships for these people between contextual factors and employment outcome after SCI and the relationships that exist between these outcomes and their demographic and psychological characteristics.

Chapter Three presented the background, methodology, results and implications of a systematic review of the qualitative literature that aimed to answer the question of what barriers and facilitators influence people's experience of return to work following spinal

cord injury. The ENTREQ statement (Tong et al., 2012) was followed to enhance the transparency of the synthesis of the included papers. Three main implications were drawn from the three analytical themes identified in the thematic synthesis. The implications included that clinicians: draw on and provide multiple strategies to support individuals in the navigation of the return to work process; need to be cognisant of individual motivations for being a worker and the adjustment process involved after SCI, while also offering sensitive yet pragmatic support in promoting employment outcomes; and provide reassurance to people that employment is both possible and health-promoting.

In designing a study to test the effectiveness of an early intervention vocational rehabilitation, it was recognised that a randomised control trial was not possible. Therefore, in order to establish usual practice before the introduction of a new program, an audit of the medical record was undertaken. That audit was presented in Chapter Four and aimed to achieve a baseline comparison for future longitudinal data that was presented in Chapter Five for individuals who received the EIVR program. There were several study limitations related to the quality and quantity of data available, however, the data collected nevertheless gave an indication of employment outcomes for people following traumatic SCI in the five years prior to service changes.

Following on from the audit of medical records and the establishment of the status quo of employment outcomes for a sample of individuals prior to the implementation of the EIVR program, Chapter Five presented longitudinal outcomes for a cohort of people who did receive the EIVR program. The relationships between employment outcome, aspects of

functioning, activities and participation, and contextual personal and environmental factors were also explored. Findings of this study indicated that the EIVR program showed promise of delivering equivalent return to work rates for people with SCI to those reported in similar studies but earlier after injury. Several factors were identified that were predictive of employment outcome and can be used to inform clinical practice in the promotion of employment outcomes. These factors included relationship status, subjective wellbeing and pre-injury education.

The final study of this thesis, presented in Chapter Six, used mixed methods to analyse quantitative and qualitative data obtained from interviews with participants across three pre-defined employment groups. The study highlighted the complex dynamics involved in seeking, gaining or maintaining employment after SCI. Its findings provided a greater understanding of the perspective of the service user, and the study offered recommendations to funders of research, system designers and policymakers. The implications of this research covered the importance of education, the need for access to accurate and clear information about entitlements or benefits and resources, the role of adequate and appropriate social supports, the value of personal drivers, and the necessity of re-establishing worker identity following SCI.

A comprehensive discussion of the main findings of this thesis, along with identification of study limitations, presentation of implications for practice and directions for future research, was provided in Chapter Seven. Six main findings were identified from across the thesis. Among these, it was shown that the EIVR program shows promise in supporting a

return to employment post-SCI, worker identity is an important issue, and positive culture plays a role in facilitating employment outcomes. The findings also revealed that strong social supports, non-compensable funding status, a higher level of pre-injury education and a greater perception of subjective wellbeing are all positively related to labour force participation. Implications drawn from the main findings of the thesis were directed at service provision from the points of view of funding, SCI services and clinical practice. At a funding and SCI service delivery level, implications included supporting innovative approaches, such as flexible worker and funding (income benefit) arrangements, and facilitating practices that promote employment as a critical rehabilitation outcome. Clinical practitioners can nurture the value and importance of vocational pathways and strengthen access to positive social supports.

Directions for future research include: strengthening the understanding of effect of the EIVR program and other vocational interventions; trialling and testing innovative programs to overcome current barriers to employment, such as low levels of education or access to compensation; further investigating environmental factors and their influence on employment, including the implementation of NDIS into the funding mix; and exploring opportunities to strengthen adaptive psychological characteristics that are facilitatory of adjustment and positive employment pathways.

This thesis has re-emphasised the importance that paid employment holds in people's lives after traumatic SCI, while recognising the uniqueness of the individual journey. The experience of seeking, gaining and maintaining employment is complex. For persons with

SCI, the pathway to employment can be supported by a program of early intervention vocational rehabilitation, further education and the existence of strong social supports, all occurring within a positive culture that endorses the importance and possibility of employment after SCI. Seeking to re-establishing worker identity, financial stability and subjective wellbeing are critical progressions for people that are facilitatory of employment outcomes. Ongoing research is required to identify additional strategies so that people's opportunities for employment success continue to be strengthened following traumatic spinal cord injury.

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Appendix A

Permission letter from Canadian Association of Occupational Therapists to use CMOP-E diagram



Canadian Association of Occupational Therapists Association canadienne des ergothérapeutes

CAOT Publications ACE Copyright Request

July 20 2016

Ms Gillean Hilton c/o Professor Carolyn Unsworth Department of Occupational Therapy Central Queensland Univerity Room 6.07,120 Spencer St Melbourne, Vic,3000 Australia

Dear Gillean,

According to your request, you would like permission to use the CMOP-E diagram to be used in your thesis titled "Employment after Spinal Cord Injury" presented at the Central Queensland University.

Figure 1.3 (CMOP-E) Canadian Model of Occupational Performance in Polatajko H., Townsend E., Craik, J. (2007). *Enabling Occupation II: Advancing an Occupational Therapy Vision for Health, Well-Being, & Justice through Occupation*. <u>Ottawa, ON,</u> CAOT Publications ACE. p. 23.

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Thank you Yours sincerely,

Stéphane Rochon CAOT Publications Administrator

Appendix B

Background, context and approaches for Spinal Community Integration Service



Background

Implementation of the Spinal Community Integration Service (SCIS) commenced in October 2009, with the first client recruited in February 2010. The team is based at the Royal Talbot Rehabilitation Centre and sit within the Victorian Spinal Cord Service to provide communitybased intervention to spinal cord injured clients from Austin Health (the spinal rehabilitation facility at Royal Talbot). Community-based intervention may include working with the client in their own home, alongside a community service provider, in their local community, at their workplace, or in a recreation facility. SCIS provides services statewide.

Clients eligible for participation are referred by the local treating team. Consent for participation in SCIS is obtained prior to the commencement of intervention.

SCIS's aim is to improve community integration and quality of life outcomes for Victorians with a spinal cord injury (SCI). The team works with clients to:

- enable optimal independence and self-management in the community setting
- minimise barriers to community integration including work and other life roles

- support an efficient and effective transition from subacute care (rehabilitation) to the community setting, within a goal-directed approach
- optimise opportunities for participation within the local community
- support adjustment to SCI through an individualised approach
- promote healthy lifestyle behaviours and maximise health outcomes.

SCIS aims to achieve the above objectives through:

- provision of specialised, interdisciplinary intervention for up to one year postdischarge from subacute care
- consultation and provision of information and education to build capacity within existing community services (e.g., sub-acute ambulatory care services, private providers, care agencies, district nursing, etc.)
- provision of flexible, innovative services based on the individual needs of the client
- working within the principles of social inclusion and community participation.

Launch

SCIS was officially launched by the Hon. Daniel Andrews, Minister for Health, on Thursday 12 November 2009 at Royal Talbot Rehabilitation Centre. The key messages delivered at the launch included:

1. Austin Health was extremely pleased to be involved with the collaborative initiative, having been the specialist providers of care for SCI since 1956. Austin Health delivers a

statewide program—the Victorian Spinal Cord Service—with a catchment that also includes southern NSW and Tasmania.

- The launch was the culmination of several years of collaboration and commitment with Alfred Health, the Transport Accident Commission, the Department of Health, and the Department of Human Services. AQA Victoria and Independence Australia were also significant contributors.
- 3. SCIS intensively supports clients with a new SCI to transition back home and into community living, working with them to address vocational, psychosocial, health and community reintegration goals in the first year after discharge from hospital. This would be done via a number of different innovative resources to reduce barriers to community participation and empower individuals to be in control of their situation. These resources have been achieved via the collaboration of the aforementioned parties.
- 4. Victorian Spinal Cord Service would utilise its skills, expertise and experience to deliver the SCIS across both Austin and Alfred Health in continued close collaboration with all other key organisations.

Benefits

Anticipated benefits of SCIS include:

 Vocational outcomes through earlier intervention, along with promotion of a positive vocational culture. Returning to work is one of the most important outcomes of community reintegration following SCI. Benefits of return to work include:

- Financial independence and security
- Physical and psychological health and wellbeing
- Self efficacy and self-esteem
- Positive self identity as a 'worker' and a productive contributor to society
- Social recognition and improved socioeconomic status
- Person fulfilment, purpose and life meaning
- Health outcomes through increased support for clients in the first year following

SCI, including improvements in:

- General, medical and psychological health
- Understanding of SCI-related conditions, resulting in better self
 management in areas of weight, bladder and bowel health, pain, skin
 integrity and sexual function
- Fewer hospital readmissions
- **Community integration outcomes** that may include but are not limited to:
 - Active, supported social participation and access to community

resources, resulting in decreased isolation

- A return to previous or similar meaningful life roles
- Exploration of and engagement in meaningful activity, including sport, recreation and leisure and/or work
- Optimal independence, choice and control
- Quality of life, which will be enhanced and achieved through combined

initiatives that should assist people with SCI adjust to a changed way of life.

SCIS staff training

SCIS staff underwent a total of five days of training. The first two days included an introduction to SCIS, the Early Intervention Vocational Rehabilitation (EIVR) program, and the various stakeholders. The training was facilitated by Arron Perriam, who at the time was manager of the early intervention vocational program known as Kaleidoscope at the Burwood Spinal Unit in Christchurch, New Zealand. The schedule of the training is presented on the following page. A selection of several key slides from Arron's presentation are included below the training schedule. The messages and principles covered in the training remain central to the delivery of SCIS and the EIVR program today. The slides are reproduced here with the permission of Kaleidoscope.
Spinal Community Integration Team training				
	The SCIT is focused and empowered to inspire all those they work with			
	2. The SCIT understands and is confident in their individual and collective skills and abilities to promote independent living			
Dringing Aims and Objections	3. To affect a change in the injury and rehabilitation culture			
Principal Aims and Objectives	4. The SCIT to embrace the role, place and conversations of vocational rehabilitation through to community reintegration			
	5. The SCIT gets a real sense that anything is possible and that they play an integral part of creating awesome futures - right now!			
	6. An overview of motivational interviewing			
Presenter/Facilitator:	Arron Perriam is the National Manager of Kaleidosco intervention vocational rehabilitation program to peop called Kaleidoscope Consulting International which is programs internationally.	ope - A New Zealand organisation that provides early le with a spinal cord injury. They also run a consulting arm s committed to partnering with current and immerging vocational		
Date / Time	Schedule	Purpose/prompts		
Monday 7th December				
9.00am - 10.15am	An Introduction to Kaleidoscope Programme			
10.15am - 10.30am	morning tea			
10.20pm 12.00pm	Vocational Rehabilitation - The models, myths and			
12.00pm - 12.30pm	lunch			
12.00011 12.00011	Communication and a Postmodern Perspective on			
12.30pm - 1.30pm	rehabilitation	Interactive sessions - likely ample opportunity to share		
	Being a Discourse for Hope, Purpose and	experiences and ideas to contribute to discussion and learning		
1.20pm - 2.00pm	Possibility in Rehabilitation that Inspires you - &			
1.30pm - 3.00pm	others!			
5.00pm - 5.13pm	Creating your own service standards and			
	distinctions - interactive group work - service			
3.15pm - 4.30pm	standards			
100 500		Several Austin and Alfred staff have been invited to come and meet the team - this will actually be the first day that the entire		
4.30pm - 5.30pm	Drinks, meet and greet	team is together:		
Tuesday 8th December - Team and be	yond: Several invitees from a variety of state and NG	organisations have been invited to share organisational		
philosophies/roles/vision and how this r	may support/partner with SCIT			
	Part 1. Role of Leisure in Rehabilitation:			
9.00am - 10.15am	Responsible use of pleasure is not a diversion.	Sal Dema		
10.15am - 10.30am	SCIT vision/purpose/philosophy - revisiting the			
10.30 - 10.45	Mission Statement	Arron to assist facilitate with Gill and Belinda		
10.45 - 11.15	Part 2. The Self Actualising Perculator	Sal Dema		
11.15 - 11.45	Department of Health	Juliet Coles - Department of Health vision - organisational objectives - how SCIT aligns?		
11 45 - 12 15	Disability Services - Department of Human Services	Heather Thompson - Disability Services vision - organisational		
12.15 - 12.45	Lunch			
		Michael Walker - Possible discussion including State Disability		
12.45 - 1.15	Michael Walker (9208 3442)	Act, Sport and Rec Victoria initiatives, Office of Disability initiatives		
1.15 - 1.45	Case Management TAC	TAC Case managers - vision and rle and how they can support SCIT - Liam or Michael		
1.45 - 2.15	AQA - Peter Trethewey with Peter VB and Naz E.	AQA's current vision and now aligns/partners with SCI1. Awareness raising of other services/resources that AQA offer. Any relevant initiatives? Independence Australia - current vision and possibilities of		
2.15 - 2.45 (or maybe swap with 10.45	Independence Australia - Suzanne Ryan-Evers - 1(9418 0417) or Kris Chapman	how it could align/partner with SCIT. Awareness raising of resources/ services offered through IA. Any relevant initiatives?		
		Wheelchair Sports Vic - Vision of organisation and how could		
2.45 - 3.15	Wheelchair Sports (9473 0133) Sean Corcoran	partner with SCIT. Any relevant initiatives		
3.15 - 3.30	Arvo tea			
3 30pm - 4 30pm	An overview of metivational interviewing	Eacilitated by Arron (more time if econicse above finish"		
4.30pm - 5.00pm	Final wrap up and Q & A time	Review of any areas if above sessions finish earlier		

Individual Context of VR Kaleidoscope Consulting International • Functional factors Individual decisional processes December 2009 Self-concept Summarized Training Notes Motivations Arron Perriam Confidences Emotional Stability Finance kaleidoscope Adaptability Bright & Associates: Change by Design, Signpost cards, Luck Readiness Assessment, WorkLife card sorts: Values, motivators, satisfiers, skills, work settings, WorkNet Iting Internatio Solutions, (WRP) Work Readiness Profile, DOA C Kaleidoscope Consulting International 2009 Community Context of VR · Family or Domestic Role Family & Friends expectations Transportation Housing Community Geographical factors Health stability Mobility Accessibility Functional Capacity Evaluation, (WRP) Work Readiness Profile, Training for Independence Assessment, C Kaleidoscope Consulting International 2009 Professional Context for VR



Functional Capacity Evaluation, **(WRP)** Work Readiness Profile, Workplace Assessments...

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A Conceptual Framework for VR

It Is...

- Colourful
- Chao*ti<u>c</u>*
- Complex
- · Creative
- Changing
- Chance
- Connected
- Choice
- Cultural

- It Is Not...
- Cross sectional
- Categorical
- Check Lists
- Clinical
- Conventional
- Confined
- Constant

C Kaleidoscope Consulting International 2009

DEFINITIONS OF 'CAREER'

- We need to appreciate the impact of the historical, social and economic context within which we understand the term 'career'. For example, "the sequence of major positions occupied by a person throughout his preoccupational, occupational and postoccupational life; includes work related roles such as those of student, employee and pensioner, together with complementary vocational, familial and civil roles." (Super, 1976)
- "the evolving sequence of a person's work experiences over time" (Arthur, Hall and Lawrence, 1989)
- "Career now needs to be defined not objectively but subjectively, describing an individual's lifetime of progression in learning and work. The career is now owned by the individual; it is a process, not a structure." (Collin & Watts, 1996)
- "Whereas the objective definition of career denotes the sequence of positions occupied by a person from school through retirement, the subjective definition used in career construction theory is not the sum of work experience but rather the patterning of these experiences into a cohesive whole that produces a meaningful story." (Savickas, 2001)

C Kaleidoscope Consulting International 2009

Generalist Models of VR

Case co-ordinated

- Holistic approach
- Individualized
 Pre-employment training
- Job placement & in-work support

Supported employment

- Quick job placement (Placement first)
- Minimal pre-employment training
- On the job training & coaching

Programme based

- Module-based programme
- Aimed at max voc outcomes
- Sequential or linear

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Kaleidoscope's Post-modern Perspectives

Where ever you're at is the perfect place to be

Your independence & choice is more important than my outcome

What matters to you matters to me

Your interest is my commitment

We have all the time it takes to achieve what you want to achieve

I stand beside you as your informed partner

Let's try it out and see how it goes

C Kaleidoscope Consulting International 2009

The context of postmodernism and narrative based VR, informs an *idiosyncratic, evolving, holistic, context-sensitive, and proactive* approach to VR with clients in contrast to traditional approaches, which emphasize norms and fixed realities, and are context-free & restrictive

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Positive Uncertainty

Positive uncertainty recommends the acceptance of chaos, a positive attitude toward instability, and an openness to changing one's preferred future as opportunities present themselves.

The role & place of Language & Communication

C Kaleidoscope Consulting International 2009

Through interactive exchanges, individuals acquire the *language* needed to reflect on their own lives and articulate to others their sense of who they are, what's important to them, and where they are heading.

C Kaleidoscope Consulting International 2009

Partnership

'A Discourse of Hope, Trust, Purpose'

An Individuals *identity and life purpose*, even their interpretation of the meaning of their experiences, depend on the *social discourses* in which they *partner & participate*

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Top 10 Critical Success Factors for Kaleidoscope

- 1. Super staff
- 2. Super Partnerships
- 3. Super Responsibility
- 4. Super Commitment to possibility
- 5. Super Servant service approach
- 6. Super Creativity
- 7. Super service specialisation
- 8. Super Early intervention
- 9. Super Inter-disciplinary team
- 10. Super location

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TOP 10 TIP'S FOR VR PRACTITIONERS

- 1.Start dreaming & scheming with your SCI client about vocational matters as soon as possible - Early intervention vocational rehabilitation makes sense and saves cents!
- Whatever the barriers are ALWAYS work towards realising solutions – be eternally optimistic!
- Embrace the SCI clients hope & sense of possibility throughout the vocational rehab 'experience'. Embrace the seemingly impossible!
- Take all the time needed to progress towards a sustainable vocational the SCI client loves – this is a marathon not a sprint!
- Communicate as soon as possible & as often as possible with the employer – RTW is a team game!

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- 6. Relate collaboratively with the client, family, key friends, employer, funder and other stakeholders as directed by the SCI client
- 7. Be mindful of creating a vocational 'experience' rather than simply following a generic vocational rehab process
- 8. Coach the client to act independently, to be self determined and to take control of their own rehabilitation
- 9. Do what you love & love what you do! This applies to the vocational practitioner and the person with the SCI!
- 10.Remember we have 2 ears & 1 mouth so there's merit to listening twice as much as we speak, be very present to the 'clients world', and do whatever it takes to serve the SCI clients RTW expectations. The clients the expert of their life!

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Following the initial training, staff participated in a two-day interactive workshop that provided an introduction to motivational interviewing. Motivational interviewing is a clientcentred, directive, therapeutic style for initiating and facilitating behaviour change through a relatively brief intervention. The course was facilitated by Mick Smith, who is the director of the Australasian Centre for Motivation and Change. Mick has extensive experience as a facilitator and a comprehensive understanding of the SCI population and service systems. A fifth day of training covered an overview of goal planning in community settings and was delivered by an occupational therapist.

Procedure for recruitment to SCIS including EIVR

The program manager for SCIS is required to:

- target eligible clients for recruitment
- ensure appropriate documentation
- develop basic service plan in consultation with SCIS
- follow admission and progress through acute and subacute setting by attendance at VSCS psychosocial meeting (Thurs 9am)
- liaise regularly with spinal consultants at Alfred and Austin
- monitor eligible clients and plan recruitment methodology, depending on identified needs
- liaise closely with inpatient treating team and spinal consultants to ensure engagement is appropriate and timely
- manage patient flow in order to provide an optimal service.

Inclusion criteria for SCIS (and EIVR)

As of 1 October 2009, clients eligible for recruitment to SCIS and the EIVR program must be within 2–4 weeks of first (subacute) rehabilitation admission at the spinal rehabilitation facility at Austin Health, and:

- Have prognosis of stable, non-progressive spinal cord injury (traumatic cause)
- Agree to participate in evaluation or have someone able to consent for them on their behalf
- Be a resident of Victoria.

This criteria includes:

- All Transport Accident Commission (TAC) clients until *n* = 40 over two years
- Work Safe (WS) clients on negotiation
- All non-TAC or non-WS clients who meet the above eligibility criteria, up until n = 40 over two years (combined over both sites).

An eligible client will be excluded if their ultimate discharge is to a nursing home or interstate destination, or if they have a significant head injury or other serious medical disorder/s and/or are experiencing substance abuse or dependence.

Methodology

Once eligible participants are identified, consent is to be obtained as soon as possible. Participation in the EIVR pilot program includes associated assessments and research.

Following consent, initial involvement by SCIS staff in the subacute setting includes:

- psychosocial care coordinator or similar to address early assessment of learning via blanket referral
- vocational consultant via blanket referral
- building consultant, when indicated as necessary via the inpatient treating occupational therapist, to support home modification process

The key contact person or psychosocial care coordinator can be introduced early if recommended by treating team.

When a client is approaching discharge, SCIS staff will:

- reintroduce team and restate purpose prior to discharge, to set expectations of community integration service
- have at least one member attend final VSCS goal planning meeting (discharge planning meeting), with other SCIS member to attend as required
- schedule separate SCIS goal planning meeting, to complete group goal setting with SCIS.

Administrative tasks for liaison role

In addition to individual discipline roles, each member of SCIS takes on a liaison role in the transdisciplinary team. When a member of SCIS becomes the key contact for a particular client, tasks include:

- Noting on inpatient file that the client is now on SCIS
- Placing name on the whiteboard in the team meeting room, indicating SCIS liaison role for client
- Establishing relationship with inpatient liaison person
- Engaging with the TAC/Worksafe case manager and support coordinator (or early support coordinator if client is allocated just one person from TAC)
- Ascertaining which community spinal nurse is allocated to the client and developing a partnership with that person in relation to coordination and so on
- Completing a team discussion form for both rehabilitation-based and communitybased clients each time a client is tabled for a team discussion, where the inpatient discussion form provides the basis for short-term goals and the community team discussion form is linked back to the Canadian Occupational Performance Measure
- Faxing the above forms to the case manager for TAC WS clients
- Attending goal planning and team meetings as able, and liaising with community spinal nurses with regard to attendance at these meetings
- Meeting regularly with clients to establish rapport, remembering that the inpatient rehabilitation team lead discharge planning and any interventions

- Organising the collection of outcome measures just prior to client discharge, including:
 - Demographic data
 - Hospital Anxiety and Depression Scale (HADS)
 - Spinal Cord Independence Measure (SCIM)
 - Functional Independence Measure (from inpatient history)
 - Canadian Occupational Performance Measure (COPM)
 - Personal Wellbeing Index (PWI)
 - Impact on Participation and Autonomy Questionnaire (IPAQ)

Goal planning and follow-up

When the Canadian Occupational Performance Measure goals are identified, SCIS staff will use the team discussion sheet for community-based clients. Goals will be based on SMART principles. The whole team will have the ability to add to the actions associated with each goal. To help with goal planning, SCIS staff will utilise the issues list form and the resources of other team members.

From the time of discharge to approximately the four week post-discharge mark, an independence plan will be completed for participants without insurance. SCIS staff will work with the TAC early support coordinator to complete an independence plan for TAC clients. Staff will also identify community providers and act as coordinators of services and information.

At six months post-discharge, SCIS staff will collect:

- Demographic data
- Canadian Occupational Performance Measure (COPM).

At approximately nine months post-discharge, SCIS staff will start preparing client for discharge from the program, while at 12 months post-discharge, the following will be reviewed:

- Demographic data
- Hospital Anxiety and Depression Scale (HADS)
- Spinal Cord Independence Measure (SCIM)
- Functional Independence Measure (from inpatient history)
- Canadian Occupational Performance Measure (COPM)
- Personal Wellbeing Index (PWI)
- Impact on Participation and Autonomy Questionnaire (IPAQ)

A discharge letter and summary for the client, GP, community providers, TAC (where appropriate) and so on will be completed at this time. This will involve liaison with the SCIS medical consultant.

Early Intervention Vocational Rehabilitation program assessment/plan

The vocational consultant who provides the EIVR program as part of SCIS uses the following form for formal data collection and planning purposes. This is in addition to an informal introduction to EIVR, which establishes vocational identity and so on, as outlined in the EIVR guidelines. Spinal Community Integration Service **Spinal Community Integration Service**

Early Intervention Vocational Rehabilitation: Assessment/Plan

Please note, this plan is intended as a tool to share information. It is NOT a request for services or referrals.

Date of Assessment:

Client Name:	Claim no (if applicable):
Address:	
Phone:	Email:
Date & Nature of Injury:	Injury Type:
Other Medical Considerations:	
Alternate Contact:	Relationship:
Phone:	
Date of admission to rehabilitation facility:	Planned discharge date:

Details of Compensation:

Compensable 🗌 compensable	Non	□ayments being received
Scheme:		
Contact:		

Recent Vocational History:

Currently Employed Studying	Unemployed	
Occupation/Course:		
Length of employment/ Stage of Course:		
Details of Work/Study:		
Duties include :		
Hobbies/Interests:		
Transferable Skills:		

Detailed Vocational History:

(Include role tasks & duration)		

Client Perceptions of Vocation: (A statement that gives impression of clients' interest in work or other vocational activity)

Current Considerations:

Physical (include functional status, transfers, mobility, continence)
Psychosocial:
Environmental (personal accommodation & proposed place of work/study)
Transportation:
Fauinment:

Return to Work/Study Details:

Employer / Institution	
Industry electrical	Address
Contact person Luke Mitchell	Contact made Y / N
Employer comments:	

Early Intervention Vocational Rehabilitation Plan

□ Exploration of vocational options

- Career Counselling
- ☐ Meet with Disability Liaison Officers
- □ Liaise with inpatient team regarding pre vocational activity
- □ Contact / support to employer
- □ Work site visit
- □ Connect with peer support
- ☐ Identification/Development of Return to Work plan
- □ Assessment/Prescription workplace equipment and/or modifications

Copies of this plan provided to:

This plan was completed by: Telephone: Email:

Australasian Spinal Cord Injury Early Intervention Vocational Rehabilitation program

The following list of possible activities undertaken by a vocational consultant has been compiled by vocational rehabilitation clinicians working in the field of spinal cord injury across Australia and New Zealand. This group is affiliated with the Australian and New Zealand Spinal Cord Society (ANZSCOS).

Roles of vocational	1. Exploring vocational options
consultant in early	2. Providing career counselling
vocational	3. Liaising with inpatient team regarding pre-vocational activity
rehabilitation	4. Contacting and/or supporting pre-injury employer
programs for	5. Connecting with peer support
people with SCI	6. Visiting worksite to assess both physical and social demands of the position and workgroup
	7. Assessing and prescribing workplace equipment and/or modifications
	8. Explaining entitlements and government benefits associated with job seeking and returning to work
	9. Developing (in coordination with both the patient/client and the putative supervisor) a return to work plan
	10. Facilitating/supporting workplace trials or industry experience
	11. Providing post-placement support (to ex-patients and family members, as well as to workplace co-workers and supervisors)
	12. Educating inpatient rehabilitation teams on the importance of work in the adjustment process and explaining the early intervention vocational rehabilitation role
	13. Educating of co-workers and supervisors at the workplace
	14. Educating family and other relevant social supports and facilitating family-based problem-solving and life planning
	15. Providing referrals, consultation and education to community-based vocational rehabilitation providers
	16. Educating health professionals
	17. Meeting with disability liaison officers at education facilities
	18. Networking with local government, not-for-profit, and private enterprises to establish possible employment links/opportunities
	19. Educating funders



(to the right hydrotherapy pool) **Royal Talbot Rehabilitation Centre** Therapy Services Building Email: SCIS@austin.org.au **Rehabilitation Centre** Phone: 03 9490 7264 Find SCIS office on: Integration Service Spinal Community Fax: 03 9490 7548 **1** Yarra Boulevard **Royal Talbot** Kew, 3101 Victoria Australia Level 2



Who is SCIS?

SCIS stands for Spinal Community Integration

Service .

It is a specialised team of professionals, with skills

in spinal cord injury.

Skills includes:

- Nursing
- Physiotherapy
- Medical Specialist
- **Occupational Therapy**
- Exercise Physiology
- Building Consultancy
- Return to work
- Return to Study
- Leisure
- Peer Support
- Mental Health
- **Counselling Support**
- Sexual Health



How does SCIS help?

spinal cord injuries in getting back to participating in their communities. SCIS helps by supporting Victorians with new

This is achieved by :

- Individualised service
- ٠ Identifying personal goals
- Providing support to family and friends Being a specialised resource for existing
- community services

•



might help with goals around: Typically when a person is still in hospital SCIS

- Return to work
- Home modifications

Then in the first year home, goals might change to include things like:

- Planning a program at the local gym
- Talking to someone with a similar injury
- Working through health issues

•

What to Expect?

They will support you during the first 12 months A key contact person will be appointed to you. Facility. following discharge from your Rehabilitation

They will ask you some questions regarding different aspects of your life that are important to



to you. goals. We will also work and support the strategies to support you in achieving these important things in your life. SCIS will develop They will help develop goals about those community therapists that are providing care



Appendix C

Appraisal tool (National Institute for Health and Clinical Excellence, 2006) used in Study One: Systematic review of the experience of attempting to return to work after SCI

A.4 Methodology checklist: Qualitative studies

Study identification	
Include author, title,	
reference, year of	
publication	
Guideline topic:	Key question no:
Checklist completed by:	

Criterion	Is the criterion clearly addressed?		
Epistemology	y		
1. Is a qualitative approach appropriate?	Appropriate	Comments:	
 Does the research seek to understand processes or structures, or illuminate subjective experiences or meanings? Could a quantitative approach better have addressed the question 	 Inappropriate Not sure 		
2. Is the study clear in what it seeks to do?	Clear	Comments:	
 Is the purpose of the research discussed – aims/objectives/research question Is there adequate reference to the literature Are underpinning values/assumptions/theory discussed 	Unclear		

Methods for development of NICE public health guidance



	[Comments:
5. Is the role of the researcher clearly described?	Clear	Commenta.
 Has the relationship between the researcher and the participants been adequately considered Is there evidence about how the research was explained and presented to the participants 	Unclear	
6. Is the context clearly	Clear	Comments:
 Are the characteristics of the participants and settings clearly defined Were observations made in a sufficient variety of circumstances Was context bias considered 	Unclear	
 7. Were the methods reliable? Was data collected by more than one method Is there triangulation, or justification for not triangulating Do the methods investigate what they claim to 	Reliable Unreliable Not sure	Comments:

Analysis		Commonte
 8. Is the data analysis sufficiently rigorous? Is the procedure explicit – l.e. is it clear how the data was processed to arrive at the results How systematic is the analysis, is the procedure reliable/dependable Is it clear how the themes and concepts were derived from the data 	Rigorous Not rigorous Not sure	Comments:
 9. Is the data rich? How well are the contexts of the data preserved Has the diversity of perspective and content been explored How well has the detail and depth been preserved Are responses compared and contrasted across groups/sites 	Rich Poor Not sure	Comments:
 10. Is the analysis reliable? Did more than one researcher theme and code transcripts If so, how were differences resolved Did participants feed back on the data if possible and relevant Were negative/ discrepant results addressed or ignored 	Reliable Unreliable Not sure	Comments:
 11. Are the findings credible? Is there a clear statement of the findings 	Credible	Comments:

 Are the findings internally coherent Are elements from the original data included Can the data sources be traced Is the reporting clear and coherent 	☐ Not sure	
12. Are the findings relevant?	Relevant	Comments:
 13. Conclusions How clear are the links between data, interpretation and conclusions Are the conclusions plausible and coherent Have alternative explanations been explored and discounted Does this enhance understanding of the research topic Are the implications clearly defined Is there adequate discussion of limitations 	Adequate	Comments:

Ethics		
 14. How clear and coherent is the reporting of ethics? Have ethical issues been taken into consideration Are they adequately discussed e.g. do they address consent and anonymity Have the consequences of the research been considered i.e. raising expectations, changing behaviour etc Was the study approved by an ethics committee 	Appropriate	Comments:
Overall Assessment		
Is this study relevant?	□Yes □No	Comments:
How well was the study conducted? (see table below)	□ ++ □ + □ -	

	Where they have not been fulfilled the conclusions of the study or review are thought very unlikely to alter.
+	Some of the criteria have been fulfilled. Those criteria that have not been fulfilled or not adequately described are thought unlikely to alter the conclusions.
-	Few or no criteria fulfilled. The conclusions of the study are thought likely or very likely to alter.

Appendix D

Declaration of co-authorship and contribution

	Hilton, G. M., Unsworth, C. A. & Murphy, G. C. (2017).
Full bibliographic reference to the item/publication, including authors, title, journal (vol/pages), year.	The experience of attempting to return to work following spinal cord injury: A systematic review of the qualitative literature. <i>Disability and Rehabilitation</i> . (April, 11), 10.1080/09638288.2017.1312566
Status	Published on line

Nature of candidate's contribution, including percentage of total

Conceived the study, developed the method, performed the systematic search, critically appraised the articles, performed thematic synthesis, and had primary responsibility for preparing drafts of the paper. 70%

Nature of all co-authors' contributions, including percentage of total

Unsworth: Involved in study design and methodology; cross-checked appraisal and thematic synthesis; edited drafts of the paper. 20%

Murphy: Involved in editing drafts of the paper, including response to reviewers following submission. 10%

Has this paper been submitted for an award by another research degree candidate (co-Author), either at CQUniversity or elsewhere? (If yes, give full details)

No

Candidate's Declaration

I declare that the publication above meets the requirements to be included in the thesis

as outlined in the Research Higher Degree Theses Policy and Procedure

.....

(Original signature of Candidate)

Date

Appendix E

Copy of published manuscript in Disability and Rehabilitation



The experience of attempting to return to work following spinal cord injury: a systematic review of the qualitative literature

Gillean Hilton, Carolyn Unsworth & Gregory Murphy

To cite this article: Gillean Hilton, Carolyn Unsworth & Gregory Murphy (2017): The experience of attempting to return to work following spinal cord injury: a systematic review of the qualitative literature, Disability and Rehabilitation, DOI: <u>10.1080/09638288.2017.1312566</u>

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The experience of attempting to return to work following spinal cord injury: a systematic review of the qualitative literature

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ABSTRACT

Purpose: This review sought to answer the question "What are the barriers and facilitators influencing people's experience of return to work following spinal cord injury?"

Methods: Studies that met the selection criteria were identified, presented and critically appraised using National Institute for Health and Care Excellence guidelines. Thematic synthesis was completed with studies possessing strong methodological rigor. Synthesis and interpretation involved three stages; coding of primary data; development of descriptive themes reflective of the primary data; and establishment of analytical themes to answer the review question.

Results: Data from nine papers were included in the thematic synthesis. Several descriptive themes and three analytical themes were drawn from the data to answer the research question. Analytical themes included: a matrix of personal and environmental factors exists requiring complex navigation in order to create possibilities and opportunities for postinjury employment; the process of seeking or gaining employment shares a reciprocal relationship with the temporal nature of adjustment to spinal cord injury; and there is an intrinsic need for occupational engagement through paid employment.

Conclusions: Returning to or gaining employment after spinal cord injury is a fundamentally difficult experience for people. Multiple strategies are required to support the navigation of the process. There is, however, a need in people with spinal cord injury, to be a worker, and with that comes the inherent benefits of being employed.

> IMPLICATIONS FOR REHABILITATION

- · Returning to work should be a significant focus of spinal cord injury rehabilitation.
- Employment is both possible and health promoting following spinal cord injury.
- Multiple strategies are required to support people to navigate the return to work process.
- It is important to be cognizant of the individual motivations for being a worker and the complexity of the adjustment process.
- Spinal cord injury centers can provide a consistent and supportive framework and culture of positivity about employment after spinal cord injury.

Introduction

Traumatic spinal cord injury (SCI) is a catastrophic event, characterized by autonomic dysfunction and total or partial motor and sensory loss below the level of the lesion [1]. People who sustain a SCI usually go through an intensive period of hospitalization and rehabilitation so that they can begin to understand the impact of injury on their bodies and learn the skills required in order to return to and engage with their community. A particularly important aspect of community integration is returning to work [2]. Participation in paid employment has been positively associated with quality of life and adjustment following SCI [2–4]; however despite this, the rate of employment after injury generally remains low, typically quoted at around 35–40% in the developed world [4–6].

The literature suggests that there are significant barriers for people in achieving employment following SCI. While there have

been efforts to identify vocational interventions that may be effective in overcoming some of these barriers [7-9], overall, as recognized in a systematic review undertaken by Roels et al, [10], there remains a dearth of high-quality studies to direct specific vocational interventions [6,10]. In addition, intervention studies of robust design are inherently difficult to undertake with people with SCI due to a small pool of potential participants many of whom are subject to "research fatigue." Despite the lack of highquality studies, there is a consistent recognition in the literature of the complexity of the return to work process following SCI and the array of contextual personal and environmental factors that can influence an individual's journey [11,12]. Hence, a number of researchers have also begun to explore this process using qualitative research designs in an effort to build a deeper and more comprehensive understanding of the dynamics, issues and challenges related to participation in paid employment after SCI that

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may then inform vocational interventions. Therefore, the aim of this paper was to answer the question "What are the barriers and facilitators influencing people's experience of return to work following SCI?"

Methods

In seeking to answer the study aim, this systematic review undertook three main steps. The first step involved a systematic search for studies focusing on the meaning for and experiences of people following spinal cord injury in seeking, gaining or maintaining paid employment in the open labor market; the second step conducted a critical appraisal of the identified literature; and lastly, a thematic synthesis of the results of these studies was undertaken.

Review process

This review was performed in a systematic and comprehensive way and followed the process for review, appraisal and synthesis of qualitative literature as documented by the Centre of Reviews and Dissemination [13] from University of York, and widely used in papers reporting meta synthesis of qualitative studies [14,15]. The review process and documentation were also informed by a framework identified by Tong et al (2012) to enhance the reporting of synthesis of qualitative research [16].

The first author (GH) developed the review protocol, performed literature searches and extracted and analyzed data. GH and second author CU critically discussed the review process and results, with CU cross checking article selection and appraisal. GH completed the thematic synthesis with all eligible articles, with CU concurrently reviewing a sample. Authors were 95% in agreement on synthesis results and discussed until full consensus was reached. GH wrote the first draft of the article and all authors contributed to the write up of the final draft.

Inclusion criteria

Included articles were published between 1996 and 2016, used a research design that allowed exploration of the individual experience from the perspective of the person with SCI, had results that reported the author's interpretation of the lived experience, meaning, decisions and/or values in relation to seeking, gaining or maintaining paid employment, were published in peer reviewed journals accessible through electronic databases; and were written in English.

Exclusion criteria

Articles where study participants were not primarily of workforce age (i.e., were <15 or >65 years old), or had significant co-morbidity of severe cognitive deficits, psychosis or other psychiatric illness were excluded from this review.

Search and selection process

The search process was preplanned and sought to comprehensively seek out all appropriate studies with the use of combined search terms. In order to ensure that the search was as explicit and reproducible as possible, only the electronic databases CINAHL Plus, MEDLINE, Psychofo and Embase were used. It was believed that use of these four databases would capture all studies related to the topic. Searches were repeated in the databases between 26th June 2016 and 3rd July 2016. Search terms used included "spinal cord injury" AND "employment" OR "work" OR "jobs" OR "labor force" OR "job tenure" OR "job retention" OR "sustain" employment" OR "maintain" employment" OR "return to work" OR "vocational rehabilitation" AND "meaning" OR "experience" OR "value" OR "employment identity." All search fields (title, keyword, abstract) were selected in all four databases. The search and selection process is presented in Figure 1.

Citations were exported into an online bibliography manager (Endnote) where duplicates were removed. Article titles, keywords or abstracts were then reviewed on the basis of the inclusion and exclusion criteria. Full text were obtained for articles that met the selection criteria. Following retrieval of full texts, articles were more closely reviewed against the selection criteria and reference lists were hand searched for additional appropriate articles. A further 15 articles were then excluded on the basis of following a quantitative design or there being an insufficient focus on paid employment. On identification of the final articles, the second author cross checked the selection process. There were no disagreements and the authors agreed on the final nine articles.

Critical appraisal and data extraction

Articles that were retained and met the full selection criteria were critically appraised in order to assess their quality. The National Institute for Health and Clinical Excellence guidelines, based on the broadly accepted principles that characterize qualitative research such as focusing on process, letting themes emerge, and following a scientific method, were utilized to appraise the selected works [17]. This was to establish the strengths and weaknesses of the studies to ensure they were of sufficient quality for data synthesis. A summary of the appraisals are included in Table 1.

Following appraisal, Thomas and Harden's [14] methods for undertaking a thematic synthesis were adopted, and data were extracted from the articles according to this. For the purposes of this review, data were defined as the results obtained in each of the selected studies. Analysis and interpretations of the researcher, rather than individual participant quotes, were extracted from the results and discussion sections of each article into a separate document and uploaded to qualitative analysis software NVivo [18].

Data analysis

As described by Thomas and Harden [14], data analysis for the purposes of thematic synthesis has three main stages. The first involves coding the primary data (text) "line by line"; the second identifies "descriptive themes" that emerge from the coding; and the final stage draws out "analytical themes." NVivo software [18], was used to assist with data management for the analytical process. An example of the coding and descriptive themes is provided in Figure 2.

Typically, in employment related research, literature generally distinguishes between three groups of people; employed, unemployed but looking for work and unemployed not looking for work. This systematic review is ultimately concerned with facilitating effective and appropriate healthcare. To this end, results and discussion in this paper will orient to services and interventions related to facilitating paid employment in the competitive workforce, as this is considered one of the optimal goals of SCI rehabilitation [19,20].

Results

Critical appraisal was completed for nine studies that met the selection criteria. All studies were of sound methodological rigor. Summaries of the nine studies that were reviewed and appraised

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Figure 1. Literature search and selection process.

are presented in Table 1. These nine studies were then included in the thematic synthesis and reported on the experience of 114 people with SCI. The age range of people with SCI was between 20 and 68 years and the time since injury ranged from two months to 41 years. All studies provided detail about employment status at the time of injury, and at the time of the study. Only three studies [21–23] included specification of the level of education achieved both pre- and postinjury. This information is shown in Table 1.

At least 19 unique codes were identified across the nine studies. Line by line coding enabled the translation of concepts from one study to another [14]. New codes were continually created where deemed necessary. In keeping with Thomas and Harden's stages of thematic synthesis, several descriptive themes inductively emerged from the coded primary data. These themes remained "close" to the data and were reflective of individual experiences of seeking or gaining employment post SCI. The third step of thematic synthesis involves going beyond the content of the original studies. Further interpretations are drawn from the descriptive themes to answer the review questions and consider clinical implications. Three broad, higher-level analytical themes were identified [14]. The descriptive and analytical themes are shown in Table 2. The analytical themes are presented in the following sections. Any quotes used in the representation of the analytical themes are derived from the author's interpretations of the primary data, not from participant quotations.

A matrix of personal and environmental factors exist requiring complex navigation in order to create possibilities and opportunities for achieving post injury employment

The experience of SCI is frequently described as complex in the context of the physical and psychological impacts of impairment [11,12]. The volition to work following SCI develops within a matrix of environmental dynamics and multiple personal factors. The terms personal and environmental are as per the contextual factors in the WHO's International Classification of Functioning, Disability and Health [24]. Different environmental contexts, such as the social, cultural or institutional environment, can present barriers and challenges to a successful return to work. Personal factors can include previous life experience, personality and motivations. Effective navigation can allow opportunities and possibilities for employment outcomes.

In the studies investigated, the cultural environment within the SCI rehabilitation center could "sow the seed" for a natural contemplation in people about work and the hope of employment following injury [25]. Conversely, people with SCI reported that the institution offered little emphasis on employment as a

Critical appraisal ⁴	Role of researcher not described; no report of ethics.	Role of researcher not described, no report of ethus	Role of researcher unclear, data ana- tysa not ngorous nor reliability reported; no report of ethics	Role of researcher unclear, data ana- iysis not rigorous nor reliability reported, no report of ethics	Role of researcher unclear
Discipline of primary researcher	Accupational Therapist	Discipline not clear possibly raychology or social work	Discipline not stated	Occupational Therapist	Discipline not stated
Findings/ recommendations	Individuals formed multiple "strands" within role reper- toirss at any point in time the meta- phor of a Life Rope emerged as a use- framework for explaining life role development, incluing that of a	Pytohological factors associated with employment were optimism, self- esteem, achieve- ment constration, and role models. Environmental fac- tors were monetary incentives, disn- centives, access and	A change of perspect tive needed which encourages the biographical pro- cess, therefore pri- may objective of aiding people would be to improve conditions around biograph- ical work	Several modifications of existing rehabili- tation intervention are necessary, as are further research directions.	Ability to work (given demots and resources), pres- ence of responsibili- that compete with work access to a suitable job, work enough benefit to be worth pursuing.
Design	Qualitative com- parative cave study	Qualitative design using semistruc- using semistruc- and gounded théory	Qualitative design using semistrue- tured interviews and syntorike interactionism	Semistructured focus group interview	Symbolic inter- actionist approach informed by grounded theory
Aim	To explore the work recently and adjust- ment process from perspective of indi- widuals attempting after SG	To examine factors that differentiated persons with SC who returned to who did not.	To analyze ways in which question of returning to employment arises in relation to blo- graphical work of people with SCI	To explore and iden- tify the barriers and important fac- cors that might hin- der people with 50 from seeking and sustaining ,obs	To identify common influences contribu- ting to decision making that would help to anform vocational rehabil- tation practices
Age and time since injury	Age range 21 45 years, time since SGI 1-14 years.	Age range 30-49 years, time since SCI 3-12 years.	Age range 29 53 years, time since SCI 4 30 years.	Age range 26-53 years, time since 5Cl 4. 21 years.	Age range 22 58 Seeus linne slice 50 2 months to 10 years.
Sample size with detail of employment and education history	16 propile with SCL unreplayed at commencentexit of study. Preinjury n = 16 employed. Preinjury = 13 had/pursuing ter had/pursuing ter fastingury n = 1 completed Masters dennee	12 people with SCI, employed" ($n = 6$), metanel with SCI, metanelweit ($n = 6$). Fre- and ($n = 6$). Fre- and tion history spec- tied ($n = 1$) some college education, n = 1 high school),	17 people with SCI, employed ($n = 9$), unemployed ($n = 9$), (n = 1), Prenjury n = 9 employed, n = 8 studying. Mit specification of education level.	J6 people with 5Cl, employed (n = 6), unemployed (n = 10). Preinjury n = 16 employed. Nil report educa- tion history.	13 propile with SCI. Sample included people with were currently working employed but not working and unemployed: how- ever, details were not provided to provided to provided to previoury of previoury of previoury of previoury of previoury of previoury of previour education history.
ear Location	999 United States	001 United States	005 France	005 Hong Kong China	010 New Zealand
References Y	Harrinel	Chaptin & Keryman	VIIe	Chan & Man 21	Fadyl & McPherson 21

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sferences	Year Location	Sample size with detail of employment and education history	Age and time since injury	Aim	Design	Findings/ recommendations	Discipline of primary researcher	Critical appraisal ^a
trgmark et al.	2011 Sweden	8 people with SC, sick leave $\ln = 2\lambda$, sickness therefore (n = 6). Frequiusy n = 6 employed, n = 1 unsupposed, n = 1 unsupposed Fortuation level, n = 0 university graduates.	Age range 20-34 years, time since SCI 1 5 years	To explore experience and expectations concerning patie work armong young adults on sick leave after SCI.	Qualitative design using semistruc- tured interviews and constant comparative method for analysis	Finding your way to everydaal life where work is possible; at the crossroads, expectations of work as part of desired fraure fife; and expectations of finding solutions within sof or with whith rest or with	Occupational	Role of researcher unclear, analysis relability not reported
øy-Smith et al	2013 New Zealand	12 people with SCI, employed ($n = 4$), foolking for wark ($n = 3$), memployed ($n = 5$), Preinjury n = 12 employed Nil report educa- tion history.	Age range 23-57 years, time since SCI 2-3 years.	To explore the exper- ences of people with SCI and voca- uional rehabilitation professionals in prostant in NZ post-SCI, in NZ post-SCI, in NZ post-SCI, in Vider to under- stand the meaning of employment, professional son of employment, professional son of employment, professional son of employment, professional son of employment, professional son	Qualitative design using semistruc- tured introviews and interpretive plenomeno- logical analysis-	Core meaning of employment post- sCI was to fine a normal file. Work advantages were social connected- ness, a verse of self-worth, earning a living, and being occupied the zenth of the zenth of post-SCI.	Discipline not stated	Nil Issues
et al	Yeway Marka	31 people (28 with SC and 3 with SC and 3 with spine bifdal, employed ($n = 17$), student ($n = 17$), student ($n = 18$ employed, n = 11 studying, n = 11 studying, n = 11 studying, n = 11 studying, n = 10 studying, ferployment is attus for of people with SC was not reported MI spec- tion level.	Age range 23 68 years, lime since SGI 3-41 years.	To examine the value of employment for people filming with SGI in Norway.	Qualifative design any open- ensing open- tensing open- tions. Analysis frintally grounded the- ory, then ory, then ory, then optime to sym- bolic bolic	Value of employment described in terms of personal and social interaction with others, as a hegemonic social norm and a sense of obligation to contribute to soci- ety. The value of meaningful regular projects jobs or projects j	Occupational Therapist	Nil ISSUES
libanks & Ivankova	2015 United States	4 people with SCI who were currently employed. Prenjury employed. Unclear specification of education fistory pre- and positivury.	Age range 42–57 years, time since SCI 4–37 years.	To explore factors factuating audits with SCI rejoining the workfore in an urban area in order to identify items to identify items that may be uff- liked in the creatification moreas	Qualitative design using semistruc- tured interviews and phenom- enological approach to analysis	Motivation was the most common facilitator, family and rehabilitation professionals extrim- sic motivators, were resources and perceived benefits	Discipline not stated	Nil issues.

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Nodes	
Name	
a_pre	- injury - the experiences, paradigms, personality that exist with individual pre-injury
0 0	isting disability paradigm_social, attitudes, expectations, culture
E 🔘 in	dividual personality traits optimism_pessimism, roles, identity,
0	optimism_pessimism influencing
i he	e experiences _ opportunities _ foundations for resilience
- 🕞 b Ari	njury_early adjustment (unknowns, identity confronted) comb w environmental (social, cultural, institutional) influences, comb with pre-mor
6 Q Q	ilture within SCI centre or facility_focus on physical vs roles, health, wellbeing
0	facility focus on physical recovery or recognition of life roles
	supportive messages received from SCI facility during acute and rehabilitation about work
C Le	aming and re-creation process_identity
6 🔘 V	sknowns_lack of knowledge, understanding, information, sense of what possible and how
-0	fear of future related to lack of understanding about SCI
n 🔘 cjife	after injury_work value challenged by environmental factors (soc, inst, cuit, phys) and personal factors (emotional, physical, spintual)
0 8	lance
() M	eaning of work and meaningful work_identity, roles
0 \$	icial policy_system negotiations_insurance vs welfare
O St	icial supports_employer, family, personal care assistance, rehab profs
🔘 d_per	r support_above challenged by peers, people w SCI who are living successfully with injury_show, inspire, challenge, motivate, educate, lead
D e_phy	sical and environmental contextual factors_this is the known stuff

Figure 2. Example of data analysis process, from codes to descriptive themes.

Table 2. Overview of descriptive and analytical themes.

Descriptive themes Preinjury: The experiences, paradigms, personality that exist with individual preinjury

At injury: Early adjustment (unknowns, identity confronted), combined with environmental (social, cultural, institutional) influences, combined with premorbid

Life after injury: Work value challenged by environmental factors (a/a) and personal factors (emotional, physical, spiritual)

Peer support: Above challenged by peers (i.e., people living successfully with SCI) show, inspire, challenge, motivate, educate, lead Physical and environmental contextual factors – this is the known

Analytical themes

A matrix of personal and environmental factors exist requiring complex navigation in order to create possibilities and opportunities for achieving post injury employment The process of seeking or gaining post injury employment shares a reciprocal

The process of seeking or gaining post injury employment shares a reciprocal relationship with the temporal nature of adjustment to SCI There is an intrinsic need for occupational engagement through paid

employment

rehabilitation goal, with a focus instead on meeting "basic survival needs" [23].

People who have experienced employment after SCI reported an explicit link to the extent of their social connectedness [25]. This manifested as a positive relationship with their preinjury employer who supported a return to work, existing social contacts who used their networks to offer opportunities for work and/or exposure to a peer mentor who challenged an individual's perspective of what might be possible in relation to employment [22,25–27].

Opinions of people with SCI varied about access to insurance or social welfare in relation to work, with both being described as a support, but also a disincentive to employment [21,22,25,26]. Given the extent of physical and psychological impacts of SCI, while people expressed having an interest or desire to work [22,26], it was often counteracted by the notion of "Is work worth the effort?' [25]. Similarly, an overriding wish for security [21] in the sense of having a stable income, influenced the decisions people made about work [27]. Where people could find a balance between the different demands and expectations, employment became a possibility [22].

People with SCI needed to negotiate the cultural, social and institutional environmental factors, as mentioned earlier, to achieve employment after SCI. They did this intrinsically, drawing on personality traits, previous life experience and sense of self. People who achieved employment after SCI were motivated and optimistic [22,26,28], had confidence in their ability to cope with challenges that arose and had a determination to work against barriers [27]. People who were unemployed reported pessimism about finding a job, they were anxious and fearful about working [26] and had negative experiences in relation to returning to work [22].

The process of seeking or gaining postinjury employment shares a reciprocal relationship with the temporal nature of adjustment to SCI

Informed by Moss-Morris' [29] theory of adaption to chronic illness, Craig et al [30] defines adjustment following SCI as the rate of social participation in people living in the community following injury. Adjustment is impacted on by multiple factors including sociodemographic, injury related, environmental and social relationships [29]. These forces around adjustment are also evident in individual life trajectories, including the path to employment. This analytical theme, therefore, reflects the interrelationship that exists in people following SCI, between adjustment and employment.

Pre- and postinjury exposure to social paradigms of disability appeared to be influential to adjustment and return to employment. People with SCI described instances of discrimination and stigma [22,26,28] and employer and others' misconceptions about their abilities, both physical and cognitive [22,25,27,28,31].

Studies suggest that in the initial 2–3 years after SCI, people reported an initial focus on understanding their body, of re-learning and needing time to create new routines in daily life [21,32]. Personal resources were required to deal with emotional issues, particularly adaption to the physical and functional changes and also concerns about supporting themselves and/or their families [27]. People with SCI reported that when there was a sense of disengagement from the worker role, the longer this continued, the less able they were to redevelop the connection [23]. While new life priorities and timelines were found, unresolved health issues continued to impact on adjustment [25].

In the years after injury, there was an increase in discussion about the benefits of employment while living with SCI. People reported finding a sense of identity through employment [22,25], along with feelings of balance about the place of work in their lives [28]. This recognition of the value of work is reflected in the third analytical theme.

There is an intrinsic need for occupational engagement through paid employment

People in employment with SCI reported feelings of satisfaction from the mental stimulation of work, social integration, sense of purpose and opportunity for personal growth and independence [22,26]. Work was a sign of independence, proof of productivity and a way of contributing to society [26]. The opportunity to contribute to society was reported by people who were employed as crucial to their self-esteem, personal identity, pride and social value [28,31]. Being a worker was part of their identity and represented "living a normal life," being socially connected, confident, having a sense of worth and earning a living [25]. Finances were reported as being motivating to people but were not the main benefit of employment. Not working was unimaginable [25]. However, people also reported that having meaningless work did not have same benefits [25] or that jobs obtained through "welfare" were "inferior" [31]. Where people had not achieved employment they reported having little confidence [31].

Even younger people who had not yet regained employment after injury, recognized the potential value of work. They had expectations of working and that they would do well at work. They identified that participation in employment was valuable, it would be a way to express creativity and be good at something [21].

Discussion

This discussion presents reflections on the themes that emerged from the review and implications for clinical practice, a summary of the strengths and weaknesses of the studies included, and limitations of this review as well as suggestions for further research.

This review highlights the variable and challenging nature of the return to work experience for people following SCI, and also the positive impact that being a worker has on people's lives. Individual journeys are complex, influenced subtlety or extensively by numerous personal and environmental factors. Thomas and Harden [14] describe the value of synthesizing qualitative research in the evidence base is to facilitate "effective and appropriate health care." To this end, there are three main implications for clinical practice from this systematic review. These relate to the three analytical themes that emerged from the thematic synthesis. That is: complex navigation of a matrix of intrinsic factors and environmental factors creating possibilities and opportunities; experience of employment shares a reciprocal relationship with the temporal nature of adjustment to SCI; and the intrinsic need for occupational engagement through paid employment.

The first implication of this review is associated with the process of achieving employment after SCI being fundamentally difficult. The complexity of the return to work process has been identified in previous literature [11,12]. Challenges and barriers are often unavoidable, but as the reviewed papers identify, intrinsic factors such as motivation, optimism, confidence and determination among participants assisted to overcome barriers to gaining and maintaining employment [22,26–28]. The reviewed studies also demonstrate the utility of peer support, social connectedness, a positive institutional culture regarding return to work and the importance of identifying and balancing economic goals, in facilitating trajectories toward employment. It is critical that clinicians draw on and provide multiple strategies to support individuals in the navigation of the return to work process.

The second implication relates to the processes of adjustment and return to work after SCI being intertwined. This relationship is evident from the reviewed studies and further emphasized in other existing literature [29,30]. The clinical team therefore, while remaining cognizant to the individual motivations for being a worker, and the adjustment process, can play a sensitive, yet pragmatic role in promoting employment outcomes with the person. They can do this by concurrently offering and linking to appropriate resources and benefits, being mindful of timing, and above all doing this from a consistent and supportive framework and culture of positivity about employment after SCI.

The third analytical theme of the need for occupation, guides the final implication of this review. Expounded in the findings of the reviewed papers is an overall drive from the participants to be engaged in productive activity which is broadly termed "occupation," regardless of whether people have achieved employment or not. This is well documented in established theories of occupation such as the Canadian Model of Occupational Performance - Engagement [33] and the Model of Human Occupation [34] which teach that occupation is central to human existence. The findings from this review reinforce that principally, the benefits of being in paid work outweigh the negative experiences encountered when seeking, gaining and maintaining employment. In the clinical environment, a focus on the value of employment as "occupation" can be encouraged. Clinicians should provide reassurance that employment is both possible and health promoting, and this can offer a powerful and positive message about the future to people who are newly injured.

Strengths and weaknesses of reviewed studies

The reviewed studies employed a variety of research designs. While studies sought to answer different research questions, they all contributed to the understanding of the experience of return to work for people with SCI. The studies were generally of very high quality with good methodological rigor. Subsequently, all reviewed studies were included in the thematic synthesis with no studies rejected on the basis of the weak methodology.

Where studies scored lower in the critical appraisal according to the National Institute for Health and Clinical Excellence guidelines [17], the issues were similar with several studies neglecting to document the relationship of the researcher to the participants, nor describing how the research was explained to the participants.

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Only four studies provided detail about the background discipline of the primary researcher. Clear and coherent reporting of ethics was also lacking in four studies and three studies did not provide sufficient detail regarding how they ensured reliable analysis such as using a second researcher to check themes and coding. Future research should describe the position of the researcher, provide detail regarding ethical considerations and undertake techniques to ensure analysis is reliable, in order to limit bias.

Challenges exist in accurately synthesizing research from different countries and their respective insurance and social welfare policy environments. For example, two papers were written in the context of a comprehensive no fault accident social insurance system (including income support) in New Zealand, compared with three papers from the United States of America where rehabilitation and supports are largely driven by private health insurance policies. Similarly studies had recruited participants from across broad age ranges, time since injury, and employment history, bringing varying perspectives and experiences. Bergmark's [21] study, for example, specifically recruited participants who were young adults, with no postinjury employment experience and all within 5 years of injury. Comparatively Wilbanks's [28] work focused on participants who were all employed, and at least >30 years postinjury. All of the studies described employment history of the participants to some extent both pre- and postinjury. Only three studies provided specific detail about the level of education achieved by the participants pre- or postinjury. These are not necessarily weaknesses of the reviewed studies, but an inherent challenge due to the high number of influencing variables to be considered when undertaking research with this population.

Limitations and directions for further research

There are several limitations of this review. A publication bias exists since studies were selected only from peer-reviewed journals across four databases. In addition, while only nine papers met the inclusion criteria for appraisal and synthesis, they combined data from several different methodological traditions, adding strength to the review [13], Researcher bias is also possible as the first author as an experienced occupational therapist in SCI rehabilitation and service development. However, this preexisting knowledge provides a depth of understanding which is a strength in synthesizing and making sense of the issues and scenarios presented.

Studies reviewed reflected a wide range of dates, 1999 to 2015. As discussed in reference to individual studies, the policy and practice landscape in relation to vocational rehabilitation specific interventions, the labor market and societal attitudes about SCI may have changed over this time. These factors may have impacted on the individual experience and subsequent study results.

The varying contexts and sample populations included in this review highlight possible gaps in this body of literature about people's experiences of employment following SCI. Time since injury in the reviewed studies ranged from two months to 40 years yet there was no particular acknowledgement of this with differing experiences. A consistent finding in reports of employment outcome is that employment rates increase over the first 10–15 years postinjury [5,35] and that Krause [36] suggested that it can take time for an individual to reach full vocational potential, particularly if an early "window of opportunity" is missed. Given this, the explicit exploration of employment experiences at different time ranges post injury, could be useful in producing data to guide the nature and extent of vocational interventions in clinical settings.

Some understanding has emerged from this synthesis of the nature and extent of experiences and behaviors associated with different employment outcomes (such as employed versus unemployed). There is, however, scope for further exploration of these and in relation to individual trajectories, particularly observing vocational pathways such as employment and education history pre- and postinjury. Gaining more information from research will help us understand the impact of these variables on achieving employment after SCI.

The findings of this systematic review could also be used to demonstrate the importance of return to work in the context of other health conditions (such as heart failure, organ transplant or limb amputation) for overall health and well-being [33]. Indeed, in terms of occupational engagement, the views of people with SCI would seem to parallel those of the general population [37,38].

Conclusions

This review identified three analytical themes in answering the question "What are the barriers and facilitators influencing people's experience of return to work following spinal cord injury?" Seeking, gaining and maintaining employment for people after SCI involves a complex navigation of a matrix of personal and environmental factors creating possibilities and opportunities. The experience of employment shares a reciprocal relationship with the temporal nature of adjustment to SCI. And lastly, it is clear that there exists an intrinsic need in people following SCI, for occupational engagement through paid employment. The implications of these findings are that clinicians: draw on and provide multiple strategies to support individuals in the navigation of the return to work process; be cognizant of individual motivations for being a worker, and the adjustment process, whilst offering sensitive, yet pragmatic support in promoting employment outcomes; and provide reassurance that employment is both possible and health promoting.

Disclosure statement

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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Gillean Hilton @ http://orcid.org/0000-0002-1551-0914 Carolyn Unsworth @ http://orcid.org/0000-0001-6430-2823

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EMPLOYMENT FOLLOWING SPINAL CORD INJURY () 9

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Appendix F

Ethics approval documentation from Human Research Ethics Committee



AUSTIN HEALTH HUMAN RESEARCH ETHICS COMMITTEE

ETHICAL APPROVAL FOR NEW STUDY

Associate Professor James S Olver

Austin Health

Department of Psychiatry

Level 10 Lance Townsend Building, Austin Hospital

145 Studley Rd

3084

Australia

12 April 2016

Dear Associate Professor James S Olver

AU RED HREC Reference Number: LNR/15/Austin/478

Austin Health Project Number: Audit 15/478

Project Title: Retrospective audit medical record for vocational outcome following traumatic spinal cord injury

I am pleased to advise that the above project has received ethical approval from the Austin Health Human Research Ethics Committee (HREC). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRMC) National Statement on Ethical Conduct in Research Involving Humans (2007), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

HREC Approval Date: 12/04/2016

Participating Sites:

Ethical approval for this project applies at the following sites:

Site	
Austin Health	

Approved Documents:

The following documents have been reviewed and approved:

Document	Version	Date
Audit Application tool incorporating Protocol	1.0	14 October 2015

Conditions of Ethics Approval:

- You are required to submit to the HREC:
 - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.

A comprehensive Final Report upon completion of the project.

- Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.
- Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: *Monitoring and reporting of safety for clinical trials involving therapeutic products May 2009*.
- Notify the reviewing HREC of your inability to continue as Coordinating Principal Investigator.
- Notify the reviewing HREC of the failure to commence the study within 12 months of the HREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.
- Notify the reviewing HREC of any matters which may impact the conduct of the project.

• If your project involves radiation, you are legally obliged to conduct your research in accordance with the Australian Radiation Protection and Nuclear Safety Agency Code of Practice 'Exposure of Humans to Ionizing Radiation for Research Purposes' Radiation Protection series Publication No.8 (May 2005)(ARPANSA Code).

The HREC may conduct an audit of the project at any time.

Yours sincerely

Ms Chelsea Webster Ethics and Research Governance Manager

Office for Research, Austin Health Level 8 HSB.

Phone: +61 3 9496 3248

E-mail: <u>chelsea.webster@austin.org.au</u> Web: <u>http://www.austin.org.au/researchethics</u>

Carbon Copy: Ms Gillean Hilton

Austin Health Ethics Approval Letter Version 1, dated 03 Sept 2015 based on REx Ethics Approval letter template Version 1, dated 6 Aug 2015

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Appendix G

Memorandum of Understanding between Austin Health and Central Queensland

University



Austin Hospital

145 Studiey Road PO Box 5555 Heidelberg Victoria Australia 3084 Telephone 03 9496 5000 Facsimile 03 9458 4779 www.austin.org.au

This MEMORANDUM OF UNDERSTANDING is dated the last date on which it is executed is BETWEEN:

AUSTIN HEALTH (ABN 96 237 388 063) of 145 Studley Road, Heidelberg, Victoria 3084 AUSTRALIA (AH)

AND the party or parties (Collaborator) named in Item 2 of Schedule 1.

RECITAL

The parties wish to conduct research and development with a view to achieving agreed research objectives through a research or quality improvement project, the "Research Project," as specified in Item 1 of Schedule 1, on the terms and conditions set out in this Memorandum of Understanding.

IT IS AGREED AS FOLLOWS:

RESEARCH PROJECT

Each party agrees to carry out its obligations in accordance with the National Statement on Ethical Conduct in Human Research 2007 and The Australian Code for the Responsible Conduct of Research 2007 (as varied or replaced by the National Health & Medical Research Council, the Australian Research Council and Universities Australia).

- 1.1 Each party must:
 - (a) bear its own costs under this Memorandum of Understanding; and
 - (b) obtain and comply with all required authorisations from government agencies and ethics committees which are required for the Research Project unless one party is nominated at Item 4 of Schedule 1; and
 - (c) not knowingly infringe, and use its best endeavours not to infringe, the Intellectual Property rights of any person in carrying out the Research Project; and
 - (d) carry out the Research Project in accordance with all applicable laws.

PROJECT INTELLECTUAL PROPERTY (IP)

- 2.1 Except for copyright in a student thesis (see clause 2.22.2) Project IP will be jointly owned by the parties as tenants in common in the proportion set out in Item 5 of Schedule 1 and no party may:
 - (a) grant a licence of its share of any Project IP; or
 - (b) assign its share of the Project IP,

without the written consent of all parties, which shail not be unreasonably withheld.

- 2.2 The parties agree that copyright in a student thesis will be owned by the student but the party responsible for the student will ensure that the student enters into a written agreement, which is consistent with this Memorandum of Understanding, before the student commences any Research Project activities.
- 2.3 The parties will notify each other of any Project IP that might have commercial potential and the parties will negotiate in good faith the terms of any Commercialisation of the Project IP so as to share fairly any associated commercial return.
- 2.4 The parties are committed to appropriate recognition of contributions to invention and exploitation of Intellectual property for the benefit of the Australian community.

Audit Activity MOU v2 2014.12.10

3. BACKGROUND IP

- 3.1 Each party warrants that it either owns, or is properly licensed to use, its Background IP and that it has the right to grant the licence in clause 3.2.
- 3.2 Each party grants to the other party for the Term a royalty free, non-exclusive licence to use that party's Background IP for the purposes of this Memorandum of Understanding only.
- 3.3 Subject to clause 3.2, no provision of this Memorandum of Understanding affects the rights inherent in the Background IP.

4. PUBLICATION

- 4.1 At least 28 days prior to any publication, the publishing party will provide a copy of the proposed publication to each other party.
- 4.2 The other parties may provide comments and/or reasonable amendments to the publication to protect their Confidential Information and/or Intellectual Property provided they are given to the publishing party in writing no later than 14 days before the publication is proposed. If no such comments or amendments are provided within those 14 days the publishing party can publish.
- 4.3 All publications will recognise the contribution by the parties to the Research Project.
- 4.4 The parties are committed to appropriate recognition of contributions to invention and exploitation of Intellectual property for the benefit of the Australian community.

5. INSURANCE

5.1 Each party shall effect and maintain adequate insurance to cover its conduct in the Research Project.

6. GENERAL

- 6.1 This Agreement constitutes the entire agreement and understanding between the parties with respect to the subject matter of this Agreement.
- 6.2 This Agreement is governed by the laws of the State of Victoria and each Party submits to the exclusive jurisdiction of the courts of that State.

Audit Activity MOU v2 2014.12.10

Item 1	Research Project	0	Retrospective audit of medical record for vocational outcome following traumatic spinal cord injury
Item 2	Collaborator (names, ABN)	5	Austin Health ABN 96 237 388 063 Central Queensland University, ABN 39 181 103 288
Item 3	Term Commencement Date	•	Date of last signature
	End Date	•	1ª December 2016
item 4	Party responsible for obtaining all necessary ethical, administrative and governmental approvals	ê	Each party will be responsible for obtaining the relevant ethical, administrative and governmental approval for their site.
ltem 5	Ownership of Project IP	•	Equal shares

SCHEDULE 1 PROJECT DETAILS

Audit Activity MOU v2 2014.12.10

SCHEDULE 2

PARTY DETAILS

Collaborator	Austin Health
Principal Investigator	Name: James Olver Position: Consultant Psychiatrist/Assoc Prof Address: Level 8, Lance Townsend Building, Austin Hospital Telephone: 9496 5000 Facsimile: E-mail: james.olver@austin.org.au

Collaborator	Central Queensland University
Principal Investigator	Name: Carolyn Unsworth Position: Professor Address: CQU Melbourne, 120 Spencer St, Melbourne Telephone: 9616 0504 Facsimile: E-mail: c.unsworth@cqu.edu.au

EXECUTED as an agreement by the parties on the last date hereinafter appearing

AUSTIN HEALTH Head of Department

SIGNATURE AND DATE

NAME [please print]

[POSITION TITLE]

Dr Andrew Nunn, MB, BS, FAFRM (RACP) Victorian Spinal Cord Service, Austin Health PN: 0346269T Ph: 9496 5000 Fax: 9496 3626

Chelses velsoon Ethis and Rosearch Crovernance Manager 12 April 2016 Audit Activity MOU v2 2014.12.10

COLLABORATOR Head of Department

4/03/2016

SIGNATURE AND DATE

_Professor Grant Stanley ____ NAME [please print]

Pro Vice-Chancellor (Research) [POSITION TITLE]

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Appendix H

Ethical approval documentation from Human Research Ethics Committee



Austin Hospital

145 Studley Road PO Box 5555 Heidelberg Victoria Australia 3084 Telephone 03 9496 5000 Facsimile 03 9458 4779 www.austin.org.au

Date:	17 July 2014	Facsimile 03 9458 477 www.austin.org.au		
То:	A/Prof James S Olver			
	Psychiatry Austin Health			
Project:	The effectiveness of early intervention vocational rehabilitation on employment outcomes following traumatic spinal cord injury; a cohort study			
HREC Ref No: SSA Ref No:	HREC/14/Austin/256 SSA/14/Austin/257			
Agenda Item No:	6.5 (June HREC 2014)			
Approval Period:	17 July 2014 to 17 July 2017			

Document(s)	Version	Version
	No.	Date
NEAF	2	04 July 2014
Victorian Specific Module	2	25 June
		2014
Protocol	1	13 May
		2014
Austin Participant Information & Consent Form	2	13 May
		2014

Correspondence with Participants	2	25 June 2014
SCIM III – Spinal Cord independence Measure		Not dated
Personal Wellbeing Index		Not dated
Demographic Data Collection Sheet		Not dated
HADS		Not dated
SCIT Evaluation		2007
Site Specific Assessment	2	04 July 2014
Health Information Services Declaration	1	20 May
		2014
Budget		Not Dated

Further to my letter dated **24 June 2014** concerning the above detailed project, I am writing to acknowledge that your response to the issues raised by the Human Research Ethics Committee at their meeting on **19 June 2014** is satisfactory. This project now has full ethical approval and site authorisation for a period of three years from the date of this letter.

Before the study can commence you must ensure that you have (if applicable):

- A signed Clinical Trial Agreement
- Signed Standard Indemnities

A copy of the CTN acknowledgment from the TGA. Please note a copy of the acknowledgement is to be forwarded to the site Research Governance Officer (RGO).

- For trials involving radiation it is your responsibility to ensure the research is added to the site Management Licence issued by Department of Human Services – Radiation Safety Section <u>prior</u> to study commencement should it be required (check your Medical Physicist Report). The site RGO must be notified when the research has been added to the licence.
- It is a requirement that a progress report is submitted to the Committee annually, or more frequently as directed. Please note a final report must be submitted for all studies. Should you plan for your study to go beyond the 3-year ethics approval, please request in writing an extension of ethics approval prior to its lapsing. If your study will not commence within 12 months, a request must be forwarded to the HREC justifying the delay beyond 12 months. Should such a request not be received, ethics approval will lapse and a resubmission to the HREC will then be necessary.

- After commencement of your study, should the trial be discontinued prematurely you must notify the HREC of this, citing the reason.
- Any changes to the original application will require a submission of a protocol amendment for consideration as this approval only relates to the original application as detailed above.
- Please notify the HREC of any changes to research personnel. All new investigators must be approved prior to performing any study related activities.
- It is now your responsibility to ensure that all people (i.e. all investigators, sponsor and other relevant departments in the hospital) associated with this particular study is made aware of what has been approved.

The Committee wishes to be informed as soon as practicable of any untoward effects experienced by any participant in the trial where those effects in degree or nature were not anticipated by the researchers. The HREC has adopted the NHMRC Australian Health Ethics Committee (AHEC) Position Statement

'Monitoring and reporting of safety for clinical trials involving therapeutic products' May 2009

Please ensure you frequently refer to the Research Ethics website <u>http://www.austin.org.au/researchethics/</u> for all up to date information about research and ethical requirements.

DETAILS OF ETHICS COMMITTEE:

It is the policy of the Committee not to release personal details of its members. However I can confirm that at the meeting at which the above project was considered, the Committee fulfilled the requirements of the National Health and Medical Research Council in that it contained men and women encompassing different age groups and included people in the following categories:

Chairperson	Additional members include:
Ethicist	Chairs of all sub committees,
Lawyer	or nominees

Lay Man Lay Woman Person fulfilling a Pastoral Care Role Person with Counselling Experience Person with Research Experience Other persons as considered appropriate for the type/s of research usually being considered

I confirm that the Principal Investigator or Co-Investigators were not involved in the approval of this project. I further confirm that all relevant documentation relating to this study is kept on the premises of Austin Health for more than three years.

Yours sincerely,

Dr Sianna Panagiotopoulos, PhD Manager, Office for Research

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice annotated with TGA comments (July 2008) and the applicable laws and regulations; and the Health Privacy Principles in The Health Record Act 2001. The process this HREC uses to review multi-centre research proposals has been certified by the NHMRC.

Human Research Ethics Committee Office for Research, Level 8 HSB.

Phone: (03) 9496 4090

E-mail: ethics@austin.org.au

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v1 Updated 081113 SH

Appendix I

Ethical approval documentation from Human Research Ethics Committee



Melbourne Campus

18 August 2015

Dear Prof Unsworth and Ms Hilton

HUMAN RESEARCH ETHICS COMMITTEE ETHICAL APPROVAL PROJECT: H15/08-184 THE EFFECTIVENESS OF EARLY INTERVENTION VOCATIONAL REHABILITATION ON EMPLOYMENT OUTCOMES FOLLOWING TRAUMATIC SPINAL CORD INJURY: A COHORT STUDY

The Human Research Ethics Committee is an approved institutional ethics committee constituted in accord with guidelines formulated by the National Health and Medical Research Council (NHMRC) and governed by policies and procedures consistent with principles as contained in publications such as the joint Universities Australia and NHMRC *Australian Code for the Responsible Conduct of Research.* This is available at http://www.nhmrc.gov.au/publications/synopses/_files/r39.pdf.

On 18 August 2015, the Chair of the Human Research Ethics Committee acknowledged previous ethical approval for this project from the Austin Health Human Research Ethics Committee (Approval HREC/14/Austin/256), and has granted full approval as a CQUniversity project (H15/08-184) under chapter 5.3 of the National Statement, pending ratification by the full committee at its September 2015 meeting.

The period of ethics approval will be from 18 August 2015 to 17 July 2017. The approval number is H15/08-184; please quote this number in all dealings with the Committee. HREC wishes you well with the undertaking of the project and looks forward to receiving the final report.

The standard conditions of approval for this research project are that:

- (a) you conduct the research project strictly in accordance with the proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee;
- (b) you advise the Human Research Ethics Committee (email ethics@cqu.edu.au) immediately if any complaints are made, or expressions of concern are raised, or any other issue in relation to the project which may warrant review of ethics approval of the project. (A written report detailing the adverse occurrence or unforeseen event must be submitted to the Committee Chair within one working day after the event.)
- (c) you make submission to the Human Research Ethics Committee for approval of any proposed variations or modifications to the approved project before making any such changes;
- (d) you provide the Human Research Ethics Committee with a written "Annual Report" on each anniversary date of approval (for projects of greater than 12 months) and "Final Report" by no later than one (1) month after the approval expiry date; (Forms may be downloaded from the Office of Research Moodle site http://moodle.cqu.edu.au/mod/book/view.php?id=334905&chapterid=17791.)
- (e) you accept that the Human Research Ethics Committee reserves the right to conduct scheduled or random inspections to confirm that the project is being conducted in accordance to its approval. Inspections may include asking questions of the research team, inspecting all consent documents and records and being guided through any physical experiments associated with the project
- (f) if the research project is discontinued, you advise the Committee in writing within five(5) working days of the discontinuation;
- (g) A copy of the Statement of Findings is provided to the Human Research Ethics Committee when it is forwarded to participants.

Please note that failure to comply with the conditions of approval and the *National Statement on Ethical Conduct in Human Research* may result in withdrawal of approval for the project.

You are required to advise the Secretary in writing within five (5) working days if this project does not proceed for any reason. In the event that you require an extension of ethics approval for this project, please make written application in advance of the end-date of this approval. The research cannot continue beyond the end date of approval unless the Committee has granted an extension of ethics approval. Extensions of approval cannot be granted retrospectively. Should you need an extension but not apply for this before the end-date of the approval then a full new application for approval must be submitted to the Secretary for the Committee to consider.

The Human Research Ethics Committee wishes to support researchers in achieving positive research outcomes. If you have issues where the Human Research Ethics Committee may be of assistance or have any queries in relation to this approval please do not hesitate to contact the Secretary, Sue Evans or myself.

Yours sincerely,

A/Prof Tania Signal Chair, Human Research Ethics Committee

Cc: Project file

Approved

Appendix J

Demographic data collection tool used in Study Three: Longitudinal employment outcomes of the EIVR program

Demographic data	a collection sheet			
		Please circle as appropriate	baseline / 6 month / 12 month	
		a		
Relationship status	Married (incl. de facto)	Current carer availability	Has a carer	
	Single, never married	(paid or not paid)	Has no carer	
	Single, separated			
	Single, divorced	Carer residency status	Co-resident carer	
	Single, widowed		Non-resident carer	
Living arrangement	Lives alone	Main carers		
	Lives with family	relationship to client	Child	
	Lives with others		Child-in-law	
			Friend/neighbour	
Current work status	Unemployed		Other relative	
	Full time employed		Parent	
	Part time employed variable hours		Spouse/partner	
	Part time employed fixed hours			
	On leave	Property ownership	Property owned by client or family	
	Retired		private rental	
			public rental	
	Self employed		other	
	Student			
Where is client living?	(address)			
	(suburb)			
	(postcode)			
	(write no change if still living in same place as on hospital label)			
Support question	How many hours in a typical day do you have someone with you to provide physical assistant			
	for personal care activities such as eating, bathing, dressing, toileting and mobility, or			
community activities like shopping, recreation or socialising?			ng?	
	i hours paid assista	i hours paid assistance		
	ii hours unpaid (fan	nily, others)		

Appendix K

Numeric Pain Rating Scale (Jensen & Karoly, 1992) used in Study Three: Longitudinal employment outcomes of the EIVR program

Numeric Pain Rating Questionnaire			
		On a scale of 0 - 10 with zero being 'none' and 10 being worst possible, how much pain are you living with on a day to day basis?	
		Score:	
		If a client reports pain of 1 or more, does the pain interfere with your day to day activities?	
	А.	No, never	
	В.	Sometimes	
	С.	Always	

Appendix L

Hospital Anxiety and Depression Scale (Woolrich, Kennedy, & Tasiemski, 2006) used in Study Three: Longitudinal employment outcomes of the EIVR program

Statement	Response	
I feel tense or "wound up"	most of the time	
	a lot of the time	
	from time to time, occasionally	
	not at all	
I still enjoy the things I used to enjoy	definitely as much	
	not quite as much	
	only a little	
	hardly at all	
I get a sort of frightened feeling as if	very definitely and quite badly	
something award is about to happen	yes, but not too badly	
	a little, but it doesn't worry me	
	not at all	
I can laugh and see the funny side of	as much as I always could	
tnings	not quite so much now	
	definitely not so much now	
	not at all	
Worrying thoughts go through my	a great deal of the time	
mind	a lot of the time	
	from time to time but not too often	
	only occasionally	
I feel cheerful	not at all	
	not often	
	sometimes	
	most of the time	
I can sit at ease and feel relaxed	definitely	
	usually	
	not often	
	not at all	
I feel as if I am slowed down	nearly all the time	

	very often	
	sometimes	
	not at all	
I get a sort of frightened feeling, like	not at all	
	occasionally	
	quite often	
	very often	
I have lost interest in my appearance	definitely	
	I don't take so much care as I should	
	I may not take quite as much care	
	I take just as much care as ever	
I feel restless as if I have to be on the move	very much indeed	
	quite a lot	
	not very much	
	not at all	
I look forward with enjoyment to things	as much as ever I did	
	rather less than I used to	
	definitely less than I used to	
	hardly at all	
I get sudden feelings of panic	very often indeed	
	quite often	
	not very often	
	not at all	
I can enjoy a good book or radio or TV programme	often	
	sometimes	
	not often	
	very seldom	

Appendix M

Personal Wellbeing Scale (International Wellbeing Group, 2013) used in Study Three: Longitudinal employment outcomes of the EIVR program

Satisfaction with Life as a Whole and The PWI Scale (Verbal Format)

"(On this scale,) **Zero** means you feel <u>completely dissatisfied</u>. **10** means you feel <u>completely satisfied</u>. And the **middle of the scale is 5**, which means you feel <u>neutral</u> (i.e. neither satisfied nor dissatisfied)."

Completely										Completely
Dissatisfied					Neutral					Satisfied
0	1	2	3	4	5	6	7	8	9	10

Test Items

Respondent's Rating

(0-10)

Part I (Optional item]: Satisfaction with Life as a Whole

"Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole ?"

Part II: Personal Wellbeing Index

"How satisfied are you with.....?"

- 1. your standard of living ?
- 2. your health ?
- 3. what you are achieving in life?
- 4. your personal relationships ?
- 5. how safe you feel ?
- 6. feeling part of your community ?
- 7. your future security ?
- 8. your spirituality or religion?"

 -

Appendix N

Spinal Cord Independence Measure (Itzkovich et al., 2007) used in Study Three: Longitudinal employment outcomes of the EIVR program

SCIM III – Spinal Cord independence Measure – Please mark the box adjacent to the scenario that best fits your situation

SELF CARE

- **1. Feeding** (cutting, opening containers, pouring, bringing food to mouth, holding cup with fluid)
 - 0 Needs parenteral, gastrostomy or fully assisted oral feeding
 - 1 Needs partial assistance for eating and / or drinking, or for wearing adaptive devices
 - 2 Eats independently; needs adaptive devices or assistance only for cutting food and/ or pouring and/ or opening containers
 - 3 Eats and drinks independently; does not require assistance or adaptive devices
- 2. Bathing (soaping, washing, drying body and head, manipulating water tap)
 - A = Upper body
 - 0 Requires total assistance
 - 1 Requires partial assistance
 - 2 Washes independently with adaptive devices or in a specific setting (eg bars, chair)
 - 3 Washes independently; does not require adaptive devices or specific setting (not customary for healthy people)
 - B = Lower body
 - 0 Requires total assistance
 - 1 Requires partial assistance

- 2 Washes independently with adaptive devices or in a specific setting
- 3 Washes independently: does not require adaptive devices or specific setting

Dressing (clothes, shoes, permanent orthoses: dressing, wearing, undressing)

- A = Upper body
 - 0 Requires total assistance
 - 1 Requires partial assistance with clothes without buttons, zippers or laces
 - 2 Independent with clothes without buttons, zippers or laces; requires adaptive device and / or specific settings
 - 3 Independent with clothes without buttons; does not require adaptive devices and / or specific setting;

Needs assistance or adaptive device and / or specific setting only for buttons zips and laces.

- 4 Dresses (any cloth) independently; does not require adaptive devices or specific setting
- B = Lower body
 - 0 Requires total assistance
 - 1 Requires partial assistance with clothes without buttons, zippers or laces
 - 2 Independent with clothes without buttons, zippers or laces; requires adaptive device and / or specific settings
 - 3 Independent with clothes without buttons; does not require adaptive devices and / or specific setting;

Needs assistance or adaptive device and / or specific setting only for buttons zips and laces.

- 4 Dresses (any cloth) independently; does not require adaptive devices or specific setting
- **3. Grooming** (washing hands and face, brushing teeth, combing hair, shaving, applying makeup)
 - 0 Requires total assistance
 - 1 Requires partial assistance
 - 2 Grooms independently with adaptive devices
 - 3 Grooms independently without adaptive devices

SUBTOTAL (0-20)

RESPIRATION and SPHINCTER MANAGEMENT

4. Respiration

- 0 Requires tracheal tube (TT) and permanent or intermittent assisted ventilation (IAV)
- 2 Breathes independently with TT; requires oxygen, much assistance in coughing or TT management
- 4 Breathes independently with TT; requires oxygen,little assistance in coughing or TT management
- 6 Breathes independently without TT; requires oxygen, much assistance in coughing, a mask (eg PEEP) or IAV (Bipap)
- 8 Breathes independently without TT; requires little assistance or stimulation for coughing
- 10 Breathes independently without assistance or device

5. Sphincter Management – Bladder

- 0 Indwelling catheter
- 3 Residual urine volume (RUV) > 100cc; no regular catheterization or assisted intermittent catheterization

- 6 RUV < 100cc or intermittent self catheterization; needs assistance for applying drainage instrument
- 9 Intermittent self catheterization; uses external drainage instrument; does not need assistance for applying
- 11 Intermittent self catheterization; continent between catheterizations; does not use external drainage instrument
- 13 RUV <100cc; needs only external urine drainage; no assistance is required for drainage
- 15 RUV <100cc; continent; does not use external drainage instrument.

6. Sphincter Management – Bowel

- 0 Irregular timing or very low frequency (less than once in 3 days) of bowel movements
- 5 Regular timing, but requires assistance (eg for applying suppository); rare accidents (less than twice a month)
- 8 Regular bowel movements, without assistance; rare accidents (less than twice a month)
- 10 Regular bowel movements, without assistance; no accidents
- 7. Use of Toilet (perineal hygiene, adjustment of clothes before/ after, use of napkins or diapers)
 - 0 Requires total assistance
 - 1 Requires partial assistance; does not clean self
 - 2 Requires partial assistance; cleans self independently
 - 4 Uses toilet independently in all tasks but needs adaptive devices or special setting (eg bars)
 - 5 Uses toilet independently; does not require adaptive devices or special setting

SUBTOTAL (0-40)

MOBILITY (Room and toilet)

8. Mobility in bed and action to prevent pressure sores

- 0 Needs assistance in all activities; turning upper body in bed, turning lower body in bed, sitting up in bed, doing push-ups in wheelchair, with or without adaptive devices **but not with electric aids**
- 2 Performs one of the activities without assistance
- 4 Performs two or three of the activities without assistance
- 6 Performs all the bed mobility and pressure release activities independently
- **9. Transfers: bed-wheelchair** (locking wheelchair, lifting footrests, removing and adjusting armrests, transferring, lifting feet)
 - 0 Requires total assistance
 - 1 Needs partial assistance and/or supervision, and/or adaptive devices (eg sliding board)
 - 2 Independent (or does not require wheelchair)
- **10. Transfers: wheelchair toilet tub** (If uses toilet wheelchair: transfers to and from; if uses regular wheelchair: locking wheelchair lifting footrests, removing and adjusting armrests, transferring, lifting feet)
 - 0 Requires total assistance
 - 1 Needs partial assistance and/or supervision, and/or adaptive devices (eg grab rail)
 - 2 Independent (or does not require wheelchair)

MOBILITY (indoors and outdoors, on even surface)

11. Mobility indoors

- 0 Requires total assistance
- 1 Needs electric wheelchair or partial assistance to operate manual wheelchair
- 2 Moves independently in manual wheelchair
- 3 Requires supervision while walking (with or without devices)
- 4 Walks with a walking frame or crutches (swing)
- 5 Walks with crutches or 2 canes (reciprocal walking)
- 6 Walks with one cane
- 7 Needs leg orthosis only
- 8 Walks without walking aids

12. Mobility for moderate distances (10-100m)

- 0 Requires total assistance
- 1 Needs electric wheelchair or partial assistance to operate manual wheelchair
- 2 Moves independently in manual wheelchair
- 3 Requires supervision while walking (with or without devices)
- 4 Walks with a walking frame or crutches (swing)
- 5 Walks with crutches or 2 canes (reciprocal walking)
- 6 Walks with one cane
- 7 Needs leg orthosis only
- 8 Walks without walking aids

13. Mobility outdoors (more than 100m)

- 0 Requires total assistance
- 1 Needs electric wheelchair or partial assistance to operate manual wheelchair.... (cont next page)
- 2 Moves independently in manual wheelchair
- 3 Requires supervision while walking (with or without devices)
- 4 Walks with a walking frame or crutches (swing)
- 5 Walks with crutches or 2 canes (reciprocal walking)
- 6 Walks with one cane
- 7 Needs leg orthosis only
- 8 Walks without walking aids

14. Stair Management

- 0 Unable to ascend and descend stairs
- 1 Ascends and descends at least 3 steps with support or supervisions of another person
- 2 Ascends and descends at least 3 steps with support of handrail and / or crutch or cane
- 3 Ascends and descends at least 3 steps without any support or supervision
- **15. Transfers: wheelchair car** (approaching car, locking wheelchair, removing arm and footrests, transferring to and from car, bringing wheelchair into and out of car)
 - 0 Requires total assistance
 - 1 Needs partial assistance and / or adaptive devices
 - 2 Transfers independent; does not require adaptive devices (or does not require wheelchair)

16. Transfers: ground –wheelchair

- 0 Requires assistance
- 1 Transfers independent with or without adaptive devices (or does not require wheelchair)

SUBTOTAL (0-40)

TOTAL SCIM SCORE (0-100)

Appendix O

Impact on Participation and Autonomy Questionnaire (Cardol, de Haan, de Jong, van den Bos, & de Groot, 2001) used in Study Three: Longitudinal employment outcomes of the EIVR program

Impact on Participation and Autonomy

A questionnaire about choice and participation in everyday life

INTRODUCTION

This questionnaire contains questions about your daily activities. We are trying to get your views on the way your disability affects your ability to live life the way you want to – the idea of "autonomy". We would like to know how much choice you have in the way you take part in activities that are important to you – the idea of "participation".

When answering the questions, think about your **own** opinions and perceptions. There are no right or wrong answers. It is important that you give the answer that best fits your situation.

Please read the information then answer by placing a mark in the box. For instance, if you can get around in your house just where you choose to, you would answer the first question like this:

		Very Good	Good	Fair	Poor	Very Poor
1a.	My chances of getting around in my house <i>where</i> I want to are	x				

It will be very helpful if you try to answer all questions. Even when a question may seem difficult to answer, irrelevant or unimportant, please tick the box that best applies to you.

• At the end of each section you can add further comments

 All your answers will be treated in strict confidence
The questionnaire will take about 20 minutes to fill in
We thank you for your time and help.

1. MOBILITY

Mobility: getting around where and when you want (with or without aids or assistance)

First we would like to ask some questions about your mobility: your chances of getting around where and when you want. We are interested in whether you can decide yourself where and when you want to go somewhere.

		Very Good	Good	Fair	Poor	Very Poor
1a.	My chances of getting around in my house where I want to are					
1b.	My chances of getting around in my house when I want to are					
1c.	My chances of visiting relatives and friends <i>when</i> I want to are					
1d.	My chances of going on the sort of trips and holidays I want to are					

		No Problems	Minor Problems	Major Problems
1e.	If your health or disability affects your chances of getting around where and when you want, to what extent does this cause you problems?	t		
Spa (opt	ce for further comments on you tional):	r mobility		

SELF CARE

Self care (with or without aids or assistance)

The next questions concern your personal care. When answering these questions, think about whether you can decide for yourself when and how you want things done, even when you are assisted by someone else.

		Very Good	Good	Fair	Poor	Very Poor
2a.	My chances of getting washed and dressed <i>the way</i> I wish are					
2b.	My chances of getting washed and dressed <i>when</i> I want to are					
2c.	My chances of getting up and going to bed when I want to are					
2d.	My chances of going to the toilet when I wish and need to are					
2e.	My chances of eating and drinking when I want to are					

2. SELF CARE

		No Problems	Minor Problems	Major Problems
2f.	If your health or disability affects your self care, to what extent does this cause you problems?			
Spa care	ce for further comments on your e(optional):	self		

3. ACTIVITIES IN AND AROUND THE HOUSE

Activities in and around the house (with or without aids or assistance)

The next questions are about the tasks and responsibilities you have at home, and the way your health or disability influences these. We would like to know whether you can decide when and how something is done, even if you don't do it yourself.

		Very Good	Good	Fair	Poor	Very Poor
За.	My chances of contributing to looking after my home the way I want to are					
3b.	My chances of getting light tasks done around the house (e.g. making tea or coffee), either by myself or by others, the way I want them done are					
3c.	My chances of getting heavy tasks done (e.g. cleaning) either by myself or by others, the way I want them done are					
3d.	My chances of getting housework done, either by myself or by others, when I want them done are					
3e.	My chances of getting minor repairs and maintenance work done in my house and garden, either by myself or by others, <i>the</i> <i>way</i> I want them done are					
3f.	My chances of fulfilling my role at home as I would like are					
		No Probl	o ems	Minor Problem	ns Pro	lajor oblems
3g.	If your health or your disability affect your activities in and around your home, to what extent does this cause you problems?					
Spa	ce for further comments on activ	ities in a	and aro	und the		
hou	se (optional):					

4 . LOOKING AFTER MONEY

Looking after money (with or without aids or assistance)

The next questions deal with the effect of your health or disability on the control <u>you</u> have over spending your own money.

		Very Good	Good	Fair	Poor	Very Poor
4a.	My chances of choosing how I spend my own money are					
		No Problems		Minor Problem	ns Pro	/lajor oblems
4b.	If your health or your disability affects the opportunities you have over spending your own money, to what extent does this cause you problems?					
Spa	ce for further comments on your	control	over y	our finan	cial	

situation (optional):

5. LEISURE

Leisure (with or without aids or assistance)

The next questions are about whether \underline{you} can decide how you use your leisure time.

		Very Good	Good	ł	Fair	Poor	Very Poor
5a.	My chances of using leisure time the way I want to are						
		No Proble	o ems	ļ	Minor Problem	is Pr	Major oblems
5b.	If your health or your disability affects how you use your leisure time, to what extent does this cause you problems?						

Space for further comments on your leisure time (optional):

6. SOCIAL LIFE AND RELATIONSHIPS

The next questions are about the quality and frequency of your social relationships. We would like to know whether your heath or disability affects your relationships.

		Very Good	Good	Fair	Poor	Very Poor		
6a.	My chances of talking to people close to me on equal terms are							
6b.	The quality of my relationships with people who are close to me are							
6c.	The respect I receive from people who are close to me is							
6d.	The relationships with acquaintances are							
6e.	The respect I receive from acquaintances is							
6f.	My chances of having an intimate relationship are							
6g.	My chances of seeing people as often as I want are							
		No Proble	ems	Minor Problem	s Pro	lajor oblems		
6h.	If your health or your disability affects your social life and relationships, to what extent does this cause you problems?							
Spa	Space for further comments on your social life and relationships							

(optional):

7. HELPING AND SUPPORTING OTHER PEOPLE

Helping and supporting other people (with or without aids or assistance)

The next questions are about your opportunities to help and support other people such as family, neighbours, friends or members of a club.

		Very Good	Goo	d	Fair	Р	oor	Very Poor		
7a.	My chances of helping or supporting people in any way are									
		No Problems			Minor Problem	ns Pro		/lajor oblems		
7b.	If your health problems or disability affect your opportunities to help other people, to what extent does this cause you problems?									
Space for further comments on helping and supporting other people (optional):										

8. PAID OR VOLUNTARY WORK

Paid or voluntary work (with or without aids or assistance)

The next questions are about paid or voluntary work. We would like to know what your chances are of finding or keeping a paid or voluntary job, even if this does not seem relevant to you at present.

		Very Good	Good	Fair	Poor	Very Poor
8a.	My chances of getting or keeping a paid or voluntary job I would like to do are					
Please only answer Questions 8b to 8f if you do have some form of paid or voluntary work, even if you are not working at the moment due to illness. Oterwise please proceed to guestion 9.						
8b.	My chances of doing paid or voluntary work the way I want to are					
8c.	My contacts with other people at my paid or voluntary work are					
8d.	My chances of achieving or keeping the position I want in my paid or voluntary work are					
-----	--	--------------	----------	------------------	--------	-----------------
8e.	My chances of getting different paid or voluntary work are					
		No Proble	o ems	Minor Problem	ns Pro	lajor oblems
8f.	If your health or your disability affects your paid or voluntary work, to what extent does this cause you problems?					
Spa	ce for further comments on paid	or volur	ntary v	work	-	

(optional):

9. EDUCATION AND TRAINING

Education and training (with or without aids or assistance)

The next questions are about the way your health or disability affects your chances of getting the education or training you want. If you do not wish to have further education or to follow a course, you may tick the box 'not applicable'.

		Very Good	Good	Fair	Poor	Very Poor	
9a.	My chances of getting the education or training I want are						
		No Problems		Minor Problem	ns Pro	Major Problems	
9b.	If your health or your disability affect your opportunities in education or training, to what extent does this cause you problems?						

Space for further explanation regarding your chances of education or training (optional):

10. CONCLUDING IPA QUESTIONS

In this questionnaire you have answered questions that deal with the effect of your health or disability on your personal and social life. Considering all things, could you say whether, in general, you have sufficient control over your own life?

		Very Good	Good	Fair	Poor	Very Poor
10.	My chances of living life the way I want to are					

Space for further comment about the control you have over your

life (optional):

Appendix P

Declaration of co-authorship and contribution

Full bibliographic reference to the item/publication, including authors, title, journal (vol/pages), year.	Hilton, G. M., Unsworth, C. A, Murphy, G. C., Browne, M. & Olver, J. (2017). Longitudinal employment outcomes of an early-intervention Vocational Rehabilitation service for people admitted to rehabilitation with a traumatic spinal cord injury. <i>Spinal</i> <i>Cord</i> . (14 March 2017) doi:10.1038/sc.2017.24
Status	Published (online only)

Nature of Candidate's Contribution, including percentage of total

Conceived the study, developed the method, involved in data collection and primary responsibility for paper drafts. 55%

Nature of all Co-Authors' Contributions, including percentage of total

Unsworth: Involvement in study design, methodology, editing drafts of the paper 15% Murphy: Involvement in methodology, editing drafts of the paper, including response to reviewers following submission. 15%

Browne: Involvement in study design, methodology, statistical analysis and editing results section of the paper. 10%

Olver: Involvement in study design, editing drafts of paper. 5%

Has this paper been submitted for an award by another research degree candidate (Co-Author), either at CQUniversity or elsewhere? (if yes, give full details)

No

Candidate's Declaration

I declare that the publication above meets the requirements to be included in the thesis

as outlined in the Research Higher Degree Theses Policy and Procedure

.....

(Original signature of Candidate)

Date

Appendix Q

Copy of published manuscript in journal Spinal Cord

Longitudinal employment outcomes of an early intervention vocational rehabilitation service for people admitted to rehabilitation with a traumatic spinal cord injury

G Hilton^{1,2}, CA Unsworth^{1,3,4,5}, GC Murphy⁵, M Browne¹ and J Olver^{2,6}

Study design: Longitudinal cohort design.

Objectives: First, to explore the longitudinal outcomes for people who received early intervention vocational rehabilitation (EIVR); second, to examine the nature and extent of relationships between contextual factors and employment outcomes over time.

Setting: Both inpatient and community-based clients of a Spinal Community Integration Service (SCIS).

Methods: People of workforce age undergoing inpatient rehabilitation for traumatic spinal cord injury were invited to participate in EIVR as part of SCIS. Data were collected at the following three time points: discharge and at 1 year and 2+ years post discharge. Measures included the spinal cord independence measure, hospital anxiety and depression scale, impact on participation and autonomy scale, numerical pain-rating scale and personal wellbeing index. A range of chi square, correlation and regression tests were undertaken to look for relationships between employment outcomes and demographic, emotional and physical characteristics.

Results: Ninety-seven participants were recruited and 60 were available at the final time point where 33% (95% confidence interval (CI): 24–42%) had achieved an employment outcome. Greater social participation was strongly correlated with wellbeing (ρ =0.692), and reduced anxiety (ρ =-0.522), depression (ρ =-0.643) and pain (ρ =-0.427) at the final time point. In a generalised linear mixed effect model, education status, relationship status and subjective wellbeing increased significantly the odds of being employed at the final time point. Tertiary education prior to injury was associated with eight times increased odds of being in employment at the final time point; being in a relationship at the time of injury was associated with increased odds of being in employment of more than 3.5; subjective wellbeing, while being the least powerful predictor was still associated with increased odds (1.8 times) of being employed at the final time point.

Conclusions: EIVR shows promise in delivering similar return-to-work rates as those traditionally reported, but sooner. The dynamics around relationships, subjective wellbeing, social participation and employment outcomes require further exploration. *Spinal Cord* advance online publication, 14 March 2017; doi:10.1038/sc.2017.24

INTRODUCTION

For most people who experience a traumatic spinal cord injury (SCI), gaining or returning to durable employment is a significant achievement¹ and a measure of rehabilitation success.² Reengagement in vocational roles has a positive influence on quality of life³ and is held to be an important part of the adjustment process following injury.^{4,5} Despite the health-promoting nature of work⁶ and the vocational potential of this group.² employment rates after injury generally remain very low.⁵ Where there has been no explicit vocational intervention, rates are typically quoted as being around 35–40% in developed nations,^{1,2} but often are far less.⁷ Previous literature reporting post-injury vocational achievement has focussed on calculating crude employment rates following SCI or exploring the relationship with physical function.^{5,8} Similarly personal factors relating to employment outcomes such as the individual's education, pre-injury worker role and psychological traits have been examined.⁸⁻¹⁰ Relatively little, however, is known about how the passage of time may influence employment outcomes, as well as the nature and extent of influence of possible effects of environmental factors such as access to social support, funding and compensation arrangements, the geographical area where the individual lives including amenities and infrastructure, and the use of vocational services.¹

The availability of novel forms of vocational interventions that are accessible, individualised and flexible, and are therefore capable of meeting the multifaceted rehabilitation requirements of people with SCI is needed.¹¹ There is some evidence for the effectiveness of evidence-based supported employment (EBSE) for people with SCI,¹² but it is limited to the US veteran population and for people who have lived with SCI for several years. Early vocational rehabilitation interventions targeting individuals soon after injury have shown potential for enhancing post-injury labour force participation.¹³ The

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potentially crucial role of an early vocational service is also suggested by Krause,¹⁴ who noted that it can take time for people to reach their vocational potential following SCI, particularly if an early 'window of opportunity' is missed. Therefore, the specific aims of this study were (1) to explore employment outcomes at three follow-up time points for people who received Early Intervention Vocational Rehabilitation (EIVR); and, (2) to explore the relationships between employment outcomes over time and a variety of variables as described by the International Classification of Functioning, Disability and Health (ICF).¹⁵ These variables can be grouped as aspects of functioning (physical and pain), activities and participation (psychological, social participation, relationships, pre-injury education and pre-injury worker role) and contextual personal and environmental factors (emotional/wellbeing, social support, funding arrangement and where one lives).

MATERIALS AND METHODS

Study design

The current study was a longitudinal cohort design following a group of people who had received EIVR as part of the Spinal Community Integration Service (SCIS) attached to the Austin Hospital's SCI Rehabilitation Unit.

Participants

Participants eligible for recruitment to the study had all sustained a new traumatic SCI, were residents of the state of Victoria, Australia, of working age at the time of injury (between 15 and 65) and admitted for inpatient rehabilitation with the state's SCI trauma service between the years 2010 and 2013. Individuals were not eligible if they had a co-morbidity of significant brain injury or cognitive impairment or a lack of English limiting their ability to participate, and became ineligible if discharged to a high-level care facility or interstate destination.

All consecutive admissions of people with SCI who met the inclusion criteria were approached to participate in the study. All potential participants accepted and were enroled in the study (n=97) early in their admission to inpatient rehabilitation. Baseline data (time point one) were collected for all participants at discharge from inpatient rehabilitation. Data were available for 74 (76.3%) people at the second time point (12 month following discharge) and 60 (61.9%) at the third and final time point (2+ year following discharge). Fourteen (14.4%) people declined to participate in data collection at the final time point (12 month following discharge). Fourteen (14.4%) at n = 23 (23.7%) were unable to be contacted (2 of whom were deceased). At least 2 individuals who declined to participate stated being 'too busy' because of being in ongoing employment. Figure 1 reports on the sample sizes and data collection at different time points. Demographic data of the participant cohort are available in Table 1.

Intervention

Upon recruitment, participants received EIVR as part of SCIS. The SCIS was implemented in 2010 to provide specialist support for 12 months to individuals with newly acquired SCI transitioning home after a period of hospitalisation and rehabilitation. The initiative was supported by a collaboration between the state government health department and the state motor accident social insurance scheme. The role of the SCIS focused on improved community integration, and enhanced vocational and quality of life outcomes. The service also acted as a specialist SCI resource for community providers who required extra support in working with people with a SCI. A core component of SCIS was the delivery of EIVR within 2–4 weeks of admission to inpatient rehabilitation.

The SCIS staffing comprised 15 individuals totalling ~7 full-time equivalent (FTE) positions, representing allied health (physiotherapy, occupational therapy and exercise physiology) (1.5 FTE), nursing and sexual health counselling (0.7 FTE), medical (0.1 FTE), vocational rehabilitation (1.0 FTE), leisure (0.4 FTE), formal peer support (0.9 FTE), psychosocial (1.0 FTE), building consultancy (0.2 FTE) and a programme manager (1.0 FTE). A predominant and unique feature was the recruitment of a VR professional to focus on enhancing the

return to work (RTW) culture within the rehabilitation setting, to encourage early, positive expectations about work,⁵ and to provide vocational interventions to encourage and facilitate vocational pathways and employment outcomes. The VR professional was also responsible for providing education about EIVR to other members of SCIS and to the inpatient rehabilitation team. Theoretical underpinnings to SCIS work were drawn from the concepts of occupational performance,¹⁶ participation¹⁷ and community development.¹⁸ The service also drew on the experiences and knowledge of existing programmes in other states of Australia and New Zealand such as Spinal Outreach Service in New South Wales,¹⁹ Transitional Rehabilitation Program in Queensland²⁰ and Kaleidoscope in New Zealand.²¹

A coordination team (a project coordinator and the SCIS programme manager) led the implementation of SCIS including the development and delivery of a training package to reinforce theoretical underpinnings and a consistent practice approach. The training sessions focused on building skills in the following: engaging and building a relationship with the individual with SCI, motivational interviewing.²² goal planning and community development. The training also included an introduction to vocational rehabilitation theory and practice, including guiding principles for an early intervention approach.²³

The driving philosophy of EIVR was to instil the individual as early as possible, with a sense of hope and possibility about returning to or gaining work following SCI. The VR professionals from SCIS aimed to make initial contact with the individual within 2–4 weeks of admission to inpatient rehabilitation, unless advised otherwise by the inpatient treating team. Their role included acknowledging the vocational identity of the individual, forming a vocational plan and tailoring interventions to suit the person's goals and situation. Although outcomes such as study or volunteer work were legitimate achievements and considered an important part of the vocational pathway, the ultimate goal of EIVR was for the person to achieve a paid employment outcome. In doing so, there were no constraints on process nor timeline, recognising that each individual needed to assume his/her own journey of recovery, learning and adjustment post injury. A summary of the EIVR 'practice guidelines' is presented in Table 2. Every person who was enroled in the study was offred at least step one and two of the EIVR process.

Measures

Data collection occurred at three time points: discharge from inpatient rehabilitation (time 1); 12 months following discharge (time 2); and at least 2 years following discharge (time 3). Basic demographic and injury data were collected at baseline. This included age, gender, relationship status, neurological level of lesion (including American Spinal Injury Association impairment scale (AIS) definitions), impairment type (tetraplegia, paraplegia), compensation availability, where someone resided, living arrangement and estimates of care and support (hours of paid and unpaid care in a typical day). Information about where someone lived was then converted to a geographical area, or statistical local area (SLA), an Australian Standard of Geographical Classification. SLA can be used in Geographical Information Systems to analyse against other available government data such as area remoteness, area economics, labour force activity and ease of access to amenities.²⁴ For simplicity, geographical area was dichotomised to 'regional' or 'metropolitan'. On aggregation, 'metropolitan' indicates a lower level of area remoteness and a higher level of area socio-economic status, labour force activity and ease of access to amenities.

Vocationally related data included pre-injury education background (highest level achieved), type of occupation (professional, manual labour and so on) and employment status ('employed' was defined as ' ≥ 1 h work in which you were paid' and was recorded from self-report as full time (that is, over 35 h per week), part-time variable, part-time fixed and also as a dichotomous variable, 'in the labour force' versus 'all others'). Any changes in demographic or injury data were noted at follow-up time points. Several self-rated standardised scales of psychosocial functioning were used as indices of rehabilitation progress at all three data collection points, as described in the following sections.

Numeric pain-rating scale. An 11-point numeric pain-rating scale was used as a measure of pain intensity where participants were asked to rate their experience of pain on a scale of 0-10, (where 0 is 'no pain' and 10 is 'the



Figure 1 Flow chart of recruitment. A full colour version of this figure is available at the Spinal Cord journal online.

worst possible'). Numeric pain scales have demonstrated their validity as Hospital anxiety and depression rating scale. The Einspital anxiety and measures of pain by their strong association with other measures of pain depression rating scale (HADS) is a 14 question, 4 point, self report rating intensity, as well as by their responsivity to meatments known to impact pain.25

scale designed to assess depressive and anxiety symptoms in patients with

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Table 1 Demographic data (n = 97)

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	N	Mean	s.d
Age at injury (years)	97	35.070	14.908
15-45	72		
4665	25		
Sex		%	
Male	79	81.4	
Female	18	18.6	
Severity of SCI neurology			
C1-C4 AIS A, B or C	10	10.3	
C5-C8 AIS ¹ A, B or C	23	23.7	
T1–S5 AIS A, B or C	45	46.4	
AIS D any level	19	19.6	
Impairment level			
Tetraplegia	43	44.3	
Paraplegia	54	55.7	
Compensation status			
Insured	51	52.6	
Public/uninsured	46	47.4	
Education level prior to injury	96		
Higher (tertiary)	16	16.5	
Lower	80	82.5	
Occupation type prior to injury	78		
Professional	27	27.8	
Trade or unskilled	51	52.6	

Abbreviations: AIS, American Spinal Injuries Association impairment scale; SCI, spinal cord injury.

medical illness. Preliminary findings support the psychometric integrity of the HADS within an outpatient population with SCL²⁶ Separate subscale scores, ranging from 0 to 21, for depression (HADS—depression) and anxiety (HADS—anxiety) can be derived. Higher scores indicate greater psychological distress.

The personal wellbeing index. The personal wellbeing index (PWI) is a selfreport scale developed as a measure of subjective wellbeing and holds high cross-cultural validity.²⁷ Part one can be used as a single-construct measure of global life satisfaction, or part two as a multi-item life satisfaction domain scale. The statements use an 11-point (0–10) end-defined response scale addressing domains such as health, relationships, future security and personal achievement²⁸ with a final score between 0 and 100 with higher scores indicating greater subjective wellbeing.

Spinal cord independence measure. The spinal cord independence measure (SCIM) measures self-care, respiration, sphincter management and mobility. It consists of 16 questions with a final score ranging between 0 and 100 (SCIM-total), with higher scores indicating greater functional independence. SCIM is a reliable and valid measure of functional status for people with SCI.²⁹

Impact on participation and autonomy. The impact on participation and autonomy (IPA) is a generic outcome measure designed for adults with a range of conditions. The english version³⁰ contains 32 items that create five subscales —autonomy indoors, family roles, autonomy outdoors, social life and relation-ships, and work and education. Each subscale is averaged to produce a median score from 0 to 4. In addition, a total 32-item score can be derived. A lower score on the IPA suggests greater perceived autonomy and participation. The questionnaire takes ~20 min to complete and it can be self-administered. It has been found to be a reliable and valid instrument for assessing autonomy and

participation in chronic disorders, including SCL³¹ As participants were inpatients at the time of the first data collection, the IPA was collected at the second and final time point only.

Procedure

Ethical approval for this study HREC/14/Austin/256 was obtained from the Hospital and University Human Research Ethics Committees. The authors certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

The SCIS programme manager was responsible for screening eligible individuals for recruitment to the research and obtaining a signed informed consent form. This was done in close consultation with the inpatient treating team. A member of the SCIS was responsible for collecting measures with the participants at the first and second time points as documented above. At the second data collection (12 months following discharge from inpatient rehabilitation), formal involvement by the SCIS ceased. Participants were then contacted by mail and telephone to complete a further follow-up (third time point) at least 2 years after injury. Participants were offered a \$20 department store gift voucher to thank them for their time in completing the third round of data collection. Finally, an audit of medical records was undertaken as an alternative method of collecting basic data of the most recent report of employment status for people who did not complete the final data collection at 2+ years following discharge.

Analyses

Initially χ^2 analysis was used to test for systematic attrition bias. Differences between people who were included in the study but without 2+ year follow-up, and people who had 2+ year follow-up were explored, on categorical variables of gender, age group, injury type, AIS group, pre-injury education level, pre-injury occupation type, compensation status and geographical area for time point 1.

Descriptive statistics (means, s.d.) and comparison between the groups of 'in the labour force' or 'all others' were used. This included summarising key variables such as age, gender, compensation status, neurological level of injury, education, pre-injury employment type, geographical area, function (SCIMtotal), perceived pain (numeric pain-rating scale), psychological status (HADS —anxiety and depression), social participation (IPA subscales) and subjective wellbeing (PWI) at each time point using means and s.d.'s where applicable. Chi square analysis was used to test for differences between participants in/out of the labour force prior to injury and at the three time points post injury for the categorical variables of gender, age group, injury type, AIS group, pre-injury education level, pre-injury occupation type, compensation status and geographical area (statistical local area). Mann–Whitney *U*-test was used to compare years since injury in participants in/out of the labour force at the final time point.

The second research question investigated in the current study related to the identification of relationships between employment outcomes and variables described according to the ICF. Aspects of functioning included injury characteristics, physical status (SCIM-total) and pain (numeric pain-rating scale). Variables relating to activities and participation included psychological (HADS—anxiety and depression), social participation (IPA total), relationship status, pre-injury education and pre-injury worker role. Variables measured as contextual personal and environmental factors included subjective wellbeing (PWI), social support (IPA subscale social life and relationships), funding arrangement and geographical area (statistical local area) over the three time points.

Interdependence between the variables was determined with Spearman's correlation coefficient. As suggested by Craig *et al.*³², a dichotomised value for social participation was established using the mean score of the sample (IPA total). That is, values equalling the mean score or less will indicate high participation, and values greater than the mean will indicate low participation. The main aim of the regression analysis was to investigate possible predictors

of employment status in recovering patients. Owing to the relatively low ratio of participants to independent variables (IVs), each was treated in a separate regression model. This approach was taken because including all IVs and time

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Process	Timeline	Tasks
Establish relationship with individual	First meeting inpatient rehabilitation setting	Gather background demographic information including education and employment history
Establish vocational identity of individual	Within 2–4 weeks of admission to inpatient rehabilitation (~6 weeks post injury)	Liaise with inpatient team regarding pre-vocational activity
		Identify relationship with pre-injury employer
		Identify motivations and future aspirations
Explore vocational options	Within inpatient setting or as required 1–6 months post injury	Exploration of vocational options, inclusive of retraining or return to study (RTS) Career counselling
		Facilitate contact/support to pre-injury employer
		Facilitate connections with peer support
		Facilitate connections with disability liaison officers at education facilities
		Facilitate connections with community-based vocational rehabilitation providers
		Assist in navigation of entitlements and government benefits associated with RTS, retraining, job seeking and RTW
Establish vocational goals, com- mence vocational pathway	Within inpatient or outpatient setting or as required	Provide expert advice, assistance with planning and practical guidance relevant to individual's situation.
	2-12 months post injury	For example: If vocational goal involved retraining or RTS, VR professional to offer community-based support such as joint visit to meeting with disability liaison officer, environmental assessment of educational facility, or work with individual to identify and practice transport options.
		For example: If vocational goal involved returning to work, VR professional to offer community-based support such as joint visit to workplace, meeting with human resource officer or equivalent, environmental assessment of workplace, or work with
		individual to identify and practice transport options.
Job support	Within outpatient setting or as required	Worksite visit to assess both physical and social demands of the position and workgroup
	When work ready	Assessment/prescription workplace equipment and/or modifications
		Assist in navigation of entitlements and government benefits associated with job seeking and RTW.
		Development (in coordination with both the patient/client and the putative super- visor) of return-to-work plan
		Facilitating/supporting workplace trials or industry experience
		Post placement support (to ex-patients and family members, as well as to workplace
Service development value	No oot time frames	Co-workers and supervisors
service development role	No set time trames	process and early intervention vocational rehabilitation role
		Education of co-workers and supervisors at the workplace
		Education of co workers and supervisors at the workplace
		problem solving life planning
		Referral/consultation/education to community-based vocational rehabilitation
		Education to health professionals
		Loucation to nearth professionals Meet with disability ligison officers at education facilities
		Networking with local government, not for profit and private enterprises to establish
		possible employment links/opportunities

Table 2 A summary of practice guidelines for EIVR

X IV interactions would result in an unacceptably high number of degrees of freedom in the model. Therefore, reported beta coefficients of these models do not reflect co-variation between predictors. Accordingly, a simultaneous multiple logistic regression was also conducted. Each model also included an effect for time (discharge, I year, 2+ years), and a time X IV interaction term. We employed generalised linear mixed effects models (GLMEs) with a binomial error distribution and a log link,³³ to manage the repeated measurements and the binary response. Apart from the fixed effects, each GLME also included a random intercept for participant. All analyses were conducted in the R statistical programming environment.³⁴ Data collected in the audit of medical records were included in this analysis and the GLMEs.

RESULTS

The mean duration of SCI at the final time point was 3.50 ± 1.08 years. Figure 1 demonstrates the sample sizes and data collection at different time points. Employment status was obtained for all participants at the third time point via self-report for study participants (n=60), and from audit for non-respondents (n=37). At the third time point, n=32 (33%, 95% CI: 24–42%) of the total cohort (n=97) were in paid employment. Chi-square test for independence to examine attrition bias indicated no significant differences between the demo-graphic characteristics of study participants and non-respondents at

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Table 3 Comparison of demographic data (n = 97) at time point 3 for people in labour force versus all others

	In labour force	%	Not in labour force	%	P- value
Years since injury, mean (s. d.)	3.32	1.16	3.58	1.04	
Age at injury (years)					
15-45	24	24.7	48	49.5	1
46–65	8	8.2	17	17.5	
Severity of SCI neurology					
C1-C4 AIS A. B or C	2	2.1	8	8.2	0.42
C5-C8 AIS A, B or C	9	9.3	14	14.4	0.43
T1-S5 AIS A, B or C	17	17.5	28	28.9	
AIS D any level	4	4.1	15	15.5	
Compensation status					
Insured	14	14.4	37	38.1	0.32
Public/uninsured	18	18.6	28	28.9	
Education level prior to injury					
Higher (tertiary)	10	10.4	6	6.3	0.01*
Lower	21	21.9	59	61.5	
Occupation type prior to injury					
Professional	11	14.1	16	20.5	0.56
Trade or unskilled	16	20.5	35	44.9	

Apprevations: Aris, American spinal injuries Association impairment scale; sof, spinal injury. P < 0.05 (2-tailed) for chi square.

the final time point, except for pre-injury education level χ^2 ((1, n=96) = 6.5, P=0.005). Twenty-five (78.1%) of those finally employed had been in full-time employment prior to their SCI, of whom n=13 (40.6%) returned to full-time employment (n=1 on leave), and n=12 (37.5%) went to part-time employment. Of the n=3 who were part-time employed prior to injury, n=1 (3.1%) went into full-time employment post injury, and n=2 (6.3%) remained in part-time employment post injury. Four participants had not been employed prior to their injury and found part-time employment followine.

Descriptive statistics and comparison between all categorical variables and the primary outcome measure of employment status are presented in Table 3, which shows that there were no significant differences between the two groups, 'in the labour force' and 'all others' across all categorical variables at the final time point, except for education level χ^2 ((1, n=96)=6.4, P=0.01). A Mann–Whitney *U*-test revealed no significant difference in the years since injury of those poople 'in the labour force' (Md=3.1, n=32) and 'all others' (Md=3.8, n=65), U=889.5, z=-1.156, P=0.248, r=-0.112.

The relationship between personal characteristics at the different time points was investigated using Spearman's correlation coefficient. Correlations for all continuous and dichotomised categorical variables with the dichotomous variable of employment status ('in the labour force' versus 'all others') are shown for the final time point in Table 4.

Table 4	Spearman	ρ correlatio	ns between al	I predictor	variables and
employm	ient status	(in the labo	our force versu	s all others) at final time
point					

Measure	Employment status
1. Gender	-0.109
2. Age at injury	0.006
3. Age group	-0.029
Injury type (para/tetra)	-0.011
5. Neurological level (AIS)	-0.137
6. Funding status	0.063
7. Pre-injury education level	0.181
8. Occupation type prior to injury	0.076
9. Where living	0.130
10. Relationship status	0.062
11. HADS—Anxiety	-0.114
12. HADS—Depression	-0.082
13. Total SCIM	0.096
14. Total PWI	0.238
15. Total care hours	-0.119
16. Numeric Pain-Rating scale	-0.177
17. IPA Autonomy indoors	-0.061
18. IPA Family roles	0.131
19. IPA Autonomy outdoors	-0.136
20. IPA Social Life and Relationships	-0.196
21. IPA Work and education	- 0.023
22. Total IPA	0.010

To include the total IPA score in analysis as a measure of social participation, the mean score in the current study of 61.11 (s.d. 21.03) was used to dichotomise this variable. Therefore, scores of 61 or below were used to indicate high levels of social participation (n=33) and scores above 61 were considered to represent low levels of social participation (n=28).

Across the three times points there were several strong, statistically significant correlations between variables. At time point 2+ years, the dichotomised variable of social participation was positively associated with subjective wellbeing ρ =0.692, n=60, P<0.0005, and negatively associated with anxiety ρ =-0.522, n=61, P<0.0005, depression ρ =-0.643, n=61, P<0.0005 and pain ρ =-0.427, n=60, P<0.0005. Higher levels of perceived participation and autonomy were correlated with high levels of subjective wellbeing, low anxiety and depression scores, and low rating of pain. The full correlation matrix between variables at the final time point is presented in Table 5.

Table 6 shows odds ratios, beta coefficients and associated standard errors for the binomial GLMEs. Education status (P < 0.01), relationship status (P < 0.05) and Total PWI (P < 0.05) were reliably associated with being employed post injury. No time-varying effects were significant at the P < 0.05 criterion. The most powerful predictor (holding a degree prior to injury) was associated with an eightfold increased odds of being employed at the follow-up point. Being in a relationship at the time of injury was another strong predictor, being associated with increased odds of being in employment of more than 350%. General health and wellbeing scores at the time of discharge were associated with a significant, but much smaller, increase in the odds of post-injury employment (OR = 1.8).

On the basis of the strength of their individual predictive ability, relationship status (at time point one), pre-injury education level and subjective wellbeing were entered into a logistic regression model over

Table 5 Spearman ρ correlat status, subjective wellbeing,	tions be perceiv	etween me /ed pain a	asures of p nd social	osychologic participatio	al, physica In at time	al (injury d. point 3 (2	ata) and p + years pc	ersonal (ag st dischar _i	e, educatic ge)	on backgrou	und, emplo	yment back	(ground) cha	racteristics,	functional
Measure	1	2	ω	4	5	9	~	ø	6	10	11	12	13	14	15
1. Age at injury		-0.009	- 0.093	- 0.103	0.223*	0.178	- 0.050	0.006	0.577**	-0.013	0.126	- 0.286*	- 0.062	0.147	-0.161
2. Injury type (para/tetra)		I	0.534**	-0.108	-0.113	- 0.048	0.058	-0.011	0.027	0.141	- 0.056	0.366**	-0.058	0.305*	-0.152
3. Neurological level (AIS)			I	-0.017	-0.141	-0.072	0.058	-0.137	0.037	0.275*	- 0.077	0.694**	-0.110	0.256*	-0.045
 Funding status 				I	0.019	0.210	0.008	0.063	-0.279*	0.015	-0.102	0.241	0.046	0.330*	0.173
5. Pre-injury education level					I	0.630**	0.298	0.181	0.058	0.080	0.056	0.019	-0.071	0.071	-0.162
6. Occupation type prior to injury						I	0.172	0.076	0.082	0.242	0.167	0.112	- 0.202	0.067	0.329*
7. Where living							I	0.130	-0.014	-0.010	-0.182	0.222	0.086	-0.047	-0.035
8. Employment status								I	0.062	-0.114	- 0.082	0.096	0.238	-0.177	0.010
9. Relationship status									-	0.025	0.001	0.053	0.108	- 0.005	0.027
10. HADSanxiety											0.708**	0.055	- 0.629**	0.496**	0.522**
 HADS—depression 											I	-0.292*	-0.762**	0.498**	-0.643**
12. Total SCIM													0.176	- 0.040	0.217
13. Total PWI														-0.485**	0.692**
14. Numeric pain-rating scale														-	0.427**
15. Total IPA															I
*P<0.05 (2-tailed). **P<0.001 (2-tailed).															

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the different time points. The model for predicting a labour force outcome at the third time point was statistically significant, χ^2 (3, N=79)=11.663, P=.009. The model as a whole explained 13.7% (Cox and Snell \mathbb{R}^2) and 18.9% (Nagelkerke \mathbb{R}^2) of the variance in employment status, and correctly classified 68.4% of cases. When controlling for all other factors, the strongest and statistically significant predictor of being in the labour force in this model was being in a relationship, recording an odds ratio of 3.406 (CI: 1.197 - 9.697) P = 0.022.

DISCUSSION

This paper described the development, implementation and results of early intervention vocational rehabilitation delivered as part of a hospital-led SCIS. It aimed to identify employment outcomes for the study cohort and the relationship between employment-related outcomes and various personal and environmental factors in the five years following injury. In this study, 33% of our cohort had returned to employment by the third time point. This post-injury employment rate is comparable to those of other studies, the rate being a slightly lower rate than that of Middleton et al.13 and a slightly higher rate than that of Ottomanelli et al.¹² With respect to reliable predictors of post-discharge employment, three influential factors were identifiedpre-injury education, relationship status at time of injury and selfreported wellbeing.

The post-discharge employment rate observed from the current early intervention programme is comparable to that reported from the observational study by Middleton et al.,13 who recently reported the outcomes of the delivery of their early vocational rehabilitation in an Australian acute and rehabilitation SCI setting when post-injury employment was assessed within one year post discharge. At case closure (median 3 weeks post discharge), 34.5% had an employment outcome. This rate is consistent with that quoted in aggregated research of 35-40%.2 However, Middleton et al.'s13 employment achievements were reached within a much shorter timeframe post injury than that is usually investigated. Although Middleton et al. has commenced the process of researching early vocational rehabilitation in Australia, similar programmes delivered into New Zealand acute spinal units since 2000, have been described but not been studied empirically. Hay-Smith *et al.*²¹ reported on the New Zealand early intervention vocational rehabilitation service, known as Kaleidoscope, and described its aim as nurturing positive expectations of future community participation after a SCI, believed to be an important precursor to employment outcome.5 Employment rates have reportedly increased since Kaleidoscope's inception²¹ but little detail regarding claimed increases has been reported. The research work led by Ottomanelli,¹² Middleton,¹³ as well as Hay-Smith²¹ all suggest that vocational rehabilitation delivered early post SCI warrants further investigation, as does determination of whether vocational outcomes are sustained beyond 12 months.

In determining whether certain functions, activities, participation and contextual factors would increase the likelihood of achieving an employment outcome over the duration of this study, three independent variables of relationship status, pre-injury education level and subjective wellbeing were identified, from which some causality may be inferred. Of these three variables, relationship status and subjective wellbeing are the only 'modifiable' factors and therefore, consideration needs to be given to these during inpatient and outpatient rehabilitation, and to the potential role of both variables in influencing employment outcomes. For allied health and nursing staff, the finding with respect to relationship status has implications for the ways that patients' level of post-injury social support is monitored and, if need

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Table 6 Odds ratios, beta coefficients and associated standard errors for binomial GLMEs predicting employment status (in the labour force versus all others)

		N	lain effect		Time interac	tion	
		OR	B (SE)	OR	B (<i>SE</i>)	N _{obs}	N _{part}
Occupation type (professi	onal)	2.46	0.90 (0.64)	1.19	0.17 (0.49)	226	78
Gender (female)		0.78	-0.25 (0.77)	0.59	-0.53 (0.77)	281	97
Age (46–65)		2.12	0.74 (0.65)	0.48	-0.53 (0.60)	281	97
Education (tertiary)		8**	2.08 (0.77)	2.41	0.88 (0.59)	278	96
Relationship status (in re	lationship)	3.71*	1.31 (0.58)	0.33	- 1.10 (0.59)	268	95
Location (urban)		0.91	-0.09 (0.58)	1.38	0.32 (0.45)	281	97
Finding status (uninsured)	2.27	0.82 (0.58)	1.55	0.44 (0.46)	281	97
Injury type (paraplegia)		0.84	-0.18 (0.58)	0.76	-0.28 (0.45)	281	97
Total PWI		1.8*	0.59 (0.29)	1.31	0.27 (0.30)	204	89
Total SCIM		0.96	0.45 (0.32)	1.57	-0.04 (0.29)	210	89
Total care		0.89	-0.12 (0.26)	0.74	-0.30 (0.25)	198	87
Pain-rating scale		0.88	-0.13 (0.27)	0.73	-0.32 (0.29)	176	85
HADSanxiety		0.53	-0.63 (0.36)	0.92	-0.08 (0.29)	188	88
HADSdepression		0.63	-0.45 (0.28)	0.96	0.04 (0.29)	188	88
Neurological level	C1-C8	Ref	Ref	Ref	Ref		
(AIS)	T1-S5 ABC	1.92	0.65 (0.68)	0.66	-0.08 (0.84)	281	97
	AIS D	0.66	-0.41 (0.54)	0.59	-0.65 (0.67)	281	97
Total IPA		3.49	1.25 (0.85)	0.32	-1.11 (1.05)	136	84

*P<0.05, **P<0.01. Each row in the table corresponds to a separate regression model

be, strengthened. In many areas of injury rehabilitation, social support has been shown to be associated with superior rehabilitation outcomes (see for example, Murphy and O'Hare³⁵). Services to enhance the subjective wellbeing of those living with SCI have been extensively researched by Kennedy³⁶ who has described programmes that reliably improve patient's coping effectiveness. Both of these areas of service provision seem worthwhile strengthening in any hospital-based rehabilitation programme.

Although research on social support is relatively limited in the SCI population, Murphy et al.37 found that practical social support was the most frequently reported contributing factor to enabling positive employment outcomes following SCI. This has been further supported by findings of Burns et al.38 who established that in a self-selected group of 83 men, greater perceived social support from significant others was related to higher employment outcome. Hence, further research to investigate the impact of environmental features such as financial as well as social support on employment outcomes achieved post SCI appears well warranted.

Finally, the impact of time as a factor related to employment outcomes must be considered. A consistent finding in reports of employment outcome is that employment rates increase over the first 10-15 years post injury.^{39,40} Krause¹⁴ studied factors related to the length of time between onset of SCI and RTW in n = 259 people who had returned to work post injury, and suggested that it can take time for an individual to reach full vocational potential, particularly if an early 'window of opportunity' is missed. Furthermore, Murphy argues that there is a clear need for vocational management as part of inpatient rehabilitation.²³ In a modelling of employment trajectory in a cohort of n = 176 with acute SCI, Ferdiana⁴⁰ identified three distinct trajectories. The first encompassed no employment prior to injury and no employment for 5 years post injury (called 'no employment'), the second included employment prior to injury and an increasing chance of employment in the 5 years post injury (termed 'low employment') and the third covered employment prior to injury and steady

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employment within 5 years post injury (described as 'steady employment'). The study found that participants with secondary education were significantly more likely to gain steady employment outcomes versus low or no employment. This reinforces the value of VR including components such as retraining and education early after injury to potentially enhance opportunities for employment outcome, particularly for people with a likely trajectory of low or no emplovment.

Although the early return to employment following SCI was associated with higher subjective wellbeing, there was no relationship with other psychosocial outcomes. A relationship did exist for these variables with social participation. There was an association between higher levels of social participation with high levels of subjective wellbeing, low anxiety and depression scores, and low rating of pain. Although social participation was not a primary focus of this study, this finding is of interest given the known relationship between this variable and employment,32 and that Craig et al.32 posit that social participation is a measure of adjustment following SCI. The literature consistently reports that employment is health promoting,6 yet it might be that early return, although overall a positive step, is still fundamentally very difficult. At a practical level, there are many personal and environmental factors to be considered and addressed in the RTW process. This research may be capturing a period of change and uncertainty as one returns to work or gains post-injury work that initially counteracts the expected benefits of being a worker. It may be valuable to explore more thoroughly this complex dynamic, and the relationship of employment with social participation in future research, as was suggested by Craig et al.³²

Limitations and directions for further research

The study as conducted had an obvious limitation in lacking a control group, but to the our knowledge, this is the first study of early intervention vocational rehabilitation that examines, longitudinally, predictors of employment outcome. When originally designing the study we planned to use a comparison group which would receive treatment as usual. However, for practical reasons owing to different funding arrangements with compensable and non-compensable clients, a suitable comparison group could not be assembled.

There was a drop-out rate of n = 37 (38.1% of participants) over the three time points, resulting in a relatively small sample size by the final time point. This drop-out rate is equivalent to that reported by other similar longitudinal studies investigating this population.⁴¹ However, in this study, although 37 participants were lost to follow-up at the third time point, their employment outcomes were still able to be obtained through an audit of their ongoing medical record. When collecting data at time point 3, there was a small proportion of people who declined to participate because of being 'too busy' owing to employment. These people may be 'happy workers' and unfortunately this data has not been captured.

Despite many similarities in the traumatic spinal cord-injured population throughout the world,⁴² the differences in local policy and service delivery create challenges in comparing or translating findings across countries and jurisdictions. However, the introduction of an early intervention approach to vocational rehabilitation could be applied to other settings, and is worthy of further investigation.

A further potential limitation to this study was the existing culture in the inpatient rehabilitation setting and the possible lack of willingness to embrace the new early vocational rehabilitation intervention. Education was provided to clinical staff in anticipation of this barrier, as historical experience has been that vocational rehabilitation has not been a priority focus of the inpatient rehabilitation setting. Murphy²³ and Ottomanelli and Lind⁸ have previously recognised this same issue. Anecdotally, as staff became more familiar with the EIVR conversation and observed individuals achieving employment outcomes (including even returning to work although still participating in inpatient rehabilitation), the rehabilitation hospital culture became more positive and supportive over the duration of the study. This culture shift may well account for some of the variance in outcomes across the three time points.

An important follow-up to this research is to interview individuals about their experiences of seeking and gaining employment. Exploring the concepts of timing and adjustment in relation to returning to work, coupled with identifying influential environmental and personal factors could deliver further insights into understanding the complexity of returning to work for people following traumatic SCI. This work is currently underway.

CONCLUSION

This research explored employment outcomes for people receiving EIVR and the relationship between these and personal and environmental factors in the first 2-5 years following injury. EIVR shows promise of delivering equivalent return to work rates to that reported in similar studies, earlier after injury, although it is premature to claim to have reliably demonstrated effectiveness of this intervention. Several factors were identified that appear facilitatory of employment outcome, including relationship status, subjective wellbeing and preinjury education. These and the relationship between social participation and employment outcomes are worthy of further investigation. particularly in relation to how they may support the return to, and maintenance of, employment in this population in the future. The findings of this study can inform clinical practice, particularly the importance of maintaining pre-injury relationships and subjective wellbeing to promote positive employment outcomes.

Early vocational rehabilitation post spinal injury

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DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest

ACKNOWLEDGEMENTS

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Appendix R

Ethics approval documentation from Human Research Ethics Committee

Austin Hospital

Austin Health

145 Studley Road PO Box 5555 Heidelberg Victoria Australia 3084 Telephone 03 9496 5000 Facsimile 03 9458 4779 www.austin.org.au

Date:	14 May 2013
То:	Dr Gillean Hilton
	Royal Talbot Rehabilitation Centre
	1 Yarra Boulevard
	Kew Vic
Project:	The experience of achieving a successful employment outcome
	following traumatic spinal cord injury; pathways and processes
Project No:	H2013-05011
Agenda Item No:	6.2

Document(s) reviewed		Date	
NEAF			
Victorian Specific Module			
Participant Information & Consent Form	2	30 Apr 2013	
Protocol	2	29 Apr 2013	
Interview Outline	1	23 Mar 2013	
Life Orientation Test			
Life Satisfaction Scale			
Advertisement	1	30 Apr 2013	

Further to my letter dated **24 April 2013** concerning the above detailed project, I am writing to acknowledge that your response to the issues raised by the Human Research Ethics Committee at their meeting on **18 April 2013** is satisfactory. This project now has full ethical approval for a period of three years from the date of this letter.

Before the study can commence you must ensure that you have:

- For trials involving radiation it is your responsibility to ensure the research is added to the Austin Health Management Licence issued by Department of Human Services

 Radiation Safety Section prior to study commencement should it be required (check your Medical Physicist Report). The HREC must be notified when the research has been added to the licence.
- It is a requirement that a progress report is submitted to the Committee annually, or more frequently as directed. Please note a final report must be submitted for all studies. Should you plan for your study to go beyond the 3-year ethics approval, please request in writing an extension of ethics approval prior to its lapsing. If your study will not commence within 12 months, a request must be forwarded to the HREC justifying the delay beyond 12 months. Should such a request not be received, ethics approval will lapse and a resubmission to the HREC will then be necessary.
- After commencement of your study, should the trial be discontinued prematurely you must notify the HREC of this, citing the reason.
- Any changes to the original application will require a submission of a protocol amendment for consideration as this approval only relates to the original application as detailed above.
- Please notify the HREC of any changes to research personnel. All new investigators must be approved prior to performing any study related activities.
- It is now your responsibility to ensure that all people (i.e. all investigators, sponsor and other relevant departments in the hospital) associated with this particular study are made aware of what has been approved.

The Committee wishes to be informed as soon as practicable of any untoward effects experienced by any participant in the trial where those effects in degree or nature were not anticipated by the researchers. The HREC has adopted the NHMRC Australian Health Ethics Committee (AHEC) Position Statement

'Monitoring and reporting of safety for clinical trials involving therapeutic products' May 2009

Please ensure you frequently refer to the Research Ethics website <u>http://www.austin.org.au/researchethics/</u> for all up to date information about research and ethical requirements.

DETAILS OF ETHICS COMMITTEE:

It is the policy of the Committee not to release personal details of its members. However I can confirm that at the meeting at which the above project was considered, the Committee

fulfilled the requirements of the National Health and Medical Research Council in that it contained men and women encompassing different age groups and included people in the following categories:

Chairperson	Additional members include:
Ethicist	Chairs of all sub committees,
Lawyer	or nominees
Lay Man	Other persons as considered
Lay Woman	appropriate for the type/s of
Person fulfilling a Pastoral Care Role	research usually being
Person with Counselling Experience	considered
Person with Research Experience	

I confirm that the Principal Investigator or Co-Investigators were not involved in the approval of this project. I further confirm that all relevant documentation relating to this study is kept on the premises of Austin Health for more than three years.

The Committee is organised and operates according to the National Statement on Ethical Conduct in Human Research (NHMRC The National Statement) and the Note for Guidance on Good Clinical Research Practice (CPMP/ICH/135/95) annotated with TGA comments (July 2008) and the applicable laws and regulations; and the Health Privacy Principles in The Health Records Act 2001.

PLEASE NOTE: The Committee requests that Research Ethics (ethics@austin.org.au) is informed of the actual starting date of the study as soon as the study commences. A written notice (e-mail, fax or letter) is considered the appropriate format for notification.

Yours sincerely,

Dr Sianna Panagiotopoulos, PhD Manager, Office for Research

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC)

National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice annotated with TGA comments (July 2008) and the applicable laws and regulations; and the Health Privacy Principles in The Health Record Act 2001. The process this HREC uses to review multicentre research proposals has been certified by the NHMRC.

Human Research Ethics Committee

Office for Research, Level 6 HSB. **Phone**: (03) 9496 4090

E-mail: <u>ethics@austin.org.au</u>

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HREC6C V2 10092012 CS

Appendix S

Ethics approval documentation from University Human Ethics Committee

At the time this study was conducted the candidate was enrolled at La Trobe University.



University Human Ethics Committee RESEARCH SERVICES MEMORANDUM

То:	Dr Marilyn Di Stefano, Department of Occupational Therapy, FHS
From:	Executive Officer, La Trobe University Human Ethics Committee
Subject:	UHEC acceptance of Austin Health HREC approval of a modification to project - H2013-05011
Title:	The experience of achieving a successful employment outcome following traumatic spinal cord injury; pathways and processes
Date:	16 January 2014

Thank you for submitting information relating to modification of the above project, which has received ethical approval by the Austin Health HREC, and for complying with the requirement to seek continuing endorsement by the La Trobe University Human Ethics Committee (UHEC). Your request was received by the Chair of the UHEC, who agrees that the project continues to comply with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and with University *Human Research Ethics Guidelines*, and notes the modifications advised as including:

• Addition of Carolyn Unsworth and Rwth Stuckey to the research team

The following conditions apply to La Trobe UHEC acceptance of the modifications approval by Austin Health HREC:

Limit of Approval. La Trobe UHEC endorsement is limited strictly to the research protocol as approved by Austin Health HREC.

Variation to Project. As a consequence of the previous condition, any subsequent modifications approved by Austin Health HREC for the project should be notified formally to the UHEC.

Application of Approval. As outlined in the original final approval letter, all conditions of approval continue to apply.

If you have any queries on the information above please e-mail: **humanethics@latrobe.edu.au** or contact me by phone.

On behalf of the La Trobe University Human Ethics Committee, best wishes with continuing your research!

Kind regards,

Ms Sara Paradowski

Executive Officer – Human Ethics

Research Integrity Unit / Research Services

La Trobe University Bundoora, Victoria 3086 P: (03) 9479 – 1443 / F: (03) 9479 - 1464

http://www.latrobe.edu.au/researchers/starting-your-research/human-ethics

Appendix T

Interview guidelines for participants of three employment groups used in Study Four: Experience of employment after SCI and pathways involved

Interview structure and questions

Introduction

Introduce self and establish rapport. Gather personal information.

Demographic details:

	Level of injury (incl.
Age (DOB)	AIS)
Gender	Compensation status
Time since injury,	Cause of injury
Place of residence	
employment history*	
education history	

*include employment at time of injury, (include industry (ABS) classification), occupation title

Q 1. Describe your current situation. What is your current situation in relation to labour force.

Stable	Unstable	No employment
Currently employed		
and have been for		Unemployed, actively
last 6 months	Precarious	seeking and available
		Unemployed, not
Apprenticeship	Temporary	looking
Self employed	Casual	Retired
		Unemployed,
		dropped out,
Part time or full time	Fragile self employed	demotivated
	Non-durable (did go	Unemployed, not
	back to work but now	available, active
	withdrawn)	rehab, study,

	domestic, sport, voluntary, hobbies	
	Other?	

Q 2. Tell us how you got here (explore, obtain detail). Note standard list of pathways (ABS).

(Thoughts, conversations, active intervention about work, in hospital, in rehab, after rehab/at home)

Biographic details – Group one – stable employment

Q 3 Think back from when you had your injury to now

3a Were there things that held you back? (both in relation to work and other life areas)

3b What has helped you? (what how when)

Q 4 You have successfully returned/obtained employment

4a What has helped you gain employment?

4b What (if anything) has held you back?

Q 5 Thinking about yourself as a person and your strengths and limitations.

5a Are there things about you that helped you get to where you are?

5b Are there things about you that held you back in what you have achieved?

Q 6 Thinking about the system that you have to interact with – ie the health system, compensation and welfare system.

6a Since your injury, what about the system has helped you?

6b Since your injury, what about the system has held you back?

Q 7 Thinking about supportive others, for example an intimate partner, family, friends (nb peers).

7a What about these supportive others has helped you?

7b What about these supportive others has held you back?

Q 8 Thinking about your employer (pre or present).8a What about your employer has helped you?8c What about your employer has held you back?

Q 9 Thinking about your occupation title

9a What about your occupation title has helped you?

9b What about your occupation title has held you back?

Q 10 How satisfied are you with your current situation?

Standardised measures

Complete 1. Satisfaction with Life Scale

2. The revised Life Orientation Test

END OF INTERVIEW

Appendix U

Quantitative outcome measures used in participant interviews in Study Four: Experience of employment after SCI and pathways involved

The Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985)

DIRECTIONS: Below are five statements with which you may agree or disagree. Using the 1-

7 scale below, indicate your agreement with each item by placing the appropriate number

in the line preceding that item. Please be open and honest in your responding.

- 1 = Strongly Disagree
- 2 = Disagree
- 3 = Slightly Disagree
- 4 = Neither Agree or Disagree
- 5 = Slightly Agree
- 6 = Agree
- 7 = Strongly Agree
- _____ 1. In most ways my life is close to my ideal.
- _____ 2. The conditions of my life are excellent.
- _____ 3. I am satisfied with life.
- 4. So far I have gotten the important things I want in life.
- 5. If I could live my life over, I would change almost nothing.

The revised Life Orientation Test (LOT-R) (Scheier, Carver, & Bridges, 1994)

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements. There are no "correct" or "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

- A = I agree a lot
- B = I agree a little
- C = I neither agree nor disagree
- D = I DISagree a little
- E = I DISagree a lot
- _____ 1. In uncertain times, I usually expect the best.
- _____ 2. It's easy for me to relax.
- _____ 3. If something can go wrong for me, it will.
- _____ 4. I'm always optimistic about my future.
- _____ 5. I enjoy my friends a lot.
- _____ 6. It's important for me to keep busy.
- _____ 7. I hardly ever expect things to go my way.
- _____ 8. I don't get upset too easily.
- _____ 9. I rarely count on good things happening to me.
- _____ 10. Overall, I expect more good things to happen to me than bad.

Appendix V

Declaration of co-authorship and contribution

Full bibliographic reference to the item/publication, including authors, title, journal (vol/pages), year. Hilton, G. M., Unsworth, C. A., Stuckey, R. & Murphy, G. C. (2017). The experience of seeking, gaining and maintaining employment after traumatic spinal cord injury. *Work*.

Status

Accepted and In Press

Nature of candidate's contribution, including percentage of total

Conceived the study, developed the method, completed all data collection, thematic, pathway and statistical analysis, and had primary responsibility for paper drafts. 65%

Nature of all co-Authors' contributions, including percentage of total Unsworth: Involved in study design and methodology; cross-checked thematic analysis; edited drafts of the paper, including response to reviewers following submission. 15% Murphy: Involved in study design and methodology; edited drafts of the paper, including response to reviewers following submission. 10% Stuckey: Involved in cross checking thematic analysis. 10%

Has this paper been submitted for an award by another research degree candidate (co-Author), either at CQUniversity or elsewhere? (if yes, give full details)

No

Candidate's Declaration

I declare that the publication above meets the requirements to be included in the thesis

as outlined in the Research Higher Degree Theses Policy and Procedure

.....

(Original signature of Candidate) Date

Appendix W

Copy of accepted and in press manuscript in *Work*

Research Manuscript: Work

Title: The experience of seeking, gaining and maintaining employment after traumatic spinal cord injury and the vocational pathways involved

Abstract

BACKGROUND: Vocational potential in people with spinal cord injury (SCI) are unrealised with rates of employment substantially lower than in the labour force participation of the general population and the pre-injury employment rates.

OBJECTIVES: To understand the experience and pathway of people achieving employment outcome after traumatic spinal cord injury by; classifying participants into employment outcome groups of stable, unstable and without employment; identifying pre and post-injury pathways for participants in each group and, exploring the experiences of people of seeking, gaining and maintaining employment.

METHODS: Thirty-one participants were interviewed. Mixed methods approach including interpretive phenomenological analysis and vocational pathway mapping of quantitative data.

RESULTS: The most common pathway identified was from study and work pre-injury to stable employment post-injury. Four super-ordinate themes were identified from the interpretive phenomenological analysis; expectations of work, system impacts, worker identity and social supports. Implications for clinical practice include fostering cultural change, strategies for system navigation, promotion of worker identity and optimal use of social supports.

CONCLUSIONS: The findings increase insight and understanding of the complex experience of employment after spinal cord injury. There is opportunity to guide experimental research, policy development and education concerning the complexity of the return to work experience and factors that influence pathways.

Keywords: mixed-methods, interpretive phenomenological analysis, return-to-work, vocational pathways

1. Introduction

Gaining durable employment is one of the most important indices of community reintegration following spinal cord injury (SCI) (Schonherr et al., 2004). The benefits of returning to employment have been well documented and include financial independence and security; physical and psychological health and well-being; and improved self-efficacy and self-esteem (Clifton, 2014; Leiulfsrud et al., 2016; Schonherr et al., 2004; Tomassen et al., 2000; Ville & Winance, 2006). It is also widely recognised however, that achieving durable (that is, stable and permanent (International Labour Organization, 2013)) employment after SCI is difficult, and involves the extensive navigation of multiple personal and environmental factors (Martins, 2015). As a result, durable employment rates remain low, (often quoted around 35-40%) (Trenaman et al., 2014; Young & Murphy, 2009) and the vocational potential of many people, unrealised (Young & Murphy, 2009). Whilst literature focusing on gaining employment after SCI is extensive (Lidal et al., 2007; Ottomanelli & Lind, 2009; Trenaman et al., 2014; Yasuda et al., 2002; Young & Murphy, 2009) there is relatively limited, qualitative research of robust scientific rigour that can contribute to our understanding of this complex community integration goal. A recent systematic review of literature focusing on what we know of the experience of returning to work after SCI, recommended further exploration of employment experiences across different environmental contexts, at varying time periods post injury, and in respect of individual vocational pathways (Hilton, Unsworth & Murphy, unpublished data).

Gaining employment involves the navigation of environmental factors such as social policy and funding arrangements, as well as the physical environment and societal attitudes, all of which can vary significantly in different countries and jurisdictions (K W Hammell, 2007). SCI management across these environmental contexts can also differ, potentially influencing the individual experience of seeking, gaining or maintaining employment. Opinions in the literature vary regarding the access to and impact of, insurance or social welfare on employment outcomes (Conroy & McKenna, 1999; Leiulfsrud et al., 2016; Paul et al., 2013). Chapin & Kewman (Chapin & Kewman, 2001) suggest that finding a balance between different life demands and personal expectations helps to alleviate the influences

of funding arrangements on decisions around return to work. Further in depth exploration of the impact of environmental factors across different countries and jurisdictions, as well as clear description of the relevant insurance and social welfare policies may draw a more comprehensive understanding of the phenomena around pathways to employment after SCI.

Existing qualitative literature has begun to expose the differing traits and experiences of people who have participated in employment following SCI versus people who are unemployed (Bergmark et al., 2011; Chapin & Kewman, 2001; Fadyl & McPherson, 2010). Few studies however, have explored the different pathways or trajectories people have taken to get to these outcomes, and factors that may influence these. Ferdiana et al (Ferdiana et al., 2014) modelled the employment trajectories for a cohort of n=176 with acute SCI, and identified three distinct paths. The first encompassed no employment preinjury and no employment for 5 years post (called no employment), the second included employment pre-injury and an increasing chance of employment in the 5 years post (termed low employment), and the third covered employment pre-injury and steady employment within 5 years post (described as steady employment). However, there was no explorative component to this study to help contextualise and understand the different contributing factors and experiences associated with certain outcomes. Chapin and Kewman (Chapin & Kewman, 2001) examined factors affecting employment after injury using semi-structured interviews and a grounded theory approach to analysis, in a matched sample of people employed and unemployed. Whilst the authors did not explore pathways per se, they did conceptualise re-employment as a process, including; job

consideration/exploration, job seeking/offer/return to work, job maintenance/advancement, and perceived advantages of being in employment. Chapin and Kewman (Chapin & Kewman, 2001) also identified a number of moderating variables that influenced each step of the process, such as the environment, psychological differences, physical limitations, and activities/skills.

The purpose of this research was to understand the experience and pathway of persons seeking and gaining paid employment outcome after traumatic SCI in the state of Victoria, Australia. Specifically this involved; identifying and allocating participants into three employment outcome categories of stable employed, unstable employed and without employment; exploring relationships between demographic variables and employment outcome; identifying pre and post injury pathways for participants in each of the groups; and, exploring the experiences of people seeking, gaining and maintaining employment.

2. Methods

2.1 Study design

This study used a mixed methods convergent design, merging concurrently collected quantitative and qualitative data to address the study aims (Klassen et al., 2012). It is increasingly recognised that a triangulated approach where both quantitative and qualitative data are collected, provides a better understanding of research problems than collecting either data type in isolation (Creswell & Plano Clark, 2006). Interpretive phenomenological analysis (IPA) (Hycner, 1985; Smith, 2015), was used to understand the qualitative data, and quantitative data were explored using descriptive statistics,

correlations and pathway mapping. The findings from analysis of each data set were then compared and the interpretation presented in the discussion (Klassen et al., 2012).

IPA is founded in phenomenology, hermeneutics and idiography. In this study, the phenomenological component refers to the lived experience of people following traumatic SCI and the idiographic refers to seeking, gaining and maintaining paid employment in Victoria, Australia. Hermeneutics is the understanding that was sought through the analysis and interpretation of what people said in participant interviews (Smith et al., 2009).

2.2. Participants

Determining the sample size for a mixed methods study requires consideration of both the quantitative and qualitative components (Onwuegbuzie & Collins, 2007). The purpose of this study was to understand the experience and pathway of individuals with SCI in relation to employment, in order to contribute to a knowledge base. The three groups; stable, unstable and no employment were chosen and defined in order to explore a variety of vocational pathways. It was believed that key differences or patterns would emerge across the groups that could be used in the future to inform implications for policy and practice. Purposive sampling of approximately 30 participants was deemed appropriate to address both the qualitative and quantitative components related to the study aim (Onwuegbuzie & Collins, 2007). The intention was to recruit at least 10 participants to each group where Group A had outcomes of stable employment; Group B outcomes of unstable employment; and Group C were without employment. Retrospective cases of 'exemplars' across three subgroups were drawn from the spinal cord injured population living in the community. In

this method of sampling, participants are selected because they hold characteristics of interest to the phenomenon being studied. Based on previous interview studies with this population, this sample size for the qualitative data was considered important to capture variance in client situations and would likely observe a plateau in the production of novel response elements (Murphy & Young, 2006). Ethical approval for this study was obtained from the Hospital and University Human Research Ethics Committees.

People eligible to be recruited to the study had sustained a traumatic spinal cord injury with persistent neurology, were of work force age at time of recruitment (15 – 65) and had sufficient English language to participate in an interview. No constraints were placed on time since injury or level of impairment. Additionally, if a potential participant had a comorbidity of severe brain injury or cognitive impairment that would limit their ability to return to employment (assessed by their ability to live independently and engage in and complete the consenting process), they were excluded from recruitment into the study.

Criteria for the outcomes subgroups included:

Group A - Stable and durable employment was defined to align with the Australian Bureau of Statistics (ABS) definition of employment (Australian Bureau of Statistics, July 2014) as having permanent employment for at least 6 months, of at least 1 hour per week of paid work. This could include an apprenticeship or steady self-employment.

Group B – Unstable employment was defined as work arrangements being precarious, temporary, casual, or contract employment. This included fragile self-employment or sole

trading, or where the employment had been non-durable, that is, the person had gone back to work and then withdrawn within the last 6 months prior to interview.

Group C – Participants who had not had any form of paid work for at least 6 months were allocated to group C. This group included people who were unemployed, whether actively seeking and available or not looking, demotivated, not available, or retired.

2.3. Measures

Basic demographic and injury data were collected. Semi-structured interviews with openended questions were developed to seek information regarding an individual's vocational pathway before and after injury, including employment and education history, timelines, health services utilised, vocational services utilised, entitlements and interventions received, and stakeholders involved. Questions were also posed to elicit responses about the experience of seeking, gaining or maintaining employment in relation to the aforementioned factors and perceived enablers or complications, difficulties, or challenges encountered. Members of the research team were experienced in the field of SCI rehabilitation with both clinical and academic experience. Development of the interview questions was informed by findings from existing literature (Murphy, 2009) and the prior knowledge and experience of the research team.

2.4. Procedure

The study was advertised and promoted via the local state spinal cord injury service and a member based community support organisation, as well as websites, newsletters and notice boards. Interested persons either telephoned or emailed the researchers for further

information. Once contacted and if able to participate, the researcher sought to ensure that the potential participants met the selection criteria, and then allocated them to the relevant subgroup. If there were concerns about correct allocation to a subgroup based on the characteristics of the participant, the first author sought a second opinion from the research team and decisions were agreed. Interviews were arranged at a place and time that were convenient to the participant. All the interviews were conducted by the first author: an occupational therapist experienced in in spinal cord injury rehabilitation. This was made known to participants, and the researcher remained reflective to the concepts, values and preconceptions which could be brought to the process of analysis (Smith et al., 2009). Once at least 10 cases for each group had been identified, recruitment ceased.

Informed consent was obtained at the commencement of each interview. The interview schedule was expected to take between 45 - 90 minutes, and began with obtaining a detailed history of the person's education and employment history, pre and post spinal cord injury. Interviews were recorded and subsequently transcribed verbatim. Each transcription was allocated a code as an identifier and to reflect the participant's employment outcome group. Transcriptions were then uploaded into NVivo qualitative data analysis software (NVivo for Windows, 2012). NVivo software allows the sorting of data under sources and nodes, so that each employment outcome group as well as participant could be coded separately.

2.5. Analysis

For analysis of the quantitative data, descriptive statistics were performed and vocational pathways were identified for each participant including education (e.g. Secondary, trade, tertiary, etc.) and employment (e.g. Part time, casual, etc.) and mapped in relation to when the person sustained their SCI. Factors such as compensation status, personal care requirements and age were incorporated into the map. For each employment group, similarities and differences in employment trajectories were observed and noted. Demographic and injury data were entered into statistical software package SPSS. Spearman's correlation coefficients were undertaken to explore relationships between employment outcomes, and demographic and injury data, and pathways were drawn to visually inspect differences between outcomes for the three employment outcome groups (A, B, and C).

For the qualitative data IPA was used to explore in detail how participants made sense of their personal and social world in the context of their lived experience of seeking, gaining and maintaining employment after SCI (Smith, 2015). The key features of IPA are phenomenology, hermeneutics and idiography. Phenomenology is the philosophical study of "being" and/or experience. IPA is informed by hermeneutics, which is the study, methodology and practice of interpretation. Idiography prioritises a focus on the particular individual event or process. Overall, IPA requires the researcher to become highly familiar with the transcripts and engage in an "interpretive relationship" (Smith, 2015) with the data.
Analysis of interview data initially followed a three-step process with each individual transcript, consistent with guidelines documented by Smith and colleagues (Smith, 2015). Firstly the researcher engaged in "free" or "open" coding, becoming familiar with a single transcript by reading and re-reading, and reflecting against any preconceptions. The second step involved phenomenological coding of the transcript line-by-line, noting descriptive, linguistic and conceptual comments in the data. Thirdly, interpretative coding was undertaken to identify emerging patterns and commonalities as "themes". Once this had been completed, the three steps were repeated with the next transcript, and so on until all cases had been analysed. Following individual case analysis, the researcher looked for patterns across the cases, including within employment outcome groups. This allowed the identification of super-ordinate themes (Smith, 2015). A second researcher then reviewed and analysed a sample of interview transcripts using the same process and where there were any discrepancies or disagreements they were discussed and resolved. On completion of analysis, 'member checking' was undertaken, as is usual in qualitative research (Letts et al., 2007). Participants were invited to read and provide feedback on a summary of the analysis. This process was followed so as to check credibility and achieve trustworthiness (Smith et al., 2009).

Findings from IPA and the mapping exercise were considered together in order to identify additional, or reinforce existing, themes, while considering the experiences within different employment outcome groups. This triangulation strengthened the analysis enabling deeper understanding of the data.

3. Results

The results are presented in three sections relevant to the study aims. Section one and two relate to quantitative data including identification of participant demographics, group characteristics, relationships between variables and results from the pathway analysis. Section three presents the results of the qualitative IPA findings.

3.1 Participant demographics, group characteristics and relationships between variables

Thirty-one participants (n=31) were successfully recruited to the study. Of these participants at the time of the interview, Group A were in stable employment (n = 12), Group B were in unstable employment (n = 10), and Group C were without employment (n = 9). Table 1 shows the demographic and injury characteristics of the study population. On initial recruitment one participant was allocated to group C. However it transpired that this participant had only recently retired after being in the labour force for over 35 years, and therefore it was more appropriate to allocate this person to Group A, stable employment.

Insert Table 1 here

Spearman's correlation coefficients showed there were no significant differences in individual nor group demographics and employment outcome except for funding status. There was a moderate, positive correlation between funding status and employment status, rho = .400, n = 31, p < .05, where being uninsured/non compensated was associated with being in the labour force.

3.2.1 Findings - Pathway analysis

A visual map was developed to demonstrate the similarities and differences in pathways taken by participants across the groups (see Table 2 and Figures 1-3). Key findings are summarised below. These pathways are further explored in the Discussion in the context of the four super-ordinate themes identified through the IPA.

Insert Table 2 here

Group A – Stable employment outcome

There were two main pathways (a) from study pre-injury, to study and then employment post injury (40%); and (b) from study and employment pre injury, and returning back into the same or similar role post injury (50%). People in stable employment were on average younger (29.3 (11.3)) at the time of their injury than participants in the other groups. Forty per cent were students (either secondary or tertiary) at the time of injury. Participants' preemployment skills were less physically oriented with only one participant having a trade background. Of the group, 70% held at least a university degree. Two participants in this group did not actually complete their pre-injury studies and therefore had no formal qualifications, however due to prior sufficient work experience had remained secure in their employment through on-the-job training programs. Half of this group were insured under the state no-fault accident compensation system, two (16.7%) of these were eligible for (and had accessed) a loss of earning benefit (or equivalent) if required, and the other two (16.7%) had received a lump-sum payment in the past. Seventy percent of the group required assistance with aspects of personal care. Fifty percent had a classification of American Spinal Injuries Association (ASIA) Impairment Scale (AIS) A and a cervical lesion, (that is, complete tetraplegia).

Insert Figure 1 here

Group B – Unstable employment

There was one main pathway for 70% of these participants, which was having studied and worked pre injury to then achieving (unstable) employment post injury. Only one participant (10%) was in similar employment post injury to that of their pre injury role. All participants in Group B had studied prior to their injury. Seventy per cent of these had completed their qualifications and of them less than half were at degree level or above. The pathway to employment following injury for this group appeared less clear, and was potentially complicated by major comorbidities such as pain or skin issues and/or additional life responsibilities such as being primary carer for a child. Twenty per cent of the group identified experiencing mental health issues. Sixty per cent of this group had insurance under a personal accident scheme and all received a loss of earning benefit or equivalent. Sixty per cent of the group had a classification of AIS A and a thoracic lesion, (that is complete paraplegia). Thirty per cent of the group required assistance with personal care.

Insert Figure 2 here

Group C – Without employment

Group C participants had variable outcomes. Eighty per cent of this group had achieved some level of employment at some stage post injury, however at the time of interview were

without employment. Forty per cent had trade backgrounds. Twenty per cent of the group had a qualification of degree or above. Significant mental health issues were reported by 50% of the group. Eighty per cent of the group were insured under a personal accident scheme, with 60% currently receiving a loss of earning benefit or equivalent. Half of the group required some assistance with personal care and 40% of the group had a classification of AIS A and a thoracic lesion, (that is complete paraplegia). The remaining 60% varied in both AIS and level of injury.

Insert Figure 3 here

3.2.2 Findings – Interpretative Phenomenological Analysis

Super-ordinate themes from the interpretive phenomenological analysis are presented providing insights into the personalities of the participants and their experiences that may have contributed toward the employment outcomes.

Expectations about employment after SCI:

Participants in Group A provided a consistent message that for them, paid employment was an accepted part of the journey post SCI. Only one participant reported questioning (at a very early stage) whether returning to employment would be possible. Participants were focused on achieving (or maintaining) employment and were motivated by financial and social reasons, as well as by gaining or maintaining a sense of purpose and meaning through the worker role. In particular, one participant emphasised that employment was an accepted part of the future after SCI;

SA07 "[at the start] I had so many people tell me like just focus on your disability and learn about that first ... I already knew what the deal was ... it's like well a job's not going to take away 24 hours of your day, you can still research, learn your disability ..."

Opportunities had arisen for people following their SCI and due to their positive expectation of work, they had actively pursued them and these opportunities had often led to an employment outcome.

SA05 "I got an opportunity ... I had people vouching for me that were high up in the company ... I was very well supported to begin. I didn't need that support so much once I started working, because I was confident with what I could do and you know the runs on the board ..."

These opportunities were often synonymous with a supportive employer: SA09 *"[they've given] me the opportunity to step back into the role, they've been hugely supportive as a company"* This highlighted the importance of remaining in contact with pre-injury employers through the rehabilitation process.

SA11 "So I was in contact with them [the company previously worked for] and they basically said to me, okay, look you know what, when you're ready give us a yell, we'll see if we can help you out. When I finished my rehab I started there three days a week..."

Participants in Group B and C held a strong motivation and desire to work. Whilst opportunities had emerged for the participants, as they had done for people in Group A, it

appeared that the pathways to stable employment were less clear with competing life demands being raised as a common concern.

SB07 "I'm a full time parent. So all my work needs to fit in within school hours usually you know"

SB07 "the medical stuff you know it's – I really hate letting people down, I really hate ringing up and saying 'look I know I'd said I'd do it but I can't' and that really bugs me"

SB08 "you know if I'm not fighting all the battles that I've had to fight over the years against [insurance company] or my ex-wife or whoever then that opens up a whole lot of extra time. And also you need some sanity time as well, because sometimes I'm just not in the mood for [work].

At times, pre-injury workplace limitations also prevented a return to the pre-injury employer. Whilst two participants in Group C had returned to work successfully in their pre-injury role within one month of their discharge from rehabilitation, organisational demands had ultimately forced those workers to cease employment.

SC10 "I just couldn't have gone back to the corporate ... job, it was really, really hard part time". Both participants have gone through, or are in the process of, reskilling and seeking new employment; SC10 "... so teaching was always something that I'd wanted to do ... I think the school holidays and things like will work in my favour that I can rest and the days are short ...". At an individual level, people achieving employment also demonstrated a motivation and willingness to problem solve and successfully deal with adversity. It wasn't so much that those who were not employed did not have these attributes, but more that people in employment had 'seen it through'. The inherent bias in a self-selecting sample must be noted here, as this potentially gives a skewed picture of personality traits and the ability to deal with adversity. Indeed the vast majority of participants interviewed presented themselves in a positive manner.

Comprehension and navigation of systems and rights

The majority of participants in Group A had an understanding of their rights as employees and an awareness of legislation and regulations. A common understanding in the maintenance of employment was having open and effective communication with the employer. Helping the employer to understand the implications of SCI meant that appropriate support for the person to do their job was reliably provided.

Several participants in Group B did not appear to have a comprehensive understanding of their regulatory based rights, whether as insurance claimants or within the broader welfare systems. Participants expressed difficulty obtaining information relevant and useful to their situation. This difficulty was often exacerbated by a concern with 'doing the wrong thing' or fear of their income/financial support being effected.

SB04 "You know and sort of like they don't tell you that from the [Insurer] and there were people that I had heard about that had got caught out by that [pre safety net] and couldn't get their benefits again and you know they tried everything to get back to work

and then are punished basically by you know they get tricked – they feel like they got tricked."

One participant had heard of the possibility that working more hours could impact on his loss of earning benefit (insurance payment). When he spoke to the agency, he noted: "...even then I had to go through a few different levels before I found the right information. Because I really didn't want to be disadvantaged in any way..." (SB03).

Four participants with no fault personal injury insurance described receiving a lump sum payment following their injury and the remaining were eligible for a loss of earnings benefit or equivalent. Commonly, for those receiving this form of compensation, participants described an uncertainty about how to navigate these systems, if they were to return to work or increase their hours. It was apparent across the groups that unclear or poor quality information had caused anxiety or confusion about entitlements, and/or the security of payments related to a person's injury. People described difficulty finding correct information that was relevant to them and their situation and on which they could then make reliable decisions about the financial implications of gaining or losing employment.

Participants who were insured also recognised the financial security compensation brought to their lives and how this in turn provided opportunity for choice.

SA03 "Well the fact that I had an accident at work is a blessing; I mean without that I think my life would be completely different. In other words being funded without that I would just shudder to – I don't know if a marriage would survive, family would survive

you know it just brings a whole lot of other pressures to bear, so that's been a huge god send, huge benefit for all of us in my family."

SB09 "I guess what that – that [having compensation] did for me was it provided me some security, it's given me some time, a chance to do some different things and work out what I want to do"

Whilst several uninsured participants received payments under the federally funded social security system there was not the same level of uncertainty about how much they could work, or indeed how the system would monitor their work involvement. Participants who were uninsured generally described additional pressures or expectations on finances to manage day by day, struggling with issues such as funding equipment or care. However this need in itself appeared to be another motivator for employment. Whilst this scenario for non-insured people would not be specific to participants in this research, there was a general awareness that it was 'tougher' for people not covered by one of the jurisdiction's no-fault accident compensation schemes.

For the majority of participants there was a clear sense of preference to be fully or partially independent of service systems. The process of negotiating with service systems such as accident compensation schemes, was commonly described as enormously time and energyconsuming, complex and bureaucratic. When it was possible to remove the reliance on welfare or loss of earning (or equivalent) payments, people described greater choice, freedom and control over their lives.

SB09 "...but yeah I'm really looking forward to not getting the loss of earnings from [insurer], I want to – I'd love to just be a [worker] and just do that rather than having to have a – get these payments from [insurer]."

The impact of worker identity on motivating employment:

While some frustrations were expressed in relation to service systems and resources, participants in Group A were motivated by employment goals to overcome these barriers. It was apparent that some participants had actively contributed to occupational roles held so as to overcome certain physical or environmental limitations – often achieved through open and effective communication with their employer.

SA01 "...managers and people are usually pretty good. Part of the job- my first job was I could do on call support, but that's not really an option, you can't get up during the night and get a laptop and a phone and start handling issues and things, but they accommodate, they said look you know you don't need to do on call support."

People were highly resourceful in their ability to problem solve through potential barriers to maintaining employment. This resourcefulness, and confidence gained in achieving independence would likely infiltrate other areas of life.

SA05 "... [I use] 1.5 litre leg bags and that gets me through the day... I had to find them [by myself]. ...without those leg bags I would have huge problems, because you know you need to keep your fluids up and ... there's a disabled toilet on my floor [at work] but I can't lock it, and I can't have people walking in on me... if I didn't have these leg bags I would effectively ... need one of those crappy one hour shifts at lunch time, which are hard to fill, for someone to empty the leg bag..."

Participants reflected on the shift in role validation post injury and how this, in itself, helped to recognise self-worth.

SA02 "And then you go home on the weekends and you can't look after the house and you can't do things with your kids and can't do this and can't do that, so it's harder to then find... that validation for the role you're playing... that you were used to... But at least during the week... even if your role is totally different, even if you were a plumber and now... you're in a role counselling people to help them ...but if that's your job now and you are getting paid for it, they're paying you, they're validating your... worth."

Due to a perceived inability or lack of interest in returning to pre-injury career/employment, a reoccurring theme of participants in Group B was that of finding and/or creating a new worker identity. Participants described a process of exploration and trialling different things, followed by a sense of satisfaction when they discovered a skill or role that suited them. This process could take some time and varied between each individual.

SB04 "Yeah I want to do something useful and productive but I just don't know what to do and now I've figured out what I want to do so it's good ... it's about sort of meeting people and spending time with people, I don't want to sit at home by myself all day and only ever see [partner], you know you need to have relationships with other people and I'm missing that, I've been missing that for too long it's huge."

Another participant in Group B reflected on their time in rehabilitation; "...thinking... what am I going to do, I don't want to work in a call centre... it was all of my horrible nightmares come true... sitting at a desk is not the kind of work I do – I just don't thrive" (SB07). They then spoke with elation of the day they realized they could do something different and be good at it.

SB07 "I was at [hospital] one day and bumped into [friend]...she thought that because I'd talked a lot apparently, it [job opportunity] would be good for me... And that was the start of my new employment."

Three participants in Group C identified their ongoing struggle with not being able to physically do and achieve what they used to pre injury. There was a sense of loss (and grieving at times) for the physical person that they 'once' were and either a lack of hope for future possibilities, or a despondence about overcoming barriers. This was a direct contrast to scenarios described by participants in Group A and B.

SC01 "I just can't stand the thought of people seeing me like this because it's just not the way I was, I was six foot tall, super fit ... But no I just don't want people seeing me like this ..."

SC03 "I suppose the work I did was very much hands on you know and probably very physically demanding and so that's out, can't come back to that obviously. So I've got to look at a whole new occupation, completely...."

Participant SC03 grappled with how to manage pain effectively so that work could

become a possibility again; "One particular day I did feel good, and when I feel that good I feel like I'm ready to tackle the world, so I went in and met them [previous employer] and had a good conversation with them, but two days later I felt like absolutely shit at the end, back to square one."

Three others in Group C described a similar stage of grieving, however had (with time and appropriate supports) been able to adjust and spoke positively about the new identity, skills and roles they were creating for themselves.

SCO6 "Yeah it was just switch flicked when I had a [serious] pressure sore ... and I thought I can't keep doing this to myself. I couldn't push myself up a ramp to get in the house I had to like get some help...I want to be – not the bread winner but I want to show [my partner] that [they] can come home and be with the family and I can go to work."

Perception-of-self featured regularly in participant's discussions about vocational activities and roles as well as directly in relation to identity gained through employment. For example, many people described the value and role of leisure in helping to establish a sense of self-worth and ability, either adding to a level of confidence in other life areas (such as relationships or employment), or providing motivation to be a worker.

SC06 "playing rugby with the boys has taught me a lot... [insert player name] works, plays rugby, has a family... there's other blokes out there that do it... that really motivates me even more..."

Conversely, others, particularly earlier after injury, appeared conflicted by their self-image and described a hope for a different future.

SC03 "I went down to [peer support organisation] one day, and I met with [names of peer support workers], so we're going across the road to the pub for lunch and... I just wanted to turn around and get into my car and just go home, this is not for me... So I just don't like being around people."

I know I'll never have my old life back... and to be honest with you my old life was 150miles an hour... it was too fast... But I know that I'll never have that back but if I got it back to 14 miles as hour I'd be happy with that life for now and I think that's what keeps me going, just the thought of... getting myself back into some sort of managing again... "

The importance of social supports and their contribution to employment outcomes:

Social support, which is a critical component of social participation, is a multi-faceted phenomenon and can be broadly understood as the perception and actuality that one is cared for, and could obtain emotional or physical assistance if required from social networks such as family, friends or associates (Murphy et al., 2010). An important component of social supports in relation to achieving employment is having access to appropriate and adequate formal support for assistance with personal care.

Several people described inadequate support – usually around accessing hours and or staff for personal care. Of participants currently employed, at least nine people (predominantly from Group A) described having to modify their work arrangement and/or lifestyle in order to maintain the worker role.

SA07 "...the main problem is its accessing care ... Luckily I've got just enough but I had to fight for ages, and ages to get enough care hours to live independently"

SA05 "I'd love to live in places like [inner city suburb]... but getting carers in places like that would be really difficult... Because most of my carers come from the lower socioeconomic areas... you've got to live within cooee of them..."

For others however, their physical limitations combined with inadequate personal care resources meant that they could not sustain employment, despite a desire to be working.

SC08 "I've only got three [carers] at the moment, I'm supposed to have 14 hours of care a day. Yeah I can't get skilled people, locally."

Participants also described a wide variety of interventions, services and entitlements that may have assisted in individual cases. But no one, single, resource stood out, possibly due to the fact that participants experienced their accidents over several decades, and therefore the experiences of different systems and processes over their histories was varied.

One recurring theme however, across the three groups regardless of time since injury, was that if an individual had access to a person or persons who had an understanding of SCI, the local insurance and support systems and what was possible in terms of outcome, this appeared to assist the individual to navigate the journey towards an employment outcome. An example of this was the phenomenon of peer support. Described in this context as people with lived experience of SCI who are willing to offer support and knowledge to other people who are recently injured or needing assistance with a particular life domain. Several

participants described the value of the peer support relationship in providing a sense of community, which in turn helped to build confidence and foster independence, whilst also being a source of motivation.

SA11 "...so that's when we started wheelchair rugby... and from then you get to meet other people in chairs and also there's another element of your life that's opened up. So that's when you can start to see the acceptance come in. You start to meet people who accept people in chairs so that's another environment altogether. So again, that sort of progressed another area of my life of acceptance. And that's where confidence starts to build in."

SC06 "Playing rugby with the boys has taught me a lot... like knowing that there's other blokes out there in the same position that do it [work] yeah really that motivates me even more"

SC05 "I still see him [peer mentor] regularly, we have the same injury and he's a walker, so we're – we're called walkers...

Yeah so I catch up with him and he actually goes to [same university] to study as well so we just catch up after classes and yeah he's probably – he's a really good help because he knows exactly how it feels, you know, people who like say like... [who's] involved with it but... hasn't had an injury so [they] can only understand to a point, same with people who are in wheelchairs they can't really relate to someone who's walking with a disability because we're really, really, we're such a minority."

Where participant's needed specific knowledge they might seek out peer connections for assistance.

SCO6 "I'm looking for anything I can do. Admin, sales, yeah I had a chat to [insert name] actually we're close mates, and he said get into HR and I've got no idea what that would entail so I've got to rack his brain a little bit more because he's in that sort of field."

Similarly, people with employment experience were willing to share what they had learnt, whether it be with other workers or people looking to work; "*We're professionals in chairs [let's] get together, let's share some ideas, let's share travel, let's share career [aspirations]*" 4. Discussion

The purpose of this research was to understand the experience and pathways of persons seeking and gaining paid employment outcome after traumatic SCI. Pre and post injury pathways of individuals were explored and four main themes were drawn from participant interview data. Consideration of the emerging pathways in the context of the four main themes, allows identification of implications for clinical practice. These implications, which involve cultural change, system navigation, worker identity and social supports, will be discussed.

Social and institutional cultural change

Participants in this research, who had gained stable employment after sustaining a SCI, had largely optimistic expectations of paid employment being part of their lives after injury.

Conversely, for people who were in unstable or no employment, achieving work was more complicated and difficult, with attitudes being more pessimistic about reaching a stable employment outcome. Participants' experiences, and previous research suggest that, typically, the culture of social and institutional environments including spinal rehabilitation centres, has not been predominantly supportive and positive about returning to work after SCI (Murphy, 2009; Ottomanelli et al., 2009). This was also found in research by Hammel (Hammel, 1999) where it was noted that spinal rehabilitation centres offered limited information and support concerning resumption of employment after injury. Ottomanelli (Ottomanelli et al., 2009) suggests there are potentially negative consequences to employment outcome for people who undergo rehabilitation in spinal centres that do not have a culture of supporting vocational goals after injury. An early intervention vocational rehabilitation service has been in place at the spinal centre where the participants in this study received services since 2010 (details of which have been described elsewhere (Hilton et al., 2017)). However, the majority of participants in our research received rehabilitation prior to this service commencing when there was very little emphasis on the benefits of employment after injury, and there was still a strong traditional focus on physical recovery. Other factors that may have also limited the employment outlook for people in the unstable or no employment group may have included fears and unknowns for the individual about living with SCI, community misconceptions of disability, and perception that social stigma existed in the workplace about people's capacity to maintain job roles. Other qualitative studies exploring employment after SCI, have also reported negative perceptions of disability and resulting discrimination as a common issue (Chan & Man,

2005; Hay-Smith et al., 2013; Leiulfsrud et al., 2014; Wilbanks & Ivankova, 2015). The inpatient rehabilitation environment, social networks and workplaces can all have a role, however, in providing positive messages about returning to employment, and backing that with practical support. In New Zealand, for example, people have described the spinal rehabilitation centre, as 'sowing the seed' to contemplating employment after SCI (Hay-Smith et al., 2013). This demonstrates the constructive influence that the social or institutional environment can have in regards to employment after injury.

The lack of supportive culture about employment after injury identified by participants also appeared to have manifested as misinformation or difficulty in information dissemination or comprehension. This was frequently reported to cause anxiety or confusion about entitlements, and/or the security of welfare or payments related to a person's injury. People often found it difficult to find relevant information to their situation and stage of their post injury pathway. This is not a scenario unique to the setting for this research and as a result, opinions vary across settings as to the value of entitlements and benefits (Bergmark et al., 2011; Chan & Man, 2005; Chapin & Kewman, 2001; Hay-Smith et al., 2013). Therefore, it is essential to ensure design for access to correct and clear information about entitlements, benefits and resources in order to assist in nurturing a culture that is positive and supportive about the possibility of employment after SCI.

System navigation

The state of Victoria, Australia has established systems of welfare or accident insurance (for motor transport or work related injuries) that can support spinal injured persons and

provide a sense of security in times of need. But characteristics of current service systems have been described in this research as enormously time and energy-consuming, as they are large, complex and bureaucratic. It was consistently evident from the experiences of study participants that if it were possible to remove the reliance on welfare or loss of earning (or equivalent) payments, people described greater choice, freedom and control over their lives. Insurance bodies and welfare programs should therefore consider innovative approaches to promote system flexibility, to in turn promote opportunities for employment, and independence from systems. An example may be giving people the opportunity to trial employment without any fear of impact on benefit entitlement.

People's knowledge of systems and what supports were available to them was very limited. This was particularly so for people in the unstable or without employment groups. Similarly, the pathways for people in this group were not straightforward and these participants often experienced major co-morbidities or complications. This highlights the need to remind funders and service providers that any vocational intervention offered must be holistic and individualised in approach in order to adequately meet the highly variable needs of service users.

Worker identity

There is a strong evidence base to suggest that, if a person can, it is definitely better to work than not (Bergmark et al., 2011; Leiulfsrud et al., 2014; Leiulfsrud et al., 2016; McKee-Ryan et al., 2005; Murphy & Athanasou, 1999). This was reinforced in this research with consistently positive messages from participants about the value of being in paid

employment, and how this also contributed to their sense and strength of identity. People in employment identified being financially better off, having greater social connectedness, and having an improved sense of purpose, worth, meaning and wellbeing. People also described receiving validation of their roles through employment and having greater opportunities to contribute to their society or community. These experiences echo the survey data of retrospectively defined employment groups by Krause (Krause, 1992). Krause (Krause, 1992) found that people in the 'current employment group' reported significantly better adjustment in many life areas. Furthermore, in a paper called "Spinal cord injury and the joy of work", Shane Clifton, who himself lives with a cervical level of spinal cord injury, reflects on the ambiguity of work and happiness. He describes our fundamental needs to participate in all elements of society, and how our contribution to the world through work, supports our overall happiness and wellbeing (Clifton, 2014). Clifton's experiences and observations further augment the value of employment after SCI to a person's identity.

Explorative research in the New Zealand setting by Hay-Smith and colleagues (Hay-Smith et al., 2013), recognised the significance of modification of 'employment identity' in the return to work process. This was also prevalent for participants in this research and particularly for people who were in the unstable and without employment groups. For most people in the stable group (as previously discussed) the pathway back to work was reasonably clear. For others in the unstable and no employment groups, there was often a process of re-thinking, re-creating and/or retraining for an employment role that could be achieved. Given the additional challenges people experience in relation to medical comorbidities and/or extra life responsibilities, there is clear rationale for promoting and encouraging the development

of skills in people for alternate or flexible worker roles. This may include scenarios such as self-employment.

Social supports

The importance of social supports and the role these played in contributing to employment outcomes, was frequently evident in the findings of this research. This mostly manifested as ensuring access to adequate number of hours and staff for personal care, but also related to having open and effective communication with potential or current employers and utilising peer support networks. Connection with peers helped to alleviate fears and 'unknowns' around returning to work, provide possible motivation to be a worker and assist with modelling employment opportunities, such as exploring flexible work arrangements. The value of social connectedness, peer networks and open communication with employers have also been identified in several other studies as facilitators to employment (Bergmark et al., 2011; Chan & Man, 2005; Chapin & Kewman, 2001; Hay-Smith et al., 2013). Clinicians and service providers can support people's employment goals by promoting peer connections, encouraging effective communication with employers and where possible, guide funding arrangements or problem solve flexible solutions for work arrangements.

In summary, this is the first study to explore people's experience of return to work following SCI, in an Australian context. It is also the first study to document the vocational pathway of people from pre-identified groups of employment outcome. With the use of survey data, Krause (Krause, 1992) allocated research participants into three employment groups to explore relationships with adjustment. In the research by Ferdiana and colleagues (Ferdiana

et al., 2014), three distinct trajectories were identified for a group of people all within 5 years of sustaining SCI. In Krause's study (Krause, 1992), results of survey data were used to retrospectively allocate participants to employment groups. The current study in comparison, purposively selected people according to their employment outcome and then collected data about individual experiences. Similar to the Dutch experiences presented by Ferdiana (Ferdiana et al., 2014) the results of this study reinforce the value of education in facilitating post-injury employment, and the research by Krause (Krause, 1992) highlights the contribution of employment to people's sense of wellbeing. The current study also provides additional insights as to the influence of social and institutional environments, social supports, worker identity and system navigation on a person's experience of seeking, gaining and maintaining employment following SCI.

Despite many similarities in the traumatic spinal cord injured population throughout the world (Bickenbach et al., 2013), the differences in local policy and service delivery create challenges when comparing or translating findings across countries and jurisdictions. Whilst there were individual perspectives in this study that were possibly unique to Australia, the majority of themes and pathways identified are both congruent with previous international research and largely translatable to other countries with developed welfare regimes such as Sweden, Canada, the UK and New Zealand. For example, research from Sweden and New Zealand recognise the role and contribution of social supports (Bergmark et al., 2011; Hay-Smith et al., 2013) in promoting employment, and the importance of nurturing worker identity is a consistent finding in studies from New Zealand, Norway and Sweden (Bergmark et al., 2011; Hay-Smith et al., 2013; Leiulfsrud et al., 2014).

4.1. Limitations of study

This study has produced results that can be used to guide future experimental research and be applied to strategic policy development. However, a number of factors relating to recruitment potentially undermine comparisons between individual or group experiences in relation to services received.

Eligibility for this study was broad and the length of time since injury variable (between 18 months and 33 years). The policy and practice landscape in relation to vocational rehabilitation specific intervention and the labour market in the period 1975-2012 has changed over this time, and therefore participants will have been exposed to a range of different services, resources and employment opportunities. The sample size was selected to compliment the aims of the study; 10 participants in each group was believed sufficient to produce a stable correlational analysis and enable data saturation in the qualitative analysis. Whilst saturation was achieved in relation to the IPA analysis, it is not clear that 10 participants in each group was adequate for the correlational analyses undertaken. Lack of statistical significance in the quantitative results may have been related to the relatively small sample size. Despite this, the triangulation of results achieved through the use of mixed methods, has itself enhanced and validated the findings (Klassen et al., 2012).

Researcher bias is also possible as the first author is an experienced occupational therapist in SCI rehabilitation and service development. As previously described, this information was shared with the participants and the researcher remained cognizant to this potential bias throughout the data collection and analyses. Occupational therapists work to support the

client in the goals that are important to them across the domains of self-care, leisure and productivity. Occupational therapists may be biased towards assuming that other health professionals and the client all want to achieve goals in these domains. However, this potential bias, and the pre-existing knowledge of the first author also provides a depth of understanding which becomes a strength for interpreting and making sense of the issues and scenarios presented.

The definition for Group C - without employment, had been set prior to participant recruitment and group allocation. Participants met the criteria for the group if, at the time of interview they had been without employment for a continuous period of at least 6 months (Australian Bureau of Statistics, July 2014). Of the 10 recruited, the majority of participants had experienced some employment post injury with only three participants having no post-injury work experience at all. As a result, there was variability observed in the group's pathways and experiences. Upon reflection, the definition for this group needed to be 'history of no post-injury employment' in order to have a cohesive group and provide a clearer contrast between this group and participants in Group B.

4.2. Priorities for further investigation

Priorities for further research and investigation are recommended to include; comprehensive tracking of individual employment outcomes over several years post SCI and research using a multi-centre experimental design to test the effectiveness of different vocational rehabilitation interventions. Also worthy of investigation would be trials of innovative programs designed to build skills in achieving alternate or flexible work

arrangements such as self-employment, or in navigating service systems related to employment. The employment outcome groups and pathways identified for people with traumatic SCI defined in this study could be used for future comparative research.

5. Conclusion

This research highlights the complex dynamics involved in seeking, gaining or maintaining employment after SCI. Results of this research will assist hospital clinicians, community based rehabilitation professionals and funders (both private and public) to reflect on optimal practice to support employment outcomes, regardless of setting and respective health care and funding systems. The findings provide a greater understanding of the perspective of the service user and the paper has offered recommendations to funders of research, system designers and policy makers. The implications of this research include a better recognition of the importance and role of further education to increase skills in appropriate work, and hence strengthening opportunities for post-injury employment. People with SCI also need access to correct and clear information about entitlements/benefits and resources. In turn, this access can empower people to negotiate the often extensive environmental factors that can exist as barriers in organisations and service systems in order to achieve and maintain employment. Adequate and appropriate social supports, such as personal care, employer connections and peer networks are also critical in facilitating pathways to employment. Finally, of utmost importance to employment outcomes are the personal drivers, and hence efforts must be made to

encourage positive motivators, inclusive of the process of re-establishing worker identity following traumatic spinal cord injury.

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