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The influence of pain on community reintegration of manual wheelchair users with spinal cord injury

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DECLARATION

I, Valerie Henderson, declare that this Research Report is my own, unaided work, and that apart from the normal guidance from my supervisor and statistician, I have received no additional assistance.

It is being submitted in partial fulfilment of the requirements for the Degree of Master of Science Physiotherapy in the branch of Neurology at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.

Signed: ……  …5th.. day of …April.. 2023 in Johannesburg

ABSTRACT

Background: Community re-integration is an important goal for people living with a spinal cord injury, however, it presents with multiple barriers such as secondary health conditions. Pain is a common secondary health complication post spinal cord injury (SCI), often resulting in limitations in daily functioning, mood and sleep. Therefore, this study aimed to determine the association between pain and community re-integration.

Method: This study involved secondary data analysis from an existing database, consisting of 122 participants with SCI from T2 and below. Data on sociodemographic, injury profile, pain characteristics, as well as community re-integration were used. The Reintegration to Normal Living Index was used to determine community re-integration, while the DN4 and Wheelchair User's Shoulder Pain Index were used to determine the presence of neuropathic and shoulder pain respectively. Spearman correlations were used to determine associations between pain and pain severity on community re-integration, and Mann Whitney U tests were used to determine if there was a difference in community re-integration between participants who had pain and those who didn't. Data was analysed at the 0.05 significance level.

Results: The median total percentage for community re-integration was 77.73 (IQR 19.88) and 85.2% of the participants reported current pain. Neuropathic pain was more common and more severe than nociceptive pain. Despite a low prevalence of shoulder pain in this study (14.8%), there was a negative association between taking trips out of town and loading a wheelchair into the car ($p < 0.05$). There was no significant difference in levels of community re-integration between participants with or without pain, and no correlation was found between the overall presence of pain and community re-integration. It was the severity of pain, particularly shoulder pain, which was negatively associated with taking trips out of town ($p < 0.01$), and with overall community re-integration ($p < 0.05$).

Conclusion: It is not the mere presence of pain that influences community re-integration, but rather the severity of pain, especially if pain is located in the shoulders. This is an important consideration when rehabilitating people with SCI back into their communities, as shoulder care and pain management will need to be included in the rehabilitation programme.

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List of Abbreviations

QOL: Quality of life

SCI: Spinal cord injury

PWSCI: People with spinal cord injury

MWU: manual wheelchair users

RNLI: Return to Normal Living Index

WUSPI: Wheelchair Users Shoulder Pain Index

ICF: International classification of functioning, disability, and health

SHC: Secondary health condition

CHAPTER 1: INTRODUCTION AND SCOPE OF THE RESEARCH REPORT

1.1 Introduction

For someone who has sustained an injury or disability, community re-integration and participation has been described as the ultimate goal (Donnelley and Eng 2005). The main aim of rehabilitation is to assist a person who has acquired a disability to return to and adapt to a new life. During the acute phase, patients spend time in an in-patient setting, learning new skills and being empowered with knowledge and resources in order to reintegrate back into their community (Kashif et al 2019). Community re-integration is the most meaningful outcome, however, it is still a challenge that a person with disability faces despite good rehabilitation programmes that are designed to increase a person's independence, improve their ability to perform new skills, and provide education regarding their condition (Kashif et al 2019; Mothabeng 2011). Barriers influencing community re-integration include health related or medical problems, physical, emotional, environmental, social and psychological aspects, with low income countries experiencing more barriers than high income countries (Kashif et al 2019, Ullrich et al 2012). Community re-integration is therefore difficult to measure due to these multiple factors influencing it. However, it has also been shown to be closely linked with quality of life (QOL) and community re-integration is therefore essential to measure (Kashif et al 2019).

A spinal cord injury (SCI) causes a devastating loss with many changes in the lives of the affected individuals. Not only are there changes or complete loss in motor and sensory function, but people with SCI (PWSCI) are faced with many secondary complications which can develop as well. Pain has been reported to be one of the greatest and most problematic of these secondary complications (Afsar et al. 2014; Rubinelli et al. 2016) and affects 70% of PWSCI, with one-third experiencing severe, disabling pain (Hadjipavlou et al. 2016; Hagen and Rekand 2015; Jang et al. 2014). Several studies have reported that the most important factor preventing daily living activities in people with SCI is pain (Afsar et al. 2014; Burke et al. 2019). Pain has been found to not only interfere with patients function, but QOL, mood and sleep (Guy et al. 2014).

Pain after SCI can be nociceptive, neuropathic, or visceral. Nociceptive pain is musculoskeletal in nature, and is described as dull, aching, stabbing, movement sensitive, and non-spontaneous. It can be at different sites of the body caused by either the initial trauma, or due to overuse injuries as seen in the shoulder, or it can be due to the secondary complications of the SCI, for example spasms, weakness or contractures (Hadjipavlou et al. 2016). Previous

literature and a recent study showed that the neck and/or shoulders account for 37% of nociceptive pain in people with SCI (Burke et al. 2019). Pain after SCI is complex, and people living with SCI can experience one or all three types of pain simultaneously, however only nociceptive and neuropathic pain are being considered in this study.

Neuropathic pain is due to damage to the nervous system; it can present above, at or below the level of injury and can be spontaneous at rest, or stimulus provoked. Its characteristics are often described as abnormal sensations including burning, electric shock, numbness as well as pins and needles (Hadjipavlou et al. 2016; Mann et al. 2013; Jang et a.l 2014). Burke et al. (2019) found that PWSCI with neuropathic pain reported more pain days, more severe pain and more time seeking medical assistance than those with nociceptive pain. Neuropathic pain was also reported to affect mood, sleep and day to day activities more than nociceptive pain. Neuropathic pain can be difficult to manage, with limited evidence regarding efficacy of medication and long-term effects; pain relief is limited and high pain levels persist even with pharmaceutical intervention (Hagen and Rekand 2015; Afsar et al. 2014; Jang et al. 2014; Burke et al. 2019).

It is of particular concern for PWSCI if pain relief is not achieved due to the reported interferences with daily activities (Burke et al. 2019), transfers, and wheelchair dexterity (Morrow et al. 2010). The ability to successfully self-propel a manual wheelchair can assist a person's ability to participate in community activities. Cooper et al. (2011) found that manual wheelchair users were able to mobilise with an increased speed and increased frequency which had a positive correlation with community participation, compared to power wheelchair users. However, the continuous use of a manual wheelchair may result in the possibility of developing an upper body repetitive strain injury. The shoulder joint is the most common site of injury and pain in manual wheelchair users (MWU), with a reported incidence of 32% - 78% due to increased forces around the shoulder during pressure relief, incline propulsion and at the start of a push (Morrow et al. 2010). Mozingo et al. (2020) recently found that shoulder impingement risk was highest during wheelchair propulsion and scaption, which is when one lifts their arms forward from the sides of the body, at a slight angle. However, in both studies it is important to note that the frequency of these tasks performed in everyday life is far more than what was done and measured in these studies. Therefore, although using a manual wheelchair provides the freedom of movement and potential to be better integrated into the community, all these high demand tasks can put MWU at risk for injury and shoulder pain.

1.2 Problem Statement

After discharge from rehabilitation centres, people with SCI have difficulty in community reintegration due to the influence of a broad range of factors such as the individuality of each person in terms of age, gender, culture and social circumstance, as well as their specific environment. Multiple studies have acknowledged that people with SCI suffer from pain (Burke et al. 2019; Hadjipavlou et al. 2016; Donnelly and Eng 2005). Pain interferes with mobility functioning and ADL's (Raichle et al. 2007), and both social and community participation (Donnelly and Eng 2005; Piatt et al. 2016). However, there is little research done specifically on pain and its relationship to community re-integration, particularly in South Africa. People living with SCI are pre-disposed to both types of pain and it is therefore essential that we determine and understand their pain and how it impacts on community re-integration. From the literature above, it is expected that PWSCI with higher pain scores will score lower on community re-integration. Thus, future treatment and appropriate pain management may facilitate community re-integration.

1.3 Research question

What is the association between pain and community reintegration of manual wheelchair users with spinal cord injury?

1.3.1 Aim of the Study

The aim of this study is to determine the association between pain and community reintegration of manual wheelchair users with SCI.

1.3.2 Objectives of the Study

The objectives of this study are to:

1. Determine if there is a significant difference between manual wheelchair users with pain and without overall pain for community reintegration.
2. Determine the association between nociceptive shoulder pain and community reintegration for manual wheelchair users
3. Determine the association between neuropathic pain and community reintegration for manual wheelchair users
4. Determine the influence of severity of pain on community reintegration.

The hypothesis is that pain will have a negative impact on community re-integration. Negative correlations are expected, as the higher the score for pain, the lower the score for community re-integration.

1.4 Significance of the Study

Knowing how pain is associated with community integration in the South African context will provide a stepping stone in understanding the multi-dimensional aspects of pain. If pain is shown to have a negative association with community re-integration, then it may highlight the need for physiotherapists to address pain during patients' rehabilitation, and not only focus on rehabilitating the patient in terms of reaching functional goals (especially during in-patient hospital stay). If patients are then also taught how to manage their pain adequately and independently in the rehabilitation phase, there may be a decrease in the cost of care post-discharge, by minimizing drug use and hospital re-admissions. If there is an association between pain and community reintegration then improved pain management, specific to neuropathic or nociceptive pain, will play a role in assisting patients to better re-integrate into their environment, which is the ultimate goal of rehabilitation. Healthcare professionals may then start to approach pain management with the aim to improve and facilitate community re-integration rather than only providing pain-relief. If there is no association between pain and community re-integration, then one must consider the other multiple barriers that influence community re-integration and prioritise these to assist a person to be re-integrated into their community.

1.5 Outline of this Research Report

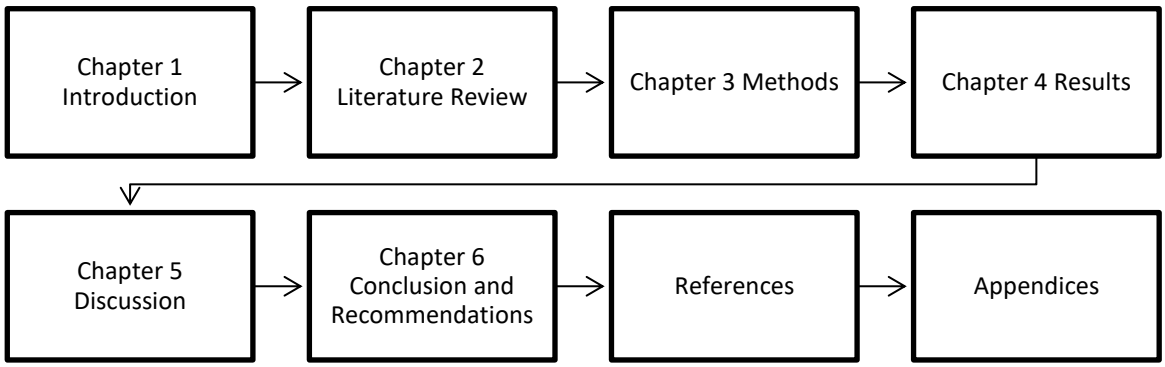

Figure 1.1 Outline of this research report

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

In this chapter, an overview of the literature will be provided on the incidence and prevalence of spinal cord injury, especially in a South African context. Secondary complications, specifically pain is reviewed, and factors that affect community re-integration are discussed. The search strategy used was Pubmed and Clinical Key, with keywords such as spinal cord injury, secondary complications, pain, neuropathic, shoulder pain, and community re-integration, participation.

The international classification of functioning, disability and health (ICF) will be used as a conceptual framework in this review and study.

The ICF is a classification of health and health-related domains, endorsed by the World Health Organisation. It depicts function and disability in relation to a health condition. It provides an overview of assessment, treatment plans and evaluation of treatment plans and outcomes (WHO, 2002). The ICF allows for a common language that looks not only at the medical disability but includes the social model of disability, including a patient's personal and environmental factors. Most importantly, the ICF allows recognition and consideration of how all three of these factors interact with each other to ultimately influence a patients function and participation, providing a more holistic approach. The ICF is a framework that all healthcare providers across the world can use for patients with a disability. It focuses on a biopsychosocial model, rather than purely a medical one. The first component of the ICF is the disability itself, a SCI in this study, and involves difficulties with function at three different levels; namely the impairment, activity and participation level. The limitations caused by impairments (e.g. pain) or activities (e.g. transfers) could ultimately effect the participation level of a person with a disability, and poor participation could equally effect function and result in more impairments (WHO, 2002). Participation is thought to be related to QOL, with participation providing positive feelings of being valued, esteemed and a sense of belonging and purpose (Müller et al. 2017).

In the context of this study using the ICF, pain following SCI is the health condition, and community re-integration is a measure of participation. The second component, personal and environmental factors are specific to the patients' background and can be either a facilitator or a barrier to their participation (WHO, 2002). Therefore, two patients with the same disability may have very different outcomes in terms of their health and level of participation in their community due to potential facilitators (motivation, accessible environment) and barriers (lack of social support, lack of transport) (Mothabeng 2011).

2.2 Overview of Spinal Cord Injury

A spinal cord injury (SCI) is damage to the spinal cord which can result in irreversible damage to the motor, sensory and autonomic nervous systems. There is a disruption of communication from the brain to the rest of the body and as a result, the spinal cord cannot perform its usual functions distal to the site of injury (Nas et al. 2015). Further to this, autonomic regulations of the body such as maintaining blood pressure, temperature control, breathing ability, bowel and bladder function as well as sexual function may also be affected (Harvey 2016). All these autonomic dysfunctions, with varied motor and sensory loss below the level of the injury, results in a significant change in the body. This may result in severe or mild disability but can have a lasting impact on the person's physical function, psychological health and social well-being (Harvey 2016).

People with spinal cord injuries (PWSCI) present in various ways depending on the location and the severity of the lesion. There can be a complete loss of sensation and motor function below the level of the injury or partial innervation of sensation and/or motor function. The International Standards for Neurological Classification of SCI, with the American Spinal Injury Association (ASIA) is used in many spinal units to classify the extent of a SCI. To classify these lesions as complete (ASIA A) or incomplete (ASIA B, C, D or E) the preservation of bowel and bladder function at S4 and S5 dermatomes and myotomes, is the determining factor. Lesions in the cervical spine, C1 – C8, affect both upper limbs and both lower limbs in varying ways of paralysis and are classified as quadriplegia. Lesions in the thoracic, lumbar or even sacral spine will cause varying degrees of paraplegia, which can include paralysis to parts of the trunk and both lower limbs (Nas et al. 2015).

There are many causes of SCI and they may fall under two major categories, traumatic and non-traumatic. Traumatic injuries may be as a result of motor vehicle accidents, falls and gunshot wounds. In Cape Town, South Africa, the main cause of traumatic injury was assault, especially in the younger age groups, age 18 – 45, with all age groups accounting for almost 60% of injuries (Joseph et al. 2015). This may be due to exposure to violent crimes, with gang cultures and criminal gang activities that are rife in Cape Town compared to other provinces (Phillips et al. 2018). For instance, traumatic causes of SCI in Gauteng is due to MVA more than anything else, due to the congested roads. Non-traumatic causes, such as tumours, are related to an underlying pathology. There is little research on the prevalence of both traumatic and non-traumatic SCIs in South Africa, but it's thought that non-traumatic cases have been on the increase due to the high numbers of HIV and TB in our population. HIV positive patients may present with spinal tuberculosis and therefore paralysis and incontinence (Candy et al. 2014). Pefile et al. (2019) found more non-traumatic SCI and in females in KZN, from infective

spondylitis due to the high numbers of HIV in this area. Furthermore in South Africa, research on the incidence of SCI's is limited. A study by Joseph et al. (2017), reported annual incidence at a rate of 75.6 per million persons, however, this only included traumatic spinal cord injuries, over the age of 18 years, done in the city of Cape Town in a certain catchment area, and in a government setting. Another study one year later, found the incidence to be 20 per million persons within the same area and with the same inclusion criteria, but in the private sector (Phillips et al. 2018).

The global incidence of SCI in 2013 according to the WHO was 40 to 80 per million. In a worldwide review conducted by Kang et al. (2018) incidence in high income countries ranged from 13.1 to 163.4 per million people, and 13.0 to 220.0 in low-income countries. It is thought that low to middle income countries have a higher incidence and prevalence rate compared to high income countries due to variables in medical services, science and technology, economic and geographical conditions (Kang et al. 2018). Poorer infrastructure with reduced economic and social conditions and decreased implementation of safety regulations increases the risk of potential traumatic causes of injury. This increased incidence and prevalence increases the strain on the healthcare system in South Africa, especially where PWSCI require a multi-disciplinary approach.

A PWSCI requires care at many stages. Ideally, after acute management, PWSCI will attend rehabilitation units to maximise their function, considering their level of injury, and environmental and personal factors (following the ICF Model). The rehabilitation approach should be patient centred, and specific goals are set for the patient with a multi-disciplinary team (Harvey, 2016). Rehabilitation should also be a progression, and can follow the outcomes based approach, where there are six chronological levels through which an individual should advance during the rehabilitation process (Hassan et al. 2012). In the initial stages, level II, education regarding their condition should be covered, management strategies for bowel and bladder function and sexual function needs to addressed and patients are also supported psychologically for their mental health. For thorough discharge planning, proper carer training and home programmes should be done to ensure a safe discharge into the home environment, to achieve residential re-integration, outcome level III. Rehabilitation services may continue with possible vocational rehabilitation, and out-patient therapy with ongoing primary care in terms of medication and equipment (Fehlings et al. 2017). During the chronic stage where PWSCI are working towards being integrated back into their communities (outcome level IV) and potentially productive (outcome level V) and leisure activity, ongoing rehabilitation and health maintenance are required. In this time, prevention of secondary complications, activities specific to community mobility, managing finances, health appointments and medication, as well as other social and leisure activities are targeted (Hassan et al. 2012). Effective long-term

rehabilitation involves input from multiple healthcare providers and hospitals or clinics. However, community rehabilitation and follow up of patient's post-discharge from the in-patient setting does not always occur. Programmes to ensure ongoing health care, health education and access to equipment and medication to prevent and avoid secondary complications are important to develop. This will potentially aid in reducing the cost of care and ensure that PWSCI will maintain healthy lifestyles, with improved participation and QOL (Pilusa et al. 2021).

2.3 Secondary complications of Spinal Cord Injury

SCI, whether traumatic or non-traumatic; high-level lesions or low-level lesions, not only have a significant impact on a person's function but also lead to the possibility of many secondary health conditions (SHCs). Secondary health conditions can be an impairment, a functional limitation, or may result in other health conditions such as cardio-vascular disease and diabetes (Jensen et al. 2013). These secondary health complications can be debilitating and some even life-threatening like pressure sores or respiratory infections. Secondary health conditions are thought to be preventable by health professionals (Piatt et al. 2016), but still occur with up to 66.1% of participants reporting SHCs as an ongoing concern. Secondary health conditions often limit the rehabilitation progress a PWSCI has made, or make their usual functioning more difficult, affecting activities of daily living, mobility and work. Secondary health conditions have been shown to not only affect a person's function, but also their mental health, personal behaviour and QOL (Pilusa et al. 2021). Jensen et al. (2013) found that pain, bowel and bladder regulation problems, muscle spasms, fatigue, heartburn and osteoporosis were the most common SHCs identified. These SHC's occurred at a greater frequency in individuals with SCI compared to healthy individuals, and also at a higher rate in the older population with SCI compared to younger individuals. Similarly, out of 29 common SHCs experienced by a SCI population in the USA, the four most problematic areas reported by participants were bladder issues; 30.4%, pain; 28.6%, bowel issues; 10.7%, and pressure sores; 5.4% (Piatt et al. 2016). Furthermore, 75% of participants expressed that their top rated SHCs impacted their social participation, 64.3% reported an effect on their daily life and a quarter of the participants felt their SHC was unavoidable.

Pain as a secondary health condition

Pain affects 70% of PWSCI, with one-third experiencing severe, disabling pain (Hadjipavlou et al. 2016; Jang et al. 2014). Pain can develop shortly after a SCI or years down the line. Chronic pain, which is pain that lasts longer than three months in PWSCI has been reported in many studies (Burke et al. 2019, Hadjipavlou et al. 2016; Donnelly and Eng. 2005) and is associated

with poorer sleep and depression (Avluk et al. 2014). Experienced pain may depend on certain activities as well as on the psychosocial environment (Hagen and Rekand. 2015). For example, low mood or cold weather may make one perceive pain as more intense. People with SCI can experience both nociceptive and neuropathic pain, and at varying intensities. Burke et al. (2019) reported that nociceptive pain affected 'activities' the most, according to the International Spinal Cord Injury Basic Pain Data Set (ISCIPDS:B), while neuropathic pain affected sleep the most. It is therefore important to distinguish between the two types of pain, assess them separately and completely, as they should be managed both medically and therapeutically in different ways.

2.3.1 Neuropathic pain

Neuropathic pain has been described as the most severe pain post SCI (Afsar et al. 2014). Furthermore, of 53% participants that experienced neuropathic pain during their in-patient stay, 78.3% of those still experienced pain more than 17 months post discharge (Afsar et al. 2014). This was a similar finding in a study done by Hagen & Rekand (2015), which showed that participants' neuropathic pain increased over time up to 12 months post injury. Burke et al. (2019) found that participants in a community setting, who experienced neuropathic pain had more severe pain, more days with pain, increased medication use and more consultations with health care professionals than those who experienced nociceptive pain. Neuropathic pain interfered not only with activities, mood and sleep, but also with social, recreational and family related activities (Burke et al. 2019). This ongoing pain affects QOL, with neuropathic pain leading to a poorer QOL when compared to nociceptive pain, and pain severity correlated to poorer QOL, regardless of the type of pain (Burke et al. 2019). People suffering from chronic neuropathic pain have expressed that they do not want to further burden their family and friends by discussing or expressing their pain and that they could only confide in others who truly understood their pain (Hearn et al. 2015). This fear of how pain may impact social relationships could lead to further withdrawal and isolation from society. It is therefore clear that neuropathic pain not only affects the physical function of a person but has a negative impact on the psychological and social aspects of a person's life.

2.3.2 Nociceptive pain in the shoulder

After sustaining a SCI, the ability to be mobile is provided using a manual wheelchair, especially in people with paraplegia. Long term wheelchair users are required to use their upper limbs for all aspects of their function and mobility, therefore putting their shoulders, elbows, and wrists at risk for overuse injury (Mason et al. 2020). The shoulder joint is one of

the most common sites of injury with a reported incidence of 32% - 78% in manual wheelchair users (MWU) (Morrow et al. 2010). The shoulder is also a highly mobile joint, and therefore susceptible to pain, where pain incidence and severity was shown to increase with time since injury (Jensen et al. 2013; Cratsenberg et al. 2015). The cause of shoulder pain can be due to overuse, weight-bearing through the upper limbs, muscle imbalances and poor posture and technique used when propelling the wheelchair. Impingement of the shoulder is likely to occur during wheelchair propulsion and scaption; a movement where the arms are lifted forward from the sides of the body, at a slight angle (Mozingo et al. 2020). Other causes of pain include rotator cuff tears and tendinopathy, bursitis, joint oedema and glenohumeral instability, which may result in reduced physical activity and ultimately lead to reduced independence and poorer QOL (Mason et al. 2020).

In a study by Kang et al. (2019), the shoulder joint was the most reported site and occurrence of pain in both paraplegic's and quadriplegics, but the presence of pain was not correlated to function. This was different to results found in a previous study done by van Drongelen et al. (2006), where upper limb pain and shoulder pain were significantly inversely related to functional outcome and muscle strength was significantly inversely related to shoulder pain. Both studies used a similar nominal scale for rating pain, and so the participants subjective response to pain, and therefore the severity of pain could have been vastly different in each study. The different demographics, one being Korean and the other Dutch, could also influence whether participants had to work through pain or if they could stop their normal function and address their pain.

Interestingly, strong predictors for pain one year after in-patient rehabilitation included musculoskeletal pain at the beginning of rehabilitation and increased body mass index (van Drongelen et al. 2006). This has important implications when considering the treatment during in-patient rehabilitation of SCI and the effects on independent functioning and potential re-integration. Pain management may be required with less intense exercises to not overload the joint. Even though the emphasis is on optimising function, physiotherapists need to be able to treat a variety of conditions that a PWSCI presents with, even though their primary condition is neurological (Harvey 2016).

2.4 Community Re-integration post Spinal Cord Injury

Following the ICF and an outcomes-based approach, community re-integration is one of the rehabilitation levels that is addressed, namely outcome level four, out of five different levels (Hassan et al. 2015). Level four is associated with a level of function that a person performs in their community, including community mobility, social aspects, and managing their own affairs

and finances. These outcome levels are progressive, and most people with disabilities will achieve outcome level four in an out-patient rehabilitation setting once they have ideally integrated back into their home environment post discharge. Hassan et al. (2015) found 65% of stroke survivors were discharged at outcome level three (residential re-integration) compared to 21% discharged at outcome level four. Community re-integration is a major goal for any person with a disability and this is especially true in someone living with SCI (Mothabeng, 2011). Regaining life roles, maintaining relationships and finding a sense of purpose is vital for integration back into the community, and is related to life satisfaction and QOL. Participation in activities outside of the home allows for these important connections (Barclay et al. 2016). In South Africa, the National Rehabilitation Policy (NRP, 2000) has been developed, and its core principles focus on "enabling people with disabilities to enjoy equal opportunities, participate socially, and become integrated members of society" (Joseph et al. 2016). Therapists and PWSCI want to achieve this meaningful outcome where the person living with an SCI returns as close as possible to their pre-injury level. Often self-care and aspects of mobility are the main focus of rehabilitation to minimize functional limitations and these goals are achievable. However, re-integrating into the community which ultimately allows for improved QOL, is complex and still a challenge for many in the disabled population (Mothabeng 2011). When living with a SCI, people do not only suffer from the injury itself and potential secondary health conditions, but from a variety of external barriers that limit their participation in the community and workplace. These barriers can be from many causes which PWSCI may experience for years after their SCI (Silver et al. 2012).

There are multiple barriers to community re-integration such as environmental, social, health issues, employment and economical barriers as well as mobility aids/equipment barriers (Akter et al. 2019; Barclay et al. 2016). More specifically, in Cape Town, South Africa, participants described their journey to participation as one "dominated by obstacles". These included challenges in the physical environment including both the outdoor terrain and the built environment. (Joseph et al. 2016). Barriers to the physical environment included limited access to buildings, accessible toilets and small spaces in shopping centres. It also included a lack of adaptability to the outside terrain, especially in the rural areas. This was a similar finding in Australia, where even recently built buildings and parks were inaccessible to users in manual wheelchairs (Barclay et al. 2016). Secondly, participants described the able-bodied(s) negative attitude towards them in society. Unsupportive negative attitudes from the greater society, a lack of sensitisation to disability and stigmatisation have been found to decrease the quality of engagement in the community and isolate PWSCI (Mothabeng 2011; Joseph et al. 2016; Barclay et al. 2016). Participants also described "system deficiencies." In this division of system

deficiencies, the main report was lack of public transport; discrimination of those in wheelchairs when using public transport, paying extra for the wheelchair when you do get transport and the inconsistency of available transport (Joseph et al. 2106). This hugely affects participation if you cannot reliably get to work, shops or religious and leisure activities. This finding was similar in a study done in the Tshwane metropolitan area, where transportation especially out of town had the greatest impact on participation for PWSCI (Mothabeng 2011). Difficulty with transportation can further limit the geographical distance travelled, and therefore effect's a person's ability to get to their necessary health appointments and services (Silver et al. 2012). Barclay et al. (2016) found that in a high-income country, PWSCI using private transport in Australia expressed difficulty with finding appropriate parking with the correct size, design and location (Barclay et al. 2016).

The financial status of a PWSCI or availability of financial support has been shown to affect many aspects of community re-integration. The ability to return to or commence studying due to financial ability showed a positive influence on community re-integration (Mothabeng, 2011), and the opposite was true. Funding influences the equipment a PWSCI receives. A specialised wheelchair required for a certain environment or type of injury could be a potential facilitator to community re-integration (Barclay et al. 2016). However, often appropriate wheelchairs are not provided due to funding limitations, therefore causing a decrease in mobility which can increase dependency on others and further affects social roles (Silver et al. 2012).

Mothabeng (2011) found only 20% of participants expressed satisfaction with their community participation. Some personal factors were found to have a positive effect on community re-integration. These included having a higher level of education, living in a suburban area as opposed to a township or farm, and employment. Participants who had access to these supporting factors perceived barriers to community re-integration as low. However, majority of the population living in this area, and even South Africa as a whole, do not come from an advantaged socio-economic background. StatsSA shows 50,5% of individuals aged over 20 have a grade 12 qualification, 11.7% live in informal dwellings, and 52,4% of household income came from salaries (Maluleke, 2021).

One of the facilitators to community re-integration is social support, from family and friends but also from peer supporters, again described in all three mentioned studies. Peer mentors provided PWSCI hope, and peer mentors matched similarly to gender, personality and injury level allowed newly acquired PWSCI ability to gain physical skills needed as well as the confidence to mobilise into their community (Barclay et al. 2016; Joseph et al. 2016). The "insider" information, someone who has themselves experienced a SCI, provided much needed support to the newly injured person. This support can come in the form of emotional

support (Mothabeng 2011), allowed for information sharing on sensitive topics, gaining a potential friend and possibly becoming a mentor themselves and advocating for improved policies to assist in participation and community re-integration (Joseph et al. 2016). Participants further explained that success in navigating obstacles to community re-integration required strong personal factors like internal motivation and the ability to resist exclusion (Joseph et al. 2016). A positive outlook and eventual acceptance of their disability also aided in better community re-integration (Mothabeng, 2011).

2.5 Pain and community re-integration

After observation of both pain and community re-integration literature, it can be hypothesised that pain may, in some way, may influence community re-integration (Müller et al. 2017). In a study where participants were followed for one year post discharge from acute rehabilitation, pain was not identified as the most frequently occurring barrier to community re-integration, but the prevalence of pain considered as a barrier in daily life progressively increased during the year (Silver et al. 2012). This could potentially continue over time and ultimately affect community re-integration. Similarly, in a qualitative study done in Bangladesh, participants spoke about their experience with barriers that influence their participation. Although health-related problems were rated the fifth most common barrier, pain and bowel and bladder function (72%) were the most common barrier in the division of health-related problems (Akter et al. 2019).

In a study done by Donnelley and Eng, (2005) pain frequency, intensity and impact were investigated on admission, discharge and at six months of community living. It showed 86% of individuals still had pain at six months of community living; 19% of them reported severe pain, and 27%, reported pain that interfered with many or most activities. Additionally, a moderate correlation was found between pain and community re-integration, with severity of pain accounting for the biggest difference in the outcome measure, reintegration to normal living index. A more recent study, conducted in Canada by Noreau et al. (2021), investigated the perceived limitations of neuropathic pain, and correlated that with 26 specific activities, using the Person-Perceived Participation in Daily Activities Questionnaire while considering the severity of the injury. Many of the daily activities were relevant to community participation, including use of transport, carrying out financial or civic duties and communicating with others. It was found that these items were most likely affected and “not done as much as wanted to” due to the presence of neuropathic pain. This study is limited to only neuropathic pain and was carried out in a high-income country. It included people with quadriplegia, where the severity of the injury may have also had an impact on the reduced participation, and not due to pain alone. Mulroy et al. (2011) found that participants with chronic pain of moderate to severe

intensity, reported “higher participation restrictions (p < 0.001) and lower frequency of participation (p < 0.001)”, compared to those with mild or no pain. It included participants of both tetraplegia and paraplegia as well, although almost two thirds were paraplegic, with a mean of 14 years post injury.

2.6 Management of Spinal Cord Injury pain and community re-integration

Community re-integration is important, yet there is limited evidence on the treatment or management of pain with the aim to improve community integration and participation. Due to the complex physical and psychosocial causes of pain, the management of SCI pain requires a multidisciplinary approach. Chronic pain is challenging to treat, both from the perspective of the patient, as well as from the health care provider. Although there are various management interventions available such as psychotherapeutic and physiotherapeutic interventions, the most common approach to treatment is with the use of pharmaceuticals. However, one type of medication often yields poor results and multiple medications may be costly and lead to more severe and several side effects, including sedation and nausea (Hearn et al. 2015). Patients may be dissatisfied with their treatment regime, and have reported an ongoing battle, particularly with neuropathic pain, loss of faith in the healthcare system and loss of hope with no control over their pain (Hearn et al. 2015, Burns et al. 2013).

This leads to determining and understanding other forms of pain management, mostly physiotherapy. There are a variety of treatment modalities to treat pain, but is this management of pain in PWSI for pain’s sake only, or does it change the way PWSCI can perform daily activities and community re-integration? An appropriate option for people living with chronic neuropathic pain is pain education. This may aid in facilitating an individual’s ability to cope with pain, by an improved response and behaviour towards pain. Cognitive behavioural therapy has shown to have positive results in people with lower back pain and this approach can be implemented in PWSCI. However, a good programme may require collaboration between chronic pain specialists and SCI specialists of various occupations (Perry et al. 2011). In Australia the traditional cognitive behavioural programme (ADAPT) was adjusted in order to accommodate specific needs of individuals with PWSCI. For example, pain education required a new element that related to pain post SCI. This therefore became quite a complex programme to develop and implement and may not be generalisable to different settings, and to all SCI patients (Perry et al. 2011). Although pain severity did not change, a mutli-disciplinary programme consisting of pain education, cognitive behavioural therapy, self-management strategies and exercise specific to PWSCI, showed an increase in learning and wanting to

maintain coping strategies for pain. This then allowed for more control over pain, with less pain interference in daily life (Burns et al. 2013). Similarly, a randomised control trial showed that a multidisciplinary cognitive behavioural programme for neuropathic pain, showed a significant decrease in pain related disability, as well as an increase in participation from end of intervention to three and six month follow up (Heutink et al. 2012). One limitation was the initial scores of participation of the control group were higher than the intervention group. But this study only completed 33 hours of intervention, compared to others of 45 or 50 hours, and still yielded positive results (Heutink et al. 2012).

Although pain in the shoulder may present similarly in patients with and without a disability, research regarding the management of shoulder pain in MWU's is limited. A scoping review by Mason et al. (2020) looked at the management of shoulder pain in MWU's and found only 21 articles, compared to a similar study (Steuri et al. 2016) in non-wheelchair users that reviewed 177 articles. Conservative interventions included mostly exercise based programmes, with strengthening and stretching home exercise programmes. Two articles looked at education, one on wheelchair fitting and propulsion and the other on upper limb preservation. Furthermore, only three studies explored a multi-disciplinary approach to treat shoulder pain (Mason et al. 2020). Exercise for shoulder pain in MWU's with SCI is effective in pain relief (Cratsenberg et al. 2015), but what is that impact on functional abilities and community reintegration? A randomised control trial by Mulroy et al. (2011) used both exercise as well as movement optimization in a 12-week home-based programme for paraplegics with shoulder pain. Shoulder pain decreased by a third post-intervention compared to the control group and was maintained at the four week follow up. Community participation and subjective QOL improved ($p = 0.03$ and $p = 0.04$) respectively (Mulroy et al. 2011).

More studies are required to look at the potential benefits of pain management on community re-integration, using standardised outcome measures. Potential benefits may also include looking at interventions early on to improve community re-integration.

2.7 Conclusion

Pain is evidently a common secondary complication of SCI, and for a variety of reasons, is difficult to manage. Due to different cultures and the subjective nature of pain, as well as varied opportunities in high-income countries versus low-income countries, it will be beneficial to discover the impact of pain on community re-integration. Understanding how pain affects community re-integration may influence the way in which we treat pain in PWSCI in South

Africa, and ultimately influence community re-integration and QOL. There is evidence to suggest that pain negatively influences community re-integration. However, to the knowledge of the researcher, there is no South African study to show the two different types of pain, and where behaviour towards pain may be different. This current study includes both types of pain, includes manual wheelchair users only who are potentially more able to access their community, and includes PWSCI in both the rural and urban setting. The following chapter will describe the methodology of the study in detail.

CHAPTER 3: METHODOLOGY

3.1 Type of Study

This was a quantitative study design which involved secondary data analysis (Johnston MP 2014) from an existing database. This secondary data analysis is of data collected during a quantitative study, with a correlational design. This research report includes details of the primary study's methods to provide background for this secondary data analysis.

3.2 Data and Participants

3.2.1 Source of Data

The data necessary for secondary analysis in this study was sourced from primary data that was collected for a PhD study entitled "*The presence of pain and its impact on functioning and disability in manual wheelchair users with spinal cord injury: a framework for self-management*". The primary researcher collected data on pain (presence of and medication use), wheelchair function, QOL, community reintegration, as well as a scapular dyskinesis and pectoralis minor muscle length. Only the relevant data on the presence and absence of pain as well as community reintegration data was used and reported in this research report. Furthermore, data pertaining to community reintegration from the above-mentioned study has not been previously analysed nor published.

3.2.2 Source of participants

The data that was analysed for this study was from participants that were included in the primary data collection. The participants were patients that were rehabilitated in government and private rehabilitation centres in Gauteng. Namely,

- Steve Biko Academic Hospital
- Tshwane Rehabilitation Hospital
- Summit Rehabilitation, Muelmed Hospital (MediClinic)
- Kalafong Hospital
- Dr George Mukhari Hospital

Participants in the primary study were only included if they lived within a 500km radius from their discharging hospitals, with all participants residing either in Gauteng, Limpopo, Northwest and Mpumalanga. Therefore, participants living environments will vary and include townships, rural and urban areas, and suburban areas. According to Stats SA, majority of informal dwellings are found in Gauteng and North West, whereas in Mpumalanga, 89.8% lived in

formal dwellings (Maluleke, 2021). Due to the nature of the study (face-to-face in the community), potential participants residing beyond the 500km driving distance were excluded from the study.

3.2.3 Sample Selection

The sample selection for this secondary data analysis was based on the number of participants that were included in the primary study. In the primary study, the sample size was determined using the events per variable approach (Peduzzi et al. 1996). The variables included were age, gender, occupation, duration of SCI, neurological level of injury, completeness of injury, pectoralis minor length and scapular dyskinesis. Using this calculation, EPV > 5, i.e. number of events > 5 x 8 = 40, therefore sample size equals 40/0.35, i.e. at least 115 participants were required. The primary researcher collected data from 122 participants.

Inclusion Criteria in the primary data

- All adults with T2 and below paraplegia irrespective of aetiology, classification and completeness of injury.
- Six months post discharge to allow for optimum levels of independency and for soft tissue changes in the shoulder to occur.

Exclusion Criteria in the primary data

- Patients who were re-admitted due to any secondary complications during the time of the primary data collection.

Inclusion Criteria in this study

- All available data from the 122 participants were included for this secondary data analysis.

3.3 Instrumentation and Outcome Measures

Measurement Instruments: The primary data was collected through face-to-face questionnaires, that included: A sociodemographic and injury profile questionnaire, the reintegration to normal living index (RNLI) questionnaire, the DN4 questionnaire and the Wheelchair User's Shoulder Pain Index (WUSPI).

Sociodemographic tool: This was used to determine the participant's demographic and injury profiles, including age, gender, age at time of injury, gender, cause of injury, where participants lived and who they lived with. It also included questions regarding the participant's current pain, number of painful areas and severity of pain (Appendix A). Yes/No frequency calculation was

done to the question ‘Do you currently have pain’ (not verbatim), and the numeric pain rating scale (0-10) was used to determine the severity of the pain.

The RNLI questionnaire: This was used to assess the degree to which participants feel they are reintegrated into normal social activities (Appendix B). The administration time is approximately 10 minutes, where 11 declarative states covering aspects of mobility, self-care, daily activity, recreational activity, and family role are included. Each question is scored on a numeric scale with statements, from zero – 10, with zero representing no reintegration and 10 representing complete re-integration. The total score is then converted to a percentage score to determine the level of perceived integration into the community. The RNLI is a reliable and valid measure for community re-integration for people living with SCI and is validated in the South African context (Mothabeng et al. 2012).

The DN4 questionnaire: This was used to determine whether participants experience neuropathic pain or not (Appendix C). It is a 10-item questionnaire totalling a score out of 10. Seven questions are related to the type of pain, and three questions are related to a clinical exam. Participants are required to give a ‘yes/no’ response, and the cut off value to diagnose neuropathic pain is a minimum of four out of ten (Bouhassira et al. 2005). Although the DN4 has been validated and is able to diagnose neuropathic pain with high accuracy (Hallstrom and Norrbrink, 2011), its psychometric properties have not yet been tested in South Africa.

The WUSPI: The WUSPI measures shoulder pain in wheelchair users during functional activities, including transfers, wheelchair mobility, self-care and general activities (Appendix D). It contains 15 questions rated on a numeric scale. In order to accommodate for items that were not applicable, the WUSPI Performance corrected score was calculated, where the total score was divided by the number of items that were performed, multiplied by 15. The WUSPI has been proven to be reliable and valid for people with SCI (Curtis et al. 1995) and is yet to be validated for the South African context.

3.4 Procedure

A letter to the gatekeeper of the primary data to request permission to use their data in this study was sent. Permission to use the intellectual property was received from the database gatekeeper, as well as from the technology transfer manager of the University of Pretoria (Annexure E). The gatekeeper then extracted the data, and extracted data was checked by the primary study PhD supervisors to ensure that only the relevant data was extracted. Once

received, the extracted data was cross checked by the researcher to ensure no data was missing. A coding sheet was used to save the full dataset, and all data was anonymised in accordance with ethical standards. No missing data was noted. Thorough analysis was then conducted by the researcher in order to meet the objectives mentioned in 1.3.2.

The primary data was collected as described below:

Primary data was collected from February 2019 – March 2020. Patient contact details were obtained from the relevant hospitals and the procedure for collection of patient data was as follows:

- Initial verbal consent was obtained from potential participants via telephonic contact to participate in the study. A meeting was then set up to commence data collection.
- An information sheet was emailed or texted to participants where possible prior to the appointment/meeting date.
- The primary researcher travelled to the participants' preferred location, either their homes, workplaces or at their discharging hospitals on the days of their follow up appointments.
- Written informed consent was obtained in person during the visit and participants were allowed an opportunity to ask any questions they may have had.
- The researcher asked each participant the questions of all questionnaires stated in 2.3 to allow for consistency of interpretation of the questions.
- The primary researcher was fluent in three languages, and no language barriers were encountered.
- The primary researcher captured all information and there were no instances that required data cleaning, such as incorrect, duplicate or incomplete data.
- The primary data is available on the University of Pretoria repository https://repository.up.ac.za/handle/2263/86353 and signed consent forms are available from the Physiotherapy Department of the University of Pretoria.

3.5 Ethical Considerations

This current study has received unconditional ethical permission from the Human Research Ethics Committee of the University of Witwatersrand (Appendix F). Permission to use the data was obtained from the primary researcher and technology transfer manager of the University of Pretoria. All information obtained in this study will remain confidential. There is already existing ethical clearance for the primary study, which was obtained from the Faculty of Health

Science Research Ethics Committee of the University of Pretoria (Appendix G). Hospital permission from the relevant hospitals was also obtained to access their databases (Appendix H). Participants completed written informed consent to participate in the original study, and copies of these informed consents have been stored for safekeeping at the Physiotherapy department of the University of Pretoria. Participants were not penalised or prejudiced for leaving the study at any time and no cost to the participants was incurred.

3.6 Data Analysis

Secondary data analysis was performed using the SPSS version 28. Descriptive data was analysed for participants demographic and injury profile. A test for normality was completed of the RNLI percentage scores, which showed that data was not normally distributed. Therefore, non-parametric testing was used to meet the objectives.

Objective 1: Inferential data analysis using Mann Whitney U test was performed to determine differences between those with pain and without overall pain with regards to their community reintegration.

Objective 2: Inferential data analysis using Spearman correlation (r) was performed to assess the associations between the presence of shoulder nociceptive pain and community reintegration.

Objective 3: Inferential data using a Linear regression test was performed to determine associations between the presence of neuropathic pain and community reintegration.

Objective 4: Bi-variate linear regression and Spearman correlations were performed to determine if severity of pain influences community reintegration.

All testing was done at the 0.05 level of significance and 95% confidence intervals. All correlations reported in this research report are done in the following manner (Safrit & Wood, cited in Zhu 2012):

- No correlation: r = 0 – 0.19
- Low correlation: r = 0.2 – 0.39
- Moderate correlation: r = 0.4 – 0.59
- Moderately high correlation: r = 0.6 – 0.79
- High correlation r = ≥ 0.8

3.7 Conclusion

The study's design, aims and objectives, sample size and inclusion and exclusion criteria have been presented in this chapter. The primary study's procedure and method of study have been described, as well as the current study's method, data collection process and statistical analysis. The results of the statistical analysis completed is presented in Chapter 4.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter will report the findings of the study. It includes a full sociodemographic and injury profile of participants, as well as descriptions of participants pain and community re-integration. All inferential results from the data analysis are presented to meet the objectives of the study. Data has been presented in tables and figures.

4.2 Sociodemographic and injury profile

A total of 122 participants were included in this secondary data analysis, 83 (68%) were males. The mean age of participants was 39.7 years (SD 11.1) with mean age of injury being 32.60 years (SD 10.7). One hundred and four injuries were traumatic and 18 non traumatic. The most common cause of traumatic injuries was motor vehicle accidents, (41%), followed by gunshot injuries (26%). The most common neurological level of injury was T6-T12, accounting for 73.8%, with levels T6 as well as T12 being the most reported NLI, both n=25 (20.5%). Sixty-two (50.8%) participants have been living with their SCI for 1 – 5 years, and 34 (27.9%) for 6-10 years. Ninety-one (74.6%) participants are currently aged between 31 and 60 years, with a mean age of 39.70, which is the range of a working population. However, a total of 59% was unemployed. Fifty-six (45.9%) of the participants lived in the township area, and n=62 (50.8%) stayed with their own family. A full socio-demographic and injury profile is included (Appendix I), published in Mashola et al. 2022.

4.3 Pain presentation

Most of the participants, 85.2%, reported current pain with up to five simultaneous painful areas reported. The different pain locations are expressed in order of severity, with P1 being the most severe and P5 the least severe pain experience. Fifty-nine participants (48.4%) reported pain in one area, 34 participants (27.9%) in two areas, 7 participants (5.7%) reported three painful areas, 3 participants (5.7%) reported 4 painful areas and 1 participant (0.8%) reported 5 painful areas. Severity of pain 1 on the 0-10 numerical pain rating scale was at a mean of 6.7 (SD 2.25).

The DN4 questionnaire confirmed that 65 participants (53.3%) reported overall neuropathic pain. Participants described this neuropathic pain as burning (n=34, 32.7%), sharp/stabbing (n=20, 19.2%), or as pins and needles (n=13, 12.5%). According to the descriptions of pain behaviour and pain location given by participants, neuropathic pain was the most common type

of pain experienced in P1 (n= 75, 72.1%) and P2 (n=29, 27.9%), whereas nociceptive pain was more common in P3 (n=7, 6.7%) and P4 (n=3, 2.9%). The most

common pain for P1 was in the lower limbs below the level of injury (n= 41, 39.4%). For P1, other than neuropathic pain, the most common site for nociceptive pain was the back at the injury site (n= 11, 9%), and the upper back above the injury site (n= 10, 8.2%). For P2 (other than neuropathic pain), the shoulders were the next most common site, (n= 11, 24.4%), with shoulder dominant side being n=1 (2.2%), shoulder non-dominant side n=5 (11.5%) and bilateral shoulders, n=5 (11.1%). Only 18 (14.8%) of the participants overall reported shoulder pain when asked if they have shoulder pain or not. The non-dominant shoulder accounting for the most pain, n=8 (44.4%), bilateral shoulders n=6 (33.3%) and the least pain occurring in the dominant shoulder n=4 (16.7%). Of these 18 participants, 5 had shoulder operations for various reasons such as ORIF post shoulder dislocation, rotator cuff repair, or ORIF of the humeral head and humeral shaft due to a gunshot wound and fracture respectively.

See tables 1, 2, 3 and 4 below for a full description of pain presentation, pain severity, pain location and pain behaviour.

Table 4.1. Pain presentation

Pain summary	***n* = *122***	***%***
Current pain	104	85.2
Nociceptive shoulder pain	18	14.8
Neuropathic pain	65	53.3
One painful area	59	48.4
Two painful areas	34	27.9
Three painful areas	7	5.7
Four painful areas	3	2.5
Five painful areas	1	0.8

Table 4.2 Pain severity rating for P1

P1 severity – numeric rating scale	***(n= 104)***	***%***
1	1	1.0
2	3	2.9
3	3	2.9
3.5	1	1.0
4	5	4.8
4.5	2	1.9
5	20	19.2
5.5	1	1.0
6	15	14.4
6.5	1	1.0
7	10	9.6
7.5	3	2.9
8	10	9.6
8.5	1	1.0
9.0	12	11.5
9.5	1	1.0
10	15	14.4

Table 4.3. Pain location summary, P1 – P4

Location	P1 (n=104)		P2 (n=45)		P3 (n=11)		P4 (n=4)		P5 (n=1)	
	n	***%***	***n***	***%***	***n***	***%***	***n***	***%***	***n***	***%***
Headache	1		-	-	-	-	-	-	-	-
Shoulder (dominant)	1		1	2.2	1	9.1	1	25	-	-
Shoulder (non-dominant)	1		5	11.1	2	18.2	-	-	-	-
Shoulder (bilateral)	-	-	5	11.1	1	9.1	-	-	-	-
Elbow (s)	1		1	2.2	-	-	-	-	-	-
Wrists(s)	1		2	4.4	-	-	-	-	1	100
Hand(s)	1		-	-	-	-	-	-	-	-
Thorax/chest (lateral)	5		3	6.7	1	9.1	-	-	-	-
Abdomen	3		-	-	1	9.1	-	-	-	-
Upper back (above NLI)	10		3	6.7	1	9.1	2	25	-	-
Back (injury site)	11		3	6.7	1	9.1	-	-	-	-
Lower back (below NLI)	11		6	13.3	-	-	-	-	-	-
Lower back (above NLI)	2		1	2.2	-	-	-	-	-	-
Waist (below NLI)	3		1	2.2	1	9.1	-	-	-	-
Hips(s)	6		2	4.4	-	-	-	-	-	-
Buttock area(s)	4		1	2.2	1	9.1	1	25	-	-
Lower limbs (below NLI)	41		11	24.4	1	9.1	-	-	-	-
General body pain	1		-	-	-	-	-	-	-	-
Groin pain	1		-	-	-	-	-	-	-	-

**n= no. of painful areas, not number of people*

Table 4.4 Pain behaviour summary, P1 – P4 (Mashola et al., 2022)

Pain behaviour	**P1 (n=104)**		**P2 (n=45)**		**P3 (n=11)**		**P4 (n=4)**	
	n	**%**	***n***	**%**	***n***	**%**	***n***	**%**
No pain	0	0	59	56.7	93	89.4	100	96.2
Nociceptive pain								
Pulling	2	1.9	1	1	0	0	0	0
Thumping	1	1	0	0	0	0	0	0
Cramping	3	2.9	0	0	1	1	0	0
Deep pressure	6	5.8	1	1	0	0	0	0
Dull	5	4.8	0	0	0	0	0	0
Ache: Muscular	6	5.8	1	1	1	1	2	1.9
Ache: Joint	4	3.8	12	11.5	5	4.8	1	1
Throbbing	1	1	0	0	0	0	0	0
Indescribable	1	1	1	1	0	0	0	0
Total	**29**	**27.9**	**16**	**15.5**	**7**	**6.7**	**3**	**2.9**
Neuropathic pain								
Burning	34	32.7	11	10.6	3	2.9	1	1
Painful cold	1	1	1	1	0	0	0	0
Electric shocks	5	4.8	1	1	0	0	0	0
Tingling	0	0	1	1	0	0	0	0
Pins & needles	13	12.5	5	4.8	0	0	0	0
Stabbing	20	19.2	9	8.7	1	1	0	0
Stinging	1	1	0	0	0	0	0	0
Itchy	1	1	1	1	0	0	0	0
Total	**75**	**72.1**	**29**	**27.9**	**4**	**3.9**	**1**	**1**

**n= no. of painful areas, not number of people*

With regards to participants who experienced shoulder pain (n=18, 14.7%), the WUSPI showed that shoulder pain was most intense when pushing up a ramp or incline outdoors (Median = 6.0, IQR = 6.0) lifting objects from an overhead shelf, (Median = 6, IQR = 5) and while transferring into bath or shower (Median = 6.0, IQR = 4.75). Total scores for the WUSPI ranged from 3/150 – 129/150 (Median = 57.0, IQR = 62.0).

Table 4.5. Individual items of WUSPI, showing mean pain score out of 10.

WUSPI activity, ***n=18***	**Median**	**IQR**
Transfer from bed to WC	4.5	5.25
Transfer from wheelchair to car	4.5	7.25
Transfer from wheelchair to tub or shower	**6.0**	4.75
Loading your wheelchair into car	4.5	3.25
Pushing your wheelchair for ten minutes or more	6.0	3.875
Pushing up ramps or inclines outdoors	**6.0**	6.0
Lifting objects down from an overhead shelf	**6.0**	5.0
Putting on pants	0	6.25
Putting on t-shirt or pullover	0	6.50
Putting on a button-down shirt	0	2.0
Washing your back	5.0	3.0
Usual daily activities at work or school	6.0	6.25
Driving	2.5	6.75
Performing household chores	4.5	5.25
Sleeping	6.0	8.25
WUSPI total	57.0	62.0
WUSPI performance corrected score	61.5	74.0

4.4 Community re-integration

The total RNLI scores ranged from 41.5/110 to 110/110, with a median of 85.5 (IQR 21.88). The median total percentage for community re-integration is 77.73% (IQR 19.88) with a minimum of 37.72% and a maximum of 100%. The least area of integration is moving around the community as necessary, with a median of 7 (IQR 4) (Table 6). There were only slight differences in the participant's re-integration scores when comparing those with pain, median 77.27% (IQR 20.69) to those without pain, median = 80.7% (IQR 15.03) (Figure 1). With the addition of p=values to analyse the difference between the two groups across each item on the RNLI, The only significant value was found for RNLI item "I move around my living quarters as necessary." However, the higher score for this RNLI item is for participants with pain, therefore

disproving the hypothesis. All other items are not significant, suggesting the mere presence of pain does not influence community re-integration. (Table 6).

Table 4.6 RNLI descriptive statistics for total sample and individuals with and without pain (N=122)

	Total sample		**With Pain (n = 104)**		**Without Pain (n = 18)**		**p-value**
Reintegration to Normal Living Index item	**Median**	**IQR**	**Median**	**IQR**	**Median**	**IQR**	
I move around my living quarters as necessary	8.5	3.0	9.0	3.0	8.0	1.63	*0.040
I move around my community as necessary	7.0	4.0	7.0	4.0	7.0	3.25	0.892
I am able to take trips out of town as necessary	8.0	5.0	8.0	5.0	7.250	3.13	0.431
I am comfortable with how my self-care needs are met	9.0	3.0	9.0	3.0	8.5	4.0	0.751
I spend most of my day occupied in a work activity that is necessary/important to me	8.0	4.0	8.0	4.0	9.0	2.0	0.075
I am able to participate in recreational activities as I want to	9.0	4.0	9.0	4.0	8.5	3.25	0.731
I participate in social activities as necessary/desirable to me	8.0	4.0	8.0	4.75	9.0	3.25	0.399
I assume a role in my family which meets my needs and those of other family members	8.0	5.0	8.0	5.0	9.0	4.13	0.208
In general, I am comfortable with my relationships	8.0	5.0	8.0	5.0	9.0	4.25	0.435
In general, I am comfortable with myself when I am in company of others	9.0	3.0	9.0	3.0	10	2.0	0.179
I feel I can deal with life events as they happen	8.25	3.0	8.0	3.0	9.0	2.0	0.287
RNLI overall percentage	77.73	19.88	77.27	20.682	80.68	15.0	0.516

*. Significant at the 0.05 level

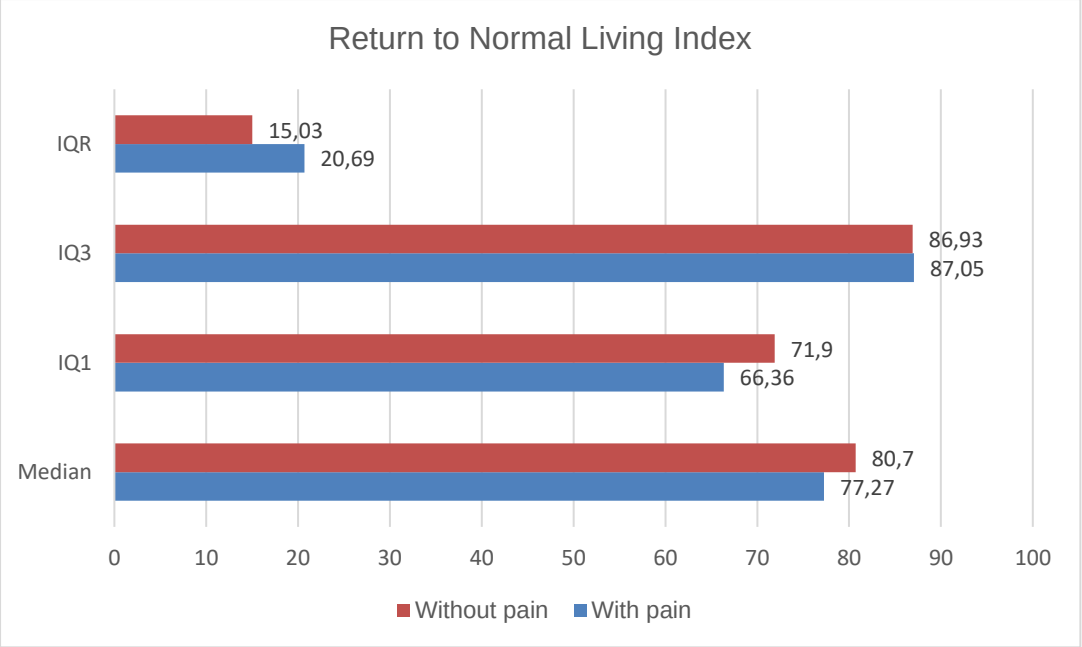

Figure 4.1. RNLI overall percentage descriptive statistics, comparing those with pain (N = 104) and those without pain (N = 18)

4.5 Associations of pain with community re-integration

A test for normality of community reintegration was completed. A histogram showed that data was not normally distributed (Figure 2), with the Shapiro-Wilk test result <0.05, indicating the data significantly deviates from a normal distribution (Table 5). Therefore, non-parametric testing was used to analyse data to meet the objectives.

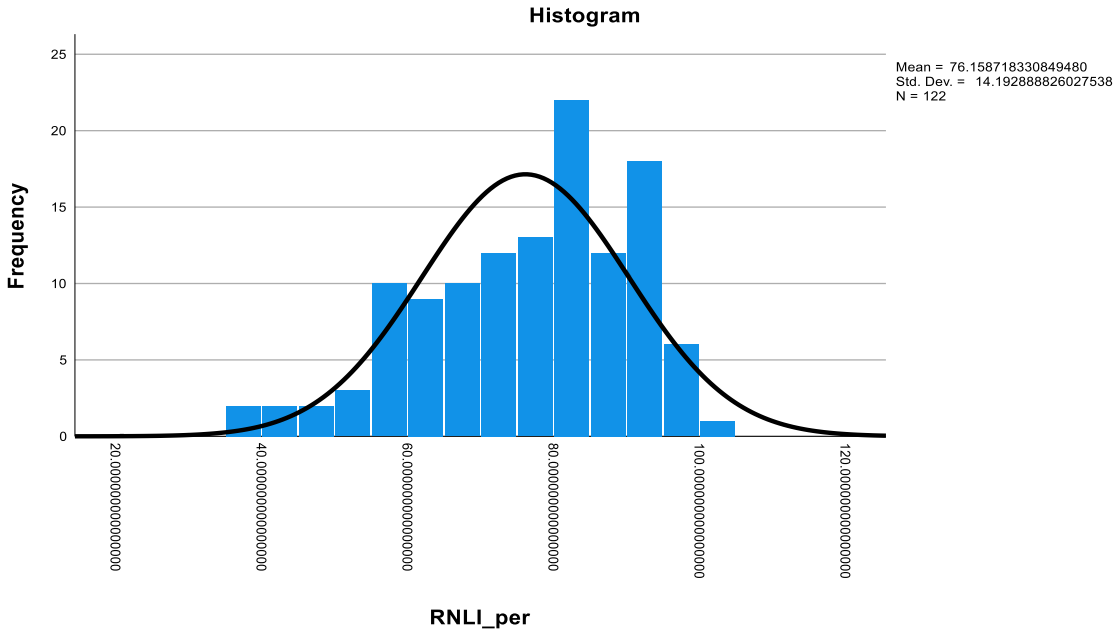

Figure 4.2. Histogram of RNLI percentage score

Table 4.7. Table test of normality for dependent variable, RNLI percentage score

	Kolmogorov-Smirnov[a]			**Shapiro-Wilk**		
	Statistic	df	Sig.	Statistic	df	Sig.
RNLI percentage	0,098	122	0,006	0,963	122	**0,002**
a. Lilliefors Significance Correction						

4.5.1 Presence of overall pain on community re-integration (Objective 1)

A Mann Whitney test was performed to determine the difference between participants with and without pain on community re-integration, percentage of RNLI. The results indicated a non-statistically significant difference between the groups, (U = 846.0, p = 0.516). Mann Whitney tests were also performed with participants who reported neuropathic pain versus those without, on the RNLI percentage, and the results were not significant, (U = 1494.50, p = 0.066). The test was repeated in participants with and without shoulder pain and the results also showed no significant difference between groups (U = 861.50, p = 0.591) (Table 8).

Table 4.8 The difference between participants with overall pain, neuropathic pain and shoulder pain, and those without, on community re-integration, using the RNLI percentage.

		Median	**IQR**	**p-value**
Overall pain	With pain (n=104)	77.27	20.68	0.516
	Without pain (n= 18)	80.68	15.0	
	RNLI percentage	77.73	19.88	
Neuropathic pain	With Nep (n=65)	76.36	21.82	0.066
	Without Nep (n=57)	81.82	18.41	
	RNLI percentage	77.73	19.88	
Shoulder pain	With Sh pain (n=18)	75.45	79.31	0.591
	Without SH pain (n=104)	79.31	20.57	
	RNLI percentage	77.73	19.88	

4.5.2 Nociceptive shoulder pain and community re-integration (Objective 2)

A Spearman correlation was done between WUSPI performance corrected score and RNLI percentage to determine if there was a relationship between shoulder pain and community re-integration. This test showed a non-statistically significant result with no correlation (r = -0.06, p = 0.499). These correlations were done with the full sample size, although only 18

participants out of the 122 expressed shoulder pain. Therefore, with only the 18 participants that did express shoulder pain, a Spearman correlation was done with WUSPI performance corrected score and RNLI percentage, to more accurately determine if there was a relationship between shoulder pain and community re-integration. This showed a low, negative correlation (r = -0.39, p = 0.115) which still shows a statistically insignificant result between shoulder pain during functional activities and community re-integration (Table 9).

Table 4.9. Spearman correlation between shoulder pain and community re-integration

	N = 122 (Full sample size)	**N = 18 (Those with shoulder pain)**
Correlation co-efficient	-0.16	-0.39
p-value	0.499	0.1115

Furthermore, Spearman correlation tests were done between all items of the WUSPI and all items of the RNLI, for participants with shoulder pain. The most significant correlation related to community re-integration was found between “experiencing pain while loading wheelchair into the car” and RNLI item, “able to take trips out of town as necessary” with correlation co-efficient r = -0.821 and a p-value of 0.045, indicating a negative high correlation. Furthermore, a negative moderate correlation was found between “pushing up ramps or inclines outdoors” and “taking trips out of town’, r = -0.546, p = 0.02. There were three other significant correlations related to self-care aspects and one to performing work activities.

- “Pain during transfer from wheelchair to tub or shower” and “I am comfortable with how my self-care needs are met” ; r = -0.650, p = 0.04 (negative moderately high correlation)
- “Pain during lifting an object from an overhead shelf” and “I am comfortable with how my self-care needs are met”; r = -0.721, p= 0.001 (negative moderately high correlation)
- “Pain during washing back” and “I am comfortable with how my self-care needs are met” ; r = -0.669, p = 0.01 (negative moderately high correlation)
- “Pain during usual activities during work/school” and “I spend most of my day occupied in a work activity that is necessary/important to me” ; r = -0.522, p = 0.03 (negative moderate correlation)

Other significant correlations were found but were not clinically relevant. E.g., “transferring from my wheelchair to car” and “moving around indoors as necessary.” The full correlation matrix between items of the RNLI and items of the WUSPI with p-values is presented in Appendix J.

4.5.3 Neuropathic pain and community re-integration (Objective 3)

A simple linear regression was used to test if having neuropathic pain resulted in lower scores on the RNLI. This showed no correlation (r = 0.19, p = 0.018), with a low predictor p-value of having pain resulting in lower scores of community re-integration (β = *-0.191,* p = 0.036). Furthermore, linear regression tests were done with neuropathic pain and all aspects of the RNLI. Although there was a trend towards less community re-integration with neuropathic pain, no sub-sections of the RNLI yielded any significant correlations.

4.5.4 Influence of severity of pain on community re-integration (Objective 4)

Although there was no significant difference between participants with and without neuropathic pain on their community re-integration (p = 0.066, Table 8), bivariate linear regression tests were conducted to confirm if neuropathic pain as the most common pain type of pain in P1, would predict reduced re-integration in the community. A scatterplot showed no specific trend between P1 severity and RNLI percentage score (Figure 3).

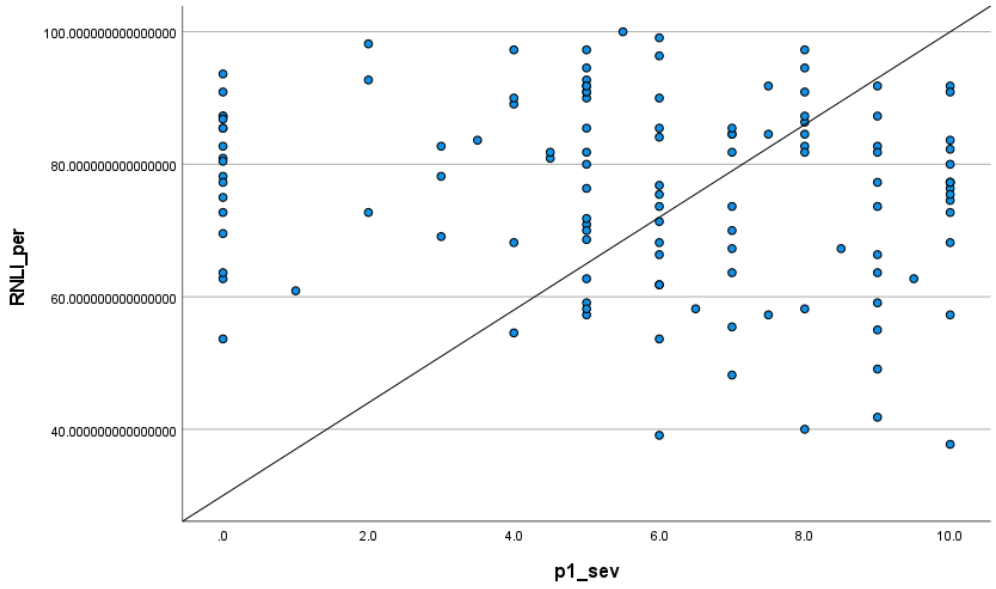

Figure 4.3. Scatterplot of P1 severity and RNLI percentage score

Findings revealed a negative and low correlation between P1 severity and community re-integration (r = -0.153, p-value = 0.046), suggesting that as pain severity increases, then community integration is poorer. However, the predictor p-value of pain severity is statistically insignificant (β = -0.686, p = 0.092), meaning pain severity was not found to predict community re-integration. Suggesting that although correlated, there may be other factors that predict community re-integration.

Further analysis using Spearman correlation tests was done between all items of the RNLI, including RNLI total and RNLI percentage score, with P1, P2, P3 and P4 severity to determine

if the severity of pain was correlated to community re-integration. P2 severity (identified as mostly neuropathic pain) showed a low negative correlation with moving around the community (r = -0.208, p = 0.022). P3 severity (identified mostly as shoulder pain), showed a low negative correlation with taking trips out of town, (r = -0.273, p = 0.002), and P3 also showed a low negative correlation with overall community re-integration, RNLI percentage (r = - 0.224, p = 0.013).

Table 4.10. Correlation matrix showing correlation co-efficient, between all aspects of the RNLI and P1-P4 severity.

RNLI item	**P1 Severity** ***(n= 104)***	**P2 Severity** ***(n=45)***	**P3 severity** ***(n=11)***	**P4 severity** ***(n=4)***
I move around my living quarters as necessary	0.072	0.034	0.068	-0.125
I move around my community as necessary	-0.117	-0.208*	-0.171	-0.033
I am able to take trips out of town as necessary	0.031	-0.144	-0.273**	-0.079
I am comfortable with how my self-care needs are met	-0.107	-0.142	-0.151	-0.078
I spend most of my day occupied in a work activity that is necessary/important to me	-0.186	-0.107	-0.044	0.077
I am able to participate in recreational activities as I want to	-0.057	-0.047	-.0149	-0.138
I participate in social activities as necessary/desirable to me	-0.030	-0.015	-0.172	-0.166
I assume a role in my family which meets my needs and those of other family members	-0.128	-0.009	-0.154	-0.142
In general, I am comfortable with my relationships	-0.002	-0.044	-0.090	-0.067
In general, I am comfortable with myself when I am in company of others	-0.074	-0.025	0.033	-0.118
I feel I can deal with life events as they happen	-0.108	-0.173	-0.064	-0.176
RNLI overall percentage	-0.154	-0.147	0.224*	-0.162

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed). **n= no. of painful areas, not number of people*

4.6 Conclusion

This chapter highlights the high prevalence of pain in people living with SCI. Neuropathic pain was experienced more than nociceptive pain, and the most common description of pain was ‘burning’ and ‘ache’, respectively. Participants who experienced pain, scored lower on the RNLI, however, results were overall not significant when comparing the difference between participants with pain, and those without. Shoulder pain specifically was reported in only 14.7% of participants, but a high negative correlation was found between participants shoulder pain when loading their wheelchair into their cars and taking trips out of town, as well as a moderate negative correlation between pain when pushing up a ramp and taking trips out of town. No associations were found with regards to neuropathic pain and community re-integration. However, results showed some significant findings when looking at the impact of pain severity on community re-integration.

CHAPTER 5: DISCUSSION

5.1 Introduction

This chapter will discuss the study findings of the research conducted. This includes both the descriptive and inferential characteristics, including pain presentation, community re-integration levels and associations between pain and community re-integration.

5.2 Sociodemographic and injury profile

This sample population is of SCI in South Africa in terms of gender, age, cause and context, but may also be relatable in some respects to other low-income countries. Most of the participants in this study were male, had traumatic spinal cord injury (SCI) from primarily motor vehicle accidents, and followed by gunshot injuries. The T6 and T12 neurological levels were most prevalent, with half of the participants living with their injury for 1 – 5 years. This sample of traumatic causes of injury, particularly in males, is common. Pilusa et al. (2021), who conducted their study in Gauteng, supports this finding with traumatic causes (82.4%) resulting in SCI in males (82.4%). However, Pefile et al. 2019, found more non-traumatic causes (54%) in women in KZN, which was attributed to the high rate of HIV infection in this area. Epidemiological data varies in different countries, for example, causes of traumatic injuries are becoming more prominent in the elderly with falls in high-income countries (Chamberlain et al. 2015), while non-traumatic causes are on the rise in African countries due to the HIV pandemic. Thus, it is important to consider all factors that may influence the injury profile in different countries as well as provinces. The young middle-age group of participants with SCI is similar to findings in other local studies, (Pilusa et al. 2019; Buys et al. 2022), reporting means ages of 44.5 years and 41 years respectively, as well as findings in other low-income countries such as Brazil (Kang et al. 2018), compared to higher mean ages (51 years) in high income countries such as USA and Australia (Kang et al. 2018). Although the age findings in this current study depicts a possible working population age, most of the participants were unemployed, and this is most likely due to not only the generally high unemployment rates in South Africa, but also the difficulties experienced in employment opportunities for people with a SCI (Pefile et al. 2019). In contrast, Buys et al. (2022) found that 80.5% of their participants were employed post SCI. In their study, 36.6% of participants had incomplete injuries, but no further information was given on the level of mobility, whereas all participants in this study used a manual wheelchair. Furthermore, in the current study, 45.9% lived in townships and 4.9% in an urban area compared to Buys et al. (2022), where 65.9% lived in urban areas, but it was not specified if this included township living.

5.3 Pain presentation

The high reports of pain reported were expected, as pain is a known secondary health complication post SCI (Hadjipavlou et al. 2016; Burke et al. 2019). Pain in more than one area, up to five different area, as well as experiencing both neuropathic pain and nociceptive pain is not uncommon. A mean rating of pain one at 6.7 is also consistent with other findings; 6.3 (Burke et al. 2019) and 6.9 (Felix et al. 2022). This pain rating falls into the moderate pain category and shows that pain is an important secondary health condition to consider. Neuropathic pain was the most common type of pain and the most severe pain reported in this study. These findings were unsurprising as neuropathic pain is known to be more common and usually more severe than nociceptive pain (Burke et al. 2019; Felix et al. 2022). The experience of neuropathic pain below the level of in the injury in the lower limbs and referred to as “burning” was a similar finding to Burke et al. (2019), who completed a national survey of pain profiles in a community-dwelling group in Ireland. The most common site for nociceptive pain being the back at the site of injury in 9%, or upper back in 8.2% is relatively low and varied in comparison to the literature. Due to the nature of nociceptive pain, a variety of painful areas can be present; Burke et al. (2019) found 50% of pain in the upper and/or lower back, and Bresnahan et al. (2022) found 55% pain in the shoulders.

Shoulder pain prevalence in this study was low compared to previous literature; 14.8% vs 73.3% (Kang et al. 2019) and 55% (Bresnahan et al. 2022). A possibility for the low rates of shoulder pain in this study is that only participants with paraplegia were included, and it is thought that patients with quadriplegia experience more shoulder pain (Bresnahan et al. 2022) due to not only the musculoskeletal impact on the shoulders, but due to the combination of weakness and neurological fallout as well. Furthermore, the likelihood of having shoulder pain increases with contracture and spasticity (Bossuyt et al. 2018), and reduced ROM (Bresnahan et al. 2022) which is more likely to occur in tetraplegics than paraplegics. The low prevalence of shoulder pain in this study is not a negative outcome and led the researcher to ask the following questions:

- Are PWSCI taking care to prevent shoulder pain?
- Is there an emphasis on preventative strategies to maintain the shoulder joint during rehabilitation?

To attempt to answer these questions, the researcher considered a randomised control trial conducted by Haubert et al. (2021), who investigated a shoulder pain prevention programme for people with paraplegia using a manual wheelchair. The prevention programme included exercises as well as education regarding movement optimization during transfers, wheelchair

propulsion, pressure relief and overhead activities. Their results showed less shoulder pain onset compared to the control group, at both 18 month and 36 month follow ups (Haubert et al. 2021). It is therefore plausible that participants in this study may have used shoulder pain prevention strategies or followed a shoulder exercise programme that decreased the likelihood of shoulder pain. Seeing as PWSCI rely heavily on their upper limbs for daily functioning, prevention of overuse, and using strategies likely to prevent shoulder pain should be a focus point during rehabilitation.

5.4 Community re-integration

Majority of the participants resided in township areas, which in South Africa means often informal living and over-crowding (Lehohla, 2014/2015). The environment is sandy, uneven and more than likely not wheelchair user friendly. The median score of the RNLI (77.73%) falls into a category of moderate restriction in participation, according to Pang et al. (2007). Although Buys et al. (2022) also found moderate restrictions in participation, their RNLI score was 9% lower at a mean score of 68% done in KZN (Buys et al. 2022). This difference was found despite both studies having similar demographics in terms of gender, age and participants living in both rural and urban environments. Buys et al. (2022) included participants with tetraplegia, which may have influenced their levels of re-integration, due to the nature of the severity of the injury with less mobility and function. Interestingly, Buys et al. (2022) found higher levels of productive activity resulted in higher scores on the RNLI, whereas majority of our participants were not employed, yet still had higher scores on the RNLI. Buys et al. (2022) included participants who were discharged 12 months prior to the start of their study, however there is no information regarding the time post SCI of participants in their study. Comparatively, half of the participants in this study have been living with their SCI for more than 5 years. It may be possible that the longer PWSCI live with their injury, the better their integration into their community is. This may be due to physical improvements in independence and mobility (van der Westhuizen et al. 2017) or due to PWSCI perceiving their integration to be better the longer they live with their injury (Boschen et al. 2003). Nizeyimana et al. (2022) found the mean score of perceived community reintegration to be significantly higher in PWSCI who lived with their injury for 11-15 years, compared to those who only lived with their injury for 1-5 years.

There are no normative values of the RNLI, but the higher percentage in this study may indicate that participants perceived their integration towards the higher end. There is an adjustment process that takes place post a SCI, and perhaps participants idea of participation may have shifted compared to what their ideas of participation prior to their SCI were. There are many

facilitators to community re-integration, which were not the aim of this study, however overall health stability (Boschen et al. 2003) and social support (Atobatele et al. 2018) have been linked as key factors to community re-integration. We do know that 80.3% of the participants reported no comorbidities, and most participants lived with their families.

5.5 Associations of pain with community re-integration

5.5.1 Presence of overall pain on community re-integration (Objective 1)

Those who experienced pain scored lower on the RNLI than those who did not have pain, but overall, the results were not significant. It could have been expected that participants with neuropathic pain would have more of a difference on their RNLI scores as neuropathic pain has been described as more severe than nociceptive pain (Burke et al.2019; Felix et al. 2022). This finding is different to that done by Buys et al. (2022) who showed that the presence of pain was significantly related to lower scores on the RNLI, with a *p*-value of 0.03. They did not specify what type of pain participants had, nor the severity. Their sample size was 41 compared to the current sample size of 122, and they included participants with tetraplegia who accounted for 36.6% of the sample size, potentially accounting for the difference in results.

5.5.2 Nociceptive shoulder pain and community re-integration (Objective 2)

This study's finding that shoulder pain showed no relation to community re-integration mirrored those by Gutierrez et al. (2007). In their study, the WUSPI was correlated with the Communities activity checklist, which has more social items compared to mobility items, and this may have contributed to the reason for their no correlation. Therefore, not finding a correlation between shoulder pain and community re-integration in this current study may be due to the low prevalence of shoulder pain reported by participants. When looking specifically at shoulder pain identified in items of the WUSPI, the most intense pain was felt with pushing up an incline, lifting objects from an overhead shelf and transferring into a bath. Both pushing up an incline and lifting arms overhead are activities that can be performed in the community, and pushing up and incline is consistent with literature for times of increased shoulder pain (Morrow et al. 2010, Mozingo et al. 2020). When investigating individual items of the WUSPI and RNLI, pain when pushing up an incline showed a moderate negative correlation with taking trips out of town. Ramps provide accessibility to PWSCI using manual wheelchairs (Mothabeng, 2011), however, it is the finding of pain during this activity that limits accessibility. Furthermore, a high negative correlation was found between shoulder pain when loading a wheelchair into the car and taking trips out of town ($p = 0.045$). The ability to use transport has been found to increase overall community re-integration as well as increase the odds of being employed (Norweg et al. 2011). Whether transferring into a privately owned car or using public transport, car transfers

are one of the most challenging transfers, and the need to load a wheelchair further increases strain on the upper limbs and shoulders (Haubert et al. 2015). At the same time, to access the community and potential workplaces, especially to areas at a further distance, one must be able to travel by a motor vehicle. If a PWSCI is using a car daily and transferring independently as well as loading his/her wheelchair, one must consider the potential for pain in the shoulders (Haubert et al. 2015). It is important that while trying to maximise PWSCI's independence and participation, we minimize potential shoulder pain. Strategies to decrease load may need to be implemented, including positioning of the leading hand during transfers (Haubert et al. 2015) and asking for assistance to load wheelchairs. Undoubtedly, there are PWSCI who rely on public transportation, however, bar a train, they will still need to transfer daily. Finding that the third-most severe pain (P3) (mainly identified as shoulder pain) negatively correlated with taking trips out of town ($p = 0.002$) and overall community re-integration ($p = 0.013$) makes the researcher conclude that it is not the general presence of pain that determines community re-integration but the severity of the pain, particularly shoulder pain.

The three significant correlations related to pain during certain activities on the WUSPI and being comfortable with how self-care needs are met, is not a surprising find (Afsar et al. 2014; Burke et al. 2019). However, further discussion around self-care will not be considered as self-care specifically is not related to the purpose or objectives of this study.

5.5.3 Neuropathic pain and community re-integration (Objective 3)

Neuropathic pain rates in this study are similar to the literature (Burke at al.2019; Bresnahan et al. 2022; Noreau et al. 2021), and therefore 53.3% of participants experiencing neuropathic pain is not surprising. Noreau et al. (2021) found that the perceived limitation of neuropathic pain on participation was more important than experiencing pain (Noreau et al. 2021). Some activities were still performed despite pain, and this may explain why this study did not find any association between neuropathic pain and community re-integration. It is possible that there are many other factors that may contribute to the level of community re-integration with the presence of pain, or perhaps individuals can maintain some level of community re-integration despite their pain levels. This may potentially be due to self-efficacy of participants (Nizeyimana et al. 2022) or cultural behaviours of South Africans, where there are high levels of resilience to adversity (Theron et al. 2020). In Nizeyimana et al. (2022), a positive correlation was found between perceived community re-integration and general self-efficacy. Furthermore, they found that the social functioning factor of the self-efficacy scale, predicted the highest variance of perceived community re-integration. In the current study, we do not know the participants self-regulation, levels of motivation or confidence that may explain our finding.

To then consider the cultural behaviour of South Africans, although Theron et al. (2020) focused on healthy individuals of youth, the findings may expand to the nature of South Africans dealing with hardships of living in townships, where 45.9% of this study's population reside. Resilience in South Africans comes mostly from self, with some family support and little social-ecological support (Theron et al. 2020). In this study, 50.8% lived with immediate family and 9.8% lived alone. Therefore, the influence of resilience and family support on community re-integration may be a potential research area for further pursuit.

5.5.4 Influence of severity of pain on community re-integration (Objective 4)

The findings in this study indicate that the more severe pain, the less overall integration in the community (p = 0.013), particularly moving around the community (p = 0.022). Donnelly and Eng. (2005) also found that pain intensity was correlated to community re-integration at six months after injury (r = 0.55, p <0.001), and pain intensity accounted for 25% of the variance in RNLI scores. In the study by Donnelly and Eng. (2005), types of pain and pain location were not identified, therefore the finding in this study further adds to clinical management. As shoulder pain severity was of particular importance in relation to community re-integration, therapists must address shoulder pain and pain prevention strategies. Individuals with lower levels of pain report interference with psychological effects like mood, sleep and life enjoyment more frequently, whereas individuals with higher pain levels more frequently report interference on social relationships and daily activities (Hand et al. 2018). Kuzu et al. (2022) found that within-person fluctuations in day-to-day pain showed no decrease in same day social participation, but between-person comparison showed that only those with higher pain severity had a decrease in social participation. Therefore, the finding of severity of both neuropathic and nociceptive pain impacting on community re-integration in this current study is meaningful when considering re-integration into outcome levels IV and V, where PWSCI are working towards participating in their community as well as potential employment. The researcher acknowledges that there are many potential barriers to community re-integration, resulting in pain severity only yielding low correlations. Other barriers can include environmental barriers, (both the natural and built environment), social and economic causes, or lack of appropriate equipment (Mothabeng 2011; Joseph et al. 2016).

5.6 Conclusion

This chapter interprets and discusses the most important findings. Low prevalence of shoulder pain in this study was an interesting finding, and reasons for this have been explored. Despite high levels of neuropathic pain, there was no impact on community re-integration, and potential reasons for this were also discussed. Due to the high correlation between shoulder pain during

car transfers and taking trips out of town, an important clinical consideration for car transfers was considered. Overall, the mere presence of pain did not negatively influence community re-integration, however, it is the intensity of pain, both neuropathic and nociceptive, that has a negative correlation with community re-integration.

CHAPTER 6: CONCLUSION

6.1 Strengths and limitations

This study allowed for an in-depth analysis of both nociceptive and neuropathic pain experienced by people living with SCI, and its relationship to community re-integration. This study's participants were visited in their home to determine their community re-integration. The study included participants from a broad geographical area, and participants who had received rehabilitation at both public and private rehabilitation facilities. Furthermore, this study delimited the participants to only those with paraplegia which allowed influences of neurological fallout and weakness to not contribute to the shoulder pain experienced. Furthermore, the main study which this current study analysed its data, intact innervation to the shoulder girdle was needed to have an active function of the pectoralis minor muscle and scapular movements, hence limiting to people with paraplegia. The primary data used for this secondary analysis did not have more information about the five participants with shoulder operations in terms of date of procedure, success and recovery etc. which may have played a role in the WUSPI scores. However, according to the literature, there is a high prevalence of shoulder pain, but in this study there was a small sample of participants with shoulder pain, which also may have influenced the results.

6.2 Implications and recommendations

Pain is prevalent in people living with SCI. Due to the complex nature of community re-integration, with many factors influencing it, pain may be one of many factors negatively influencing community re-integration. However, one should consider clinical implications when assessing the severity of pain, and how this relates to community re-integration, particularly shoulder pain during loading a wheelchair into the car. Future studies conducted around shoulder pain and SCI, may find it useful to determine whether PWSCI have been taught about shoulder pain prevention. Furthermore, possible easing factors of pain and looking at what pain prevention strategies are used may be helpful in guiding current in-patient management. By preventing shoulder pain, therapists may have a direct influence on the ability of PWSCI to re-integrate back into the community.

Due to various reasons for potential increased pain in people with tetraplegia, it may be beneficial to compare pain profiles, in paraplegia versus tetraplegia, and then compare the impact on community re-integration. Although having neuropathic pain did not directly influence community re-integration, considering that neuropathic pain levels often increase with time since injury, and severity of neuropathic pain showed less community re-integration, it confirms

that this is still an important secondary health condition to be managed. Development of pain can be predicted, and early education and treatment around neuropathic pain should be done by the full multi-disciplinary team. Neuropathic pain should be assessed in relation to specific activities that pain interferes with, as people with neuropathic pain often continue to perform tasks despite their pain. Considering each individuals' needs, and their idea of integration and participation is highlighted.

6.3 Conclusion

This study highlights that pain is prevalent post SCI. Neuropathic pain is more common and more severe than nociceptive pain, with high rates of neuropathic pain, and a low prevalence of shoulder pain in this study. RNLI scores were on the higher end, with participants with pain scoring lower in community re-integration than participants without pain, but with no significant difference. Overall community re-integration is influenced by multiple barriers and facilitators, and pain is not necessarily a barrier to community re-integration, as participants continue with activities despite pain. No correlation was found between neuropathic pain and community re-integration, and despite a high negative correlation found between shoulder pain during car transfers and taking trips out of town, and pushing up ramps and taking trips out of town, these are single items on the WUSPI and RNLI and therefore the researcher cannot conclude that the type of pain influences community re-integration. However, finding that the second most severe pain (mainly identified as neuropathic) and third-most severe pain (P3) (mainly identified as shoulder pain) negatively correlated with moving around the community, and taking trips out of town and overall_community re-integration respectively, makes the researcher conclude that it is not the general presence of pain that influences community re-integration but the severity of pain. These factors are important to consider to optimize rehabilitation of PWSCI back into their community.

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APPENDICES
Appendix A

THE SOCIO-DEMOGRAPHIC AND INJURY PROFILE (SDIP)

1. How old are you:
1 = <18 2= 18 – 29 3 = 30 – 39 4 = 40 – 49 5 = 50 – 59 6 = >60

2. Gender
1 = Male 2 = Female

3. Age when injured:
1 = <18 2= 18 – 29 3 = 30 – 39 4 = 40 – 49 5 = 50 – 59 6 = >60

4. Years living with SCI _____

5. Residential area
1 = township 2 = suburb 3 = informal settlement 4 = 0ther (specify)_____

6. With whom do you live now?
1 = Own family 2 = Friends 3 = other (e.g. shelter/home) _____

7. Do you have a carer/ caregiver?
1= No 2= Yes

8. If yes, is it a full day carer or not?
1= Full day 2= Half day 3= Other

9. Are you working?
1 = no 2 = yes

10. If yes, what kind of work? _____

11. If no, how do you get money to live? _____

12. Level of SCI (NLI)
1=T6-T12 5 = L1-L5 6 = S1-S5

13. Completeness of lesion
1 = complete 2 = incomplete 3 = don't know

14a. Have you ever been hospitalised for any health problems after discharge?
1 = Yes 2 = No

14b. If yes, how many times were you re-hospitalized after initial discharge?
1= Once 2= Twice 3= Thrice 4= Four times 5= ≥ Five times

15. If yes, which health problem_____

16. Have you experienced any other health problems that may have not needed you to be hospitalized?
a) Please specify_____

17a. Do you have any of the following conditions?
1 = Diabetes Mellitus 2 = Epilepsy 3 = Arthritis 4 = Thyroidism 5 = Hypertension

6 = Other_____

18. Dominant hand
0 = Right 1 = Left

19. Do you currently have pain present?
0 = No 1 = Yes

20. Number of painful locations
0 = No pain 1 = 1 2 = 2 3 = 3 4 = 4 5 = 5

21. Previous shoulder operation?
0 = No
If yes, Specify_____

22. Do you have shoulder pain?
0 = No 1 = Yes

23. Specify the location of pain
P1 _____ P2 _____ P3 _____ P4 _____
P5 _____

23. Specify the severity of pain (/10)
P1 _____ P2 _____ P3 _____ P4 _____
P5 _____

23. Specify the bevaviour of pain
P1 _____ P2 _____ P3 _____ P4 _____
P5 _____

Appendix B

Reintegration to Normal Living Index Worksheet:

Patient Name: _____ Date: _____

	Score (0-10):
1. I move around my living quarters as I feel is necessary. (Wheelchairs, other equipment or resources may be used.)	
2. I move around my community as I feel is necessary. (Wheelchairs, other equipment or resources may be used.)	
3. I am able to take trips out of town as I feel are necessary. (Wheelchairs, other equipment or resources may be used.)	
4. I am comfortable with how my self-care needs (dressing, feeding, toileting, bathing) are met. (Adaptive equipment, supervision and/or assistance may be used.)	
5. I spend most of my days occupied in a work activity that is necessary or important to me. (Work activity could be paid employment, housework, volunteer work, school, etc. Adaptive equipment, supervision and/or assistance may be used.)	
6. I am able to participate in recreational activities (hobbies, crafts, sports, reading, television, games, computers, etc.) as I want to. (Adaptive equipment, supervision and/or assistance may be used.)	
7. I participate in social activities with family, friends, and/or business acquaintances as is necessary or desirable to me. (Adaptive equipment, supervision and/or assistance may be used.)	
8. I assume a role in my family which meets my needs and those of other family members. (Family means people with whom you live and/or relatives with whom you don't live but see on a regular basis. Adaptive equipment, supervision and/or assistance may be used.)	
9. In general, I am comfortable with my personal relationships.	
10. In general, I am comfortable with myself when I am in the company of others.	
11. I feel that I can deal with life events as they happen.	

Total Score: _____

Adjusted Score: _____

Appendix C

DN4 Questionnaire

Please complete this questionnaire by ticking one answer for each item in the 4 questions below:

INTERVIEW OF THE PATIENT

Question 1: Does the pain have one or more of the following characteristics?

	Yes	No
1 – Burning		
2 – Painful cold		
3 – Electric shocks		

Question 2: Is the pain associated with one of more of the following symptoms in the same area?

	Yes	No
4 – Tingling		
5 – Pins and needles		
6 – Numbness		
7 – Itching		

EXAMINATION OF THE PATIENT

Question 3: Is the pain located in an area where the physical examination may reveal one or more of the following characteristics?

	Yes	No
8 – Hypoesthesia to touch		
9 – Hypoesthesia to prick		

Question 4: In the painful area, can the pain be caused or increased by:

	Yes	No
10 – Brushing		

The total score is calculated as the sum of the 10 items and the cut-off value for the diagnosis of neuropathic pain is a total score of 4/10.

Total

Appendix D

WHEELCHAIR USER'S SHOULDER PAIN INDEX

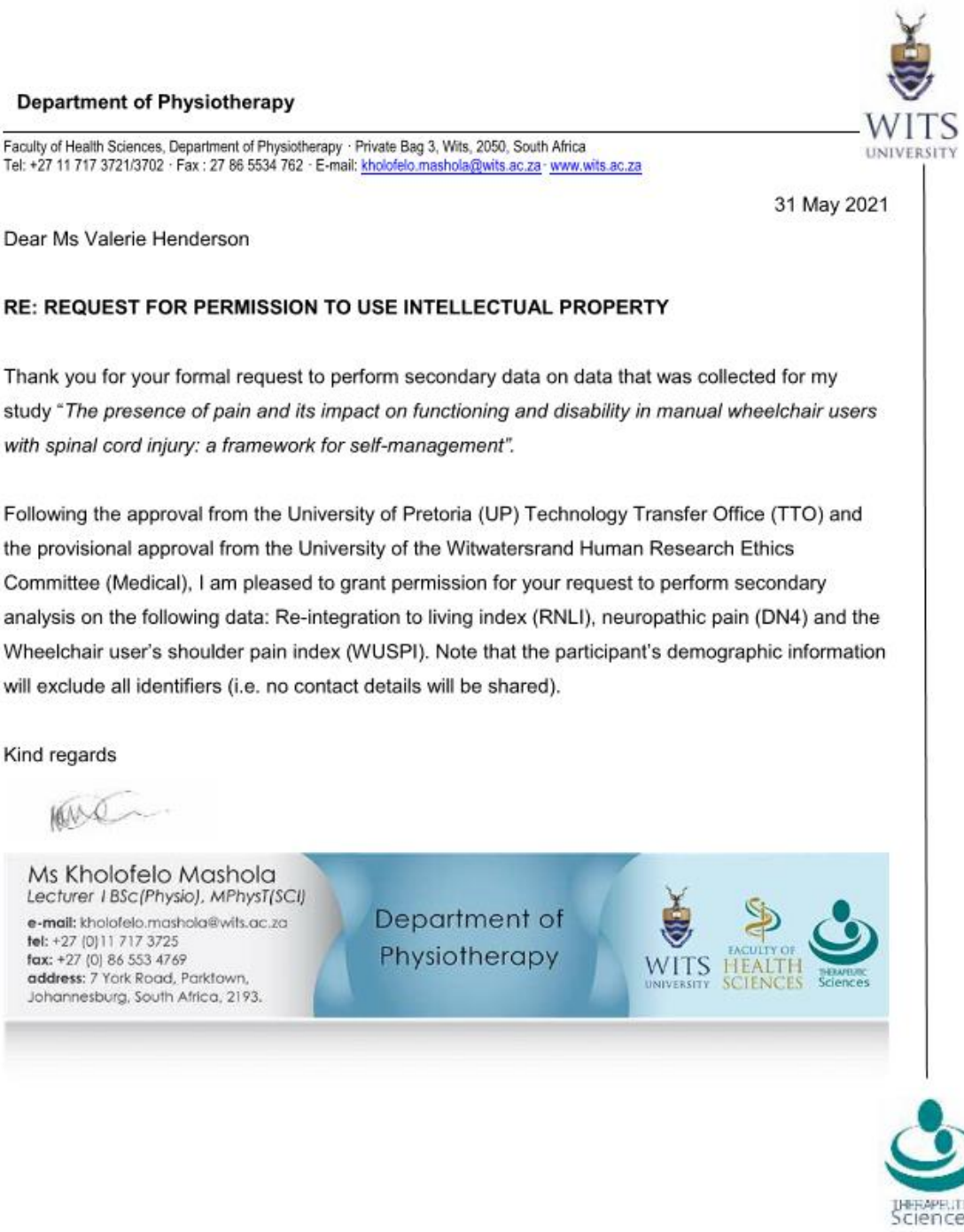
Place an 'X' on the scale to estimate your level of pain with the following activities. Check the box on the right if the activity was not performed in the last week.

Based on your experience in the past week, how much shoulder pain do you experience when:

1. Transfer from bed to wheelchair	No pain	1	2	3	4	5	6	7	8	9	Worst pain ever experienced
2. Transfer from wheelchair to car	No pain										Worst pain ever experienced
3. Transfer from a wheelchair to tub or shower	No pain										Worst pain ever experienced
4. Loading your wheelchair into car	No pain										Worst pain ever experienced
5. Pushing your chair for ten minutes or more	No pain										Worst pain ever experienced
6. Pushing up ramps or inclines outdoors	No pain										Worst pain ever experienced
7. Lifting objects down from an overhead shelf	No pain										Worst pain ever experienced
8. Putting on pants	No pain										Worst pain ever experienced
9. Putting on a t-shirt or pullover	No pain										Worst pain ever experienced
10. Putting on a button down shirt	No pain										Worst pain ever experienced
11. Washing your back	No pain										Worst pain ever experienced
12. Usual daily activities at work or school	No pain										Worst pain ever experienced
13. Driving	No pain										Worst pain ever experienced
14. Performing household chores	No pain										Worst pain ever experienced
15. Sleeping	No pain										Worst pain ever experienced

Appendix E

a. Gatekeeper



Department of Physiotherapy

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WITS UNIVERSITY

31 May 2021

Dear Ms Valerie Henderson

RE: REQUEST FOR PERMISSION TO USE INTELLECTUAL PROPERTY

Thank you for your formal request to perform secondary data on data that was collected for my study "*The presence of pain and its impact on functioning and disability in manual wheelchair users with spinal cord injury: a framework for self-management*".

Following the approval from the University of Pretoria (UP) Technology Transfer Office (TTO) and the provisional approval from the University of the Witwatersrand Human Research Ethics Committee (Medical), I am pleased to grant permission for your request to perform secondary analysis on the following data: Re-integration to living index (RNLI), neuropathic pain (DN4) and the Wheelchair user's shoulder pain index (WUSPI). Note that the participant's demographic information will exclude all identifiers (i.e. no contact details will be shared).

Kind regards

Ms Kholofelo Mashola
Lecturer I BSc(Physio), MPhysT(SCI)
e-mail: kholofelo.mashola@wits.ac.za
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Department of Physiotherapy

WITS UNIVERSITY · FACULTY OF HEALTH SCIENCES · THERAPEUTIC Sciences

THERAPEUTIC Sciences

b. Technology transfer manager (UP)

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Department Research and Innovation

24 May 2021

To whom it may concern

Dear Ma'am/sir

RE: INTELLECTUAL PROPERTY (IP) ENTITLED "DATA USAGE FOR SECONDARY ANALYSIS"

Ms Mokgadi Kholofelo Mashola who is currently a WITS University employee and a PhD student at UP, submitted a completed invention disclosure form for IP entitled "data usage for secondary analysis" to the University of Pretoria Technology Transfer Office (UPTTO) on the 8th of April 2021. The TTO organized an IP Evaluation Committee meeting to discuss the IP. The meeting took place on the 11th of May 2021 and was chaired by the Vice Principal: Research & Post Graduate Education. The Committee agreed that the IP was not patentable but could be protected by means of copyright (there was automatic protection the moment the IP was created). The Committee recommended that in terms of publications both UP & Wits University must be acknowledged as the IP belongs to both institutions.

Please feel free to contact me should you have questions.

Yours Sincerely

Ms Refilwe Ngoato

Technology Transfer Manager

Room 2-14, Level 2, Graduate Centre Building
University of Pretoria, Private Bag X20
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Tel +27 (0)12 420 4568
Fax +27 (0)12 420 4962
Email Refilwe.Ngoato@up.ac.za

Departement Navorsing-en Innovasie
Lefapha la DinyakišIšo le TŠwetŠopele

Appendix F – Ethical clearance certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Mrs Valerie Henderson

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M210516

NAME: (Principal Investigator)	Mrs Valerie Henderson
DEPARTMENT:	Physiotherapy - School of Therapeutic Sciences
PROJECT TITLE:	The association between pain and community reintegration of manual wheelchair users with spinal cord injury
DATE CONSIDERED:	28/05/2021
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Mrs Kholofelo Mashola
APPROVED BY:	CB Penny Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	09/06/2021

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions.Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **May** and will therefore be due in the month of **May** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature _____ Date _____

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix G – Ethical clearance, primary study

a. Original

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences

Institution: The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IORG #: IORG0001762 OMB No. 0990-0279 Approved for use through February 28, 2022 and Expires: 03/04/2023.

6 November 2020

Approval Certificate
Annual Renewal

Ethics Reference No.: 125/2018
Title: The Presence of pain and its impact on functioning and disability in manual wheelchair users with spinal cord injury: A Framework for self-management

Dear Ms MK Mashola

The **Annual Renewal** as supported by documents received between 2020-10-15 and 2020-11-04 for your research, was approved by the Faculty of Health Sciences Research Ethics Committee on 2020-11-04 as resolved by its quorate meeting.

Please note the following about your ethics approval:

- Renewal of ethics approval is valid for 1 year, subsequent annual renewal will become due on 2021-11-06.
- Please remember to use your protocol number (125/2018) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, monitor the conduct of your research, or suspend or withdraw ethics approval.

Ethics approval is subject to the following:

- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

Dr R Sommers
MBChB MMed (Int) MPharmMed PhD
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health)

Research Ethics Committee
Room 4-60, Level 4, Tswelopele Building
University of Pretoria, Private Bag x323
Gezina 0031, South Africa
Tel +27 (0)12 356 3084
Email: deepeka.behari@up.ac.za
www.up.ac.za

Fakulteit Gesondheidswetenskappe
Lefapha la Disaense tša Maphelo

b. Annual renewal

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences

Institution: The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved dd 18 March 2022 and Expires 18 March 2027.
- IORG #: IORG0001762 OMB No. 0990-0278 Approved for use through August 31, 2023.

Faculty of Health Sciences **Research Ethics Committee**

14 April 2022

Approval Certificate
Annual Renewal

Dear Ms MK Mashola,

Ethics Reference No.: 125/2018 – Line 4
Title: The Presence of pain and its impact on functioning and disability in manual wheelchair users with spinal cord injury: A Framework for self-management

The **Annual Renewal** as supported by documents received between 2022-03-29 and 2022-04-13 for your research, was approved by the Faculty of Health Sciences Research Ethics Committee on 2022-04-13 as resolved by its quorate meeting.

Please note the following about your ethics approval:

- Renewal of ethics approval is valid for 1 year, subsequent annual renewal will become due on 2023-04-14.
- Please remember to use your protocol number (125/2018) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, monitor the conduct of your research, or suspend or withdraw ethics approval.

Ethics approval is subject to the following:

- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

On behalf of the FHS REC, Dr R Sommers
MBChB, MMed (Int), MPharmMed, PhD
Deputy Chairperson *of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria*

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health)

Research Ethics Committee
Room 4-60, Level 4, Tswelopele Building
University of Pretoria, Private Bag x323
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www.up.ac.za

Fakulteit Gesondheidswetenskappe
Lefapha la Disaense tša Maphelo

Appendix H – Hospital permissions

a) Dr George Mukhari Hospital

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Dr. George Mukhari Academic Hospital

Office *of the Director Clinical Services*
Enquiries : Dr. C Holm
Tel : (012) 529 3691
Fax : (012) 560 0099
Email:Christene.Holm @gauteng.go.za
keitumetse.mongale@gauteng.gov.za

To Ms M Mashola
Department of Physiotherapy
University of Pretoria
Private Bag X 323
ARCARDIA
0007

Date : 07 June 2018

PERMISSION TO CONDUCT RESEARCH

The Dr. George Mukhari Academic Hospital hereby grants you permission to conduct research on "The effect of a home exercise programme of pectoralis minor muscles stretches on shoulder pain in people with paraplegia" at Dr George Mukhari Academic Hospital

This permission is granted subject to the following conditions:

- [x] That you obtain Ethical Clearance from the Human Research Ethics Committee of the relevant University
- [x] That the Hospital incurs no cost in the course of your research
- [x] That access to the staff and patients at the Dr George Mukhari Hospital will not interrupt the daily provision of services.
- [x] That prior to conducting the research you will liaise with the supervisors of the relevant sections to introduce yourself (with this letter) and to make arrangements with them in a manner that is convenient to the sections.
- [x] Formal written feedback on research outcomes must be given to the Director: Clinical Services
- [x] Permission for publication of research must be obtained from the Chief Executive Officer

Yours sincerely

DR. C. HOLM
ACTING DIRECTOR CLINICAL SERVICES
7/6/18

b) Kalafong Hospital

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

KALAFONG HOSPITAL
PRIVATE BAG X396
PRETORIA
0001

ENQUIRIES : **MS NT LEDIGA**
TEL : **012 318 6995**
FAX : **012 373 6791**
EMAIL : **Nelly.Lediga@gauteng.gov.za**
REF : **KPTH 33/2018**

TO: MS MK MASHOLA

RE: CONDITIONAL PERMISSION TO CONDUCT RESEARCH

TITLE: THE EFFECT OF A HOME EXERCISE PROGRAM OF PECTORALIS MINOR MUSCLE STRETCHES ON SHOULDER PAIN IN PEOPLE WITH PARAPLEGIA

Conditional permission is hereby granted for the research to be conducted at **Kalafong Provincial Tertiary Hospital**. Please note that full approval will be granted on receipt of Ethics approval.

This is done in accordance to the "Promotion of Access to Information Act. No 2 of 2000".

Please note that in addition to receiving approval from the hospital research committee, you are still required to seek permission from the relevant departments. Importantly, you require full approval (not conditional approval) before data collection can commence.

Furthermore, collecting of data and consent for participation remains the responsibility of the researcher.

You are also required to submit your final report or summary of your findings and recommendations to the office of the CEO.

Kind regards

DR K.E LETEBELE-HARTELL
SENIOR MANAGER: MEDICAL SERVICES

DATE: 11/05/2018

Ethics approval submitted: **YES** ✓ **NO**

Approved.

DR K.E LETEBELE-HARTELL
SENIOR MANAGER: MEDICAL SERVICES

DATE: 15/05/2018

c) Steve Biko Academic Hospital

Permission to access Records / Files / Database at the following hospital **STEVE BIKO ACADEMIC HOSPITAL**

To: Chief Executive Officer/Information Officer **Steve Biko Academic Hospital**
From: Ms MK Mashola (Investigator), University of Pretoria

Re: Permission to do research at Steve Biko Academic Hospital

I, **Mokgadi Kholofelo Mashola**, am a researcher working at the University of Pretoria, department of physiotherapy. I am requesting permission to conduct a study on your hospital grounds that involves access to patient records.

The request is lodged with you in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000.

The title of the study is: **The effect of a home exercise program of pectoralis minor muscle stretches on shoulder pain in people with paraplegia.**

The researcher request access to the following information:

- Access to the clinical files, record book and the database.
- Conduct a pilot study on admitted patients with spinal cord injury

I intend to publish the findings of the study in a professional journal and/ or at professional meeting like symposia, congresses, or other meetings of such a nature. I intend to protect the personal identity of the patients by assigning each patient a random code number.

I undertake not to proceed with the study until I have received approval from the Faculty of Health Sciences Research Ethics Committee, University of Pretoria.

Yours sincerely

SIGNATURE

Mashola MK

Permission to do the research study at this hospital and to access the information as requested, is hereby approved.

Chief Executive Officer/Information Officer Steve Biko Academic Hospital

Dr _____

Signature of the CEO

Hospital Official Stamp

GAUTENG PROVINSIALE REGERING
DEPT VAN GESONDHEID
STEVE BIKO AKADEMIESE HOSPITAAL
STEVE BIKO ACADEMIC HOSPITAL
2018 -04- 18
PRIVAATSAK/PRIVATE BAG X169
PRETORIA 0001
GAUTENG PROVINCIAL GOVERNMENT
DEPT OF HEALTH

d) Tshwane Rehabilitation Hospital

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Tshwane Rehabilitation Hospital
TEL: 012-3546163

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

DATE: 14/06/2018

NAME OF RESEARCHER: MOKGADI KHOLOFELO MASHOLA

TITLE OF RESEARCH PROJECT:
THE EFFECT OF A HOME EXERCISE PROGRAM OF PECTORALIS MINOR MUSCLE STRETCHES ON SHOULDER PAIN IN PEOPLE WITH PARAPLEGIA

OBJECTIVES OF STUDY (briefly or include a protocol):
TO DETERMINE THE ASSOCIATION BETWEEN PECTORALIS MINOR (PMI) LENGTH AND SHOULDER PAIN AND TO COMPARE CHANGE IN PAIN BETWEEN EXPERIMENTAL AND CONTROL GROUP

METHODOLOGY (briefly or include a protocol):
PHASE I – PREDICTIVE CORRELATIONAL DESIGN ON COMMUNITY-DWELLING PEOPLE WITH PARAPLEGIA
PHASE II – RANDOMISED CONTROL TRIAL IN THE COMMUNITY OF PM STRETCHES

CONFIDENTIALITY OF PATIENT MAINTAINED:
YES

COSTS TO HOSPITAL:
NONE

APPROVAL BY UNIVERSITY ETHICS (attach proof): Approval number 125/2018 (attached)

You will be obligated to present your research to Tshwane Rehabilitation Hospital upon completion of your study.

APPLICANT SIGN: ..... DATE: 14/06/2018

PRINT NAME (applicant): MOKGADI KHOLOFELO MASHOLA TEL NO (applicant): 082 524 7594

FOR OFFICIAL PURPOSES ONLY (not to be completed by applicant)

	Comments/considerations	Signature of HOD
OPERATIONAL APPROVAL	approval for database only	
NOT APPROVED OPERATIONALLY	Recommended.	

APPROVAL OF HEAD OF DEPT:

.....
CEO Tshwane Rehabilitation Hospital

DATE: 12/12/2018

APPROVED	APPROVED WITH AMMENDMENT	NOT APPROVED
	* Limited access to files as per protocol * Researcher not to copy files / take photo's * Follow relevant hospital SOPS on file access and patient mx * Translation of relevant forms to local languag	

e) Summit Rehabilitation, Meulmed Hospital (Rita Henn & Partners)

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Kholofelo Mashola <kholofelo.mashola@up.ac.za>

FW: Mail from Kholofelo

Shirley Eberlein <seberlein@rhprehab.co.za>
To: "kholofelo.mashola@up.ac.za" <kholofelo.mashola@up.ac.za>

3 September 2018 at 13:16

Hi Kholo,

Trust that you are well!

I am afraid that Tracey is not going to be able to spend time on this, please can you arrange a time to come and go through our database and get what info you need. It can be anytime during working hours. Also, please can I ask that you destroy the spreadsheet you have when done, sending it to you is problematic from a POPi point of view as I am sure you understand!

Regards,

Shirley

RITA HENN & PARTNERS REHAB

Shirley Eberlein

Practice Manager | Muelmed
Tel: +27 12 341 1909
http://www.physicalrehab.co.za/rhp-muelmed

Appendix I - Participants' socio-demographic profile (Mashola et al, 2022)

Description	Category		n (%)
Age	16-30 years		25 (20.5)
	31-45 years		65 (53.3)
	46-60 years		26 (21.3)
	61-75 years		6 (4.9)
Gender	Male		83 (68.0)
	Female		39 (32.0)
Years living with SCI (years)	< 1		3 (2.5)
	1–5		62 (50.8)
	6–10		34 (27.9)
	11–15		9 (7.4)
	16–20		8 (6.6)
	> 21		6 (4.9)
Residential area	Township		56 (45.9)
	Suburb		28 (23.0)
	Rural		26 (21.3)
	Urban		6 (4.9)
	Plot		5 (4.1)
	Campus		1 (.8)
Staying with	Own family		62 (50.8)
	Others (n=48, 39.3%)	Extended family	14 (11.5)
		Friend / Partner	3 (2.5)
		Sibling(s)	12 (9.8)
		Parent(s)	12 (9.8)
		Carer	5 (4.1)
		Roommate / house mate	1 (.8)
		Old age home	1 (.8)
	Alone		12 (9.8)
Employment status	Unemployed (n=72, 59.0%)	Government disability grant	58 (47.5)
		Work disability grant	3 (2.5)
		Dependent on spouse/ family	7 (5.7)
		Assisted by lawyer or WCA	2 (1.6)
		Struggling to make ends meet	2 (1.6)

	Pensioner (n=8, 6.6%)	Government or work pension grant)	5 (4.1)
		Early retirement payout	3 (2.5)
	Employed (n=32, 26.2%)	Previous work contract not yet ended	1 (.8)
		Administration	12 (9.8)
		Sales	3 (2.5)
		Finance	2 (1.6)
		Family business	1 (.8)
		Detective (South African Police Service)	4 (3.3)
		Information Technology	5 (4.1)
		Nurse	2 (1.6)
		Security	1 (.8)
		Manual labour	1 (.8)
		Self-employed	9 (7.4)
	Student		1 (.8)
Comorbidities	None		98 (80.3)
	Present (n=24, 19.7%)	Diabetes	2 (1.6)
		TB	2 (1.6)
		DVT	1 (.8)
		Hypertension	6 (4.9)
		Hypotension	2 (1.6)
		Immuno-suppression	3 (2.5)
		Osteoporosis	1 (.8)
		Depression	1 (.8)
		Asthma	1 (.8)
		Osteomyelitis	1 (.8)
		Epilepsy	1 (.8)
		Hypercholesterol	1 (.8)
		Combination: Hyperthyroidism & Hypercholesterol	1 (.8)
		Combination: Thyroidism + Osteoporosis + Arthritis + Lung problem	1 (.8)
Dominant hand	Right		116 (95.1)
	Left		6 (4.9)

Readmission history	No		64 (52.5)
	Yes		58 (47.5)
Reasons for readmission	No readmission		64 (52.5)
	Secondary health conditions (n=55, 45.1%)	Skin	29 (23.8)
		Urinary	8 (6.6)
		Respiratory	3 (2.5)
		Circulatory	2 (1.6)
		Nervous system (neuropathic pain)	2 (1.6)
		Skeletal	2 (1.6)
		Digestive	5 (4.1)
		Cognitive / Mental health	3 (2.5)
		Reproductive	1 (.8)
	Surgical procedures		2 (1.6)
	Further rehabilitation		1 (.8)
History of shoulder operations	No		117 (95.9)
	Yes		5 (4.1)
Completeness of injury	Complete		93 (76.2)
	Incomplete		29 (23.8)

Appendix J - Correlation matrix, items of RNLI and WUSPI

WUSPI item **RNLI Item**	Transfer from bed to WC	Transfer from wheelchair to car	Transfer from wheelchair to tub or shower	Loading your wheelchair into car	Pushing your wheelchair for ten minutes or more	Pushing up ramps or inclines outdoors	Lifting objects down from an overhead shelf	Putting on pants	Putting on t-shirt or pullover	Putting on a button-down shirt	Washing your back	Usual daily activities at work or school	Driving	Performing household chores	Sleeping
I move around my living quarters as necessary	-0.415 p=0.09	-0.668 p=0.002	-0.243 p=0.50	0.189 p=0.72	-0.606 p=0.01	-0.538 p=0.03	-0.475 p=0.054	-0.785 p=<0.001	-0.648 p=0.004	-0.653 p=0.004	-0.603 p=0.02	-0.416 p=0.09	-0.792 p=0.02	-0.543 p=0.03	-0.495 p=0.04
I move around my community as necessary	0.289 p=0.24	-0.023 p=0.93	-0.475 p=0.17	0.406 p=0.43	0.235 p=0.35	0.100 p=0.7	-0.192 p=0.46	0.047 p=0.85	0.013 p=0.96	0.080 p=0.76	-0.063 p=0.82	-0.198 p=0.43	-0.309 p=0.46	-0.255 p=0.34	-0.226 p=0.37
I am able to take trips out of town as necessary	-0.288 p=0.36	-0.181 p=0.47	-0.158 p=0.66	-0.821 p=0.045	-0.366 p=0.12	-0.546 p=0.02	-0.484 p=0.05	-0.250 p=0.32	-0.461 p=0.05	-0.193 p=0.46	-0.137 p=0.63	-0.674 p=0.002	-0.655 p=0.08	-0.081 p=0.77	-0.236 p=0.35
I am comfortable with how my self-care needs are met	-0.399 p=0.10	-0.601 p=0.008	-0.650 p=0.04	-0.464 p=0.35	-0.379 p=0.12	-0.597 p=0.01	-0.721 p=0.001	-0.297 p=0.23	-0.254 p=0.31	-0.205 p=0.43	-0.669 p=0.01	-0.364 p=0.14	-0.614 p=0.11	-0.258 p=0.33	-0.055 p=0.83
I spend most of my day occupied in a work activity that is necessary/important to me	-0.006 p=0.98	-0.238 p=0.34	-0.563 p=0.09	-0.319 p=0.54	0.052 p=0.84	-0.315 p=0.22	-0.278 p=0.28	-0.046 p=0.86	-0.018 p=0.95	-0.030 p=0.91	-0.171 p=0.54	-0.522 p=0.03	-0.494 p=0.21	-0.062 p=0.82	-0.116 p=0.65
I am able to participate in recreational activities as I want to	-0.151 p=0.55	-0.364 p=0.14	-0.270 p=0.45	-0.647 p=0.17	-0.221 p=0.38	-0.230 p=0.37	-0.366 p=0.15	-0.136 p=0.59	-0.231 p=0.36	-0.214 p=0.41	-0.267 p=0.34	-0.123 p=0.63	-0.604 p=0.11	-0.262 p=0.33	0.144 p=0.57
I participate in social activities as necessary/desirable to me	-0.140 p=0.58	-0.019 p=0.94	-0.021 p=0.96	-0.616 p=0.19	0.033 p=0.9	-0.160 P=0.54	0.040 p=0.88	-0.103 p=0.68	-0.121 p=0.63	0.006 p=0.98	-0.127 p=0.65	0.087 p=0.73	0.079 p=0.85	0.173 p=0.52	0.507 p=0.03
I assume a role in my family which meets my needs and those of other	-0.141 p=0.59	-0.275 p=0.29	-0.268 p=0.45	-0.406 p=0.43	0.04 p=0.99	-0.136 p=0.62	-0.105 p=0.70	0.121 p=0.65	0.027 p=0.92	0.056 p=0.84	-0.207 p=0.48	0.066 p=0.80	0.050 p=0.91	0.169 p=0.55	0.565 p=0.02

family members															
In general, I am comfortable with my relationships	0.046 p=0.86	-0.271 p=292	-0.399 p=0.25	-0.087 p=0.87	0.231 p=0.37	0.038 p=0.89	-0.183 p=0.50	0.316 p=0.22	0.217 p=0.40	0.146 p=0.59	-0.108 p=0.71	0.214 p=0.41	0.117 p=0.78	0.028 p=0.92	0.308 p=0.23
In general, I am comfortable with myself when I am in company of others	-0.294 p=0.24	-0.314 p=0.2	-0.159 p=0.66	0.17 p=0.97	-0.280 p=0.26	-0.211 p=0.42	-0.034 p=0.90	-0.341 p=0.17	-0.365 p=0.14	-0.306 p=0.23	-0.128 p=0.65	0.078 p=0.76	-0.314 p=0.45	-0.066 p=0.81	0.026 p=0.92
I feel I can deal with life events as they happen	-0.126 p=0.63	-0.473 p=0.06	-0.489 p=0.15	0.250 p=0.63	-0.05 p=0.85	-0.168 p=0.53	-0.381 p=0.15	-0.249 p=0.34	-0.252 p=0.33	-0.236 p=0.38	-0.383 p=0.18	0.120 p=0.65	-0.111 p=0.79	-0.290 p=0.30	0.10 p=0.7
RNLI percentage	-0.167 p=0.51	-0.423 p=0.08	-0.337 p=0.34	-0.667 p=0.15	-0.148 p=0.56	-0.321 p=0.21	-0.378 p=0.13	-0.152 p=0.55	-0.211 p=0.40	-0.138 p=0.56	-0.336 p=0.22	-0.260 p=0.30	-0.586 p=0.13	-0.188 p=0.49	0.119 p=0.637

Significant mobility items, clinically relevant

Significant self-care and IADL items, clinically relevant

Significant but clinically irrelevant