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The Influence of the Inpatient Rehabilitation Experience on the Transition to Home Among People with Spinal Cord Injury in South Africa: A Qualitative Study

11 October 2024

Cleopatra Floudiotis (2507835)

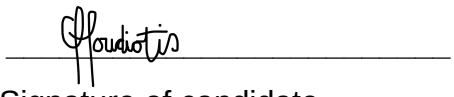
Supervisor: Dr Sonti Pilusa

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the Masters of Science in Physiotherapy.

Johannesburg, 2024

Declaration

I, Cleopatra Floudiotis, declare that this Research Report is my own, unaided work. It is being submitted for the University of the Witwatersrand, Johannesburg, South Africa for a degree of Masters in Physiotherapy. It has not been submitted before for any degree or examination at any other University.

Cleopatra Floudiotis 

Name of candidate Signature of candidate

Date: 11 October 2024

University of Witwatersrand, Johannesburg South Africa

Dedication

I dedicate this to my parents, John and Maria. Thank you for encouraging me to learn, create and grow.

To my siblings, Andrea, Niki, Kosta and Maria-Paula, who have blazed this trail before me.

To Sean, who has shown me what it means to be consistent, disciplined and determined.

Abstract

Background:

Spinal cord injury (SCI) can have a significant impact on a person's ability to self-manage, engage in home life, and participate in community activities. The purpose of rehabilitation following SCI is to empower patients to optimize their ability to do these activities. The experience of inpatient rehabilitation can impact the transition back to home and to the community. However, studies looking at the experience of inpatient rehabilitation in low-middle income countries are scarce. Thus, the aim of this study was to explore how the experience of inpatient rehabilitation following SCI influences the transition to home.

Methods:

This was a qualitative study which used an explorative design. Eleven participants were included in the study, and data was collected using semi-structured interviews. Participants were interviewed within their last week of inpatient rehabilitation in a spinal unit in a private rehabilitation hospital. Interviews were transcribed verbatim, and we used inductive analysis to identify the themes and categories.

Results:

Most of the participants in the study were male, had incomplete spinal cord injuries, and thoracic-level injuries. The themes which emerged from the interviews were overall rehabilitation experience was good," "factors influencing rehabilitation experience" and "unmet care needs influencing readiness for transition to home." The environmental factors which influenced the experience of rehabilitation and the transition to home included the attitude of the health staff, physical space, and care approach. The personal factors included emotions and beliefs. The unmet needs included closing the gap between skills acquired and skills practiced, the physical environment to simulate the home environment, formal and individualized psychological support, and for patients to be involved in decision-making.

Conclusion:

Although the inpatient rehabilitation was good and some patients felt prepared to go home, there are multiple factors which influence the transition to home as well.

Rehabilitation units should take these factors into consideration when developing rehabilitation programmes and training rehabilitation staff to provide specialized, patient-centred SCI care.

Keywords: Spinal cord injury, transition home, rehabilitation, experience, discharge, specialised care, in-patient

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South African Society of Physiotherapy

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List of abbreviations

ABI – Acquired brain injury

ICF – International Classification on Functioning, Disability and Health

MDT – Multi-disciplinary team

MVA – Motor vehicle accident

NTSCI – Non-traumatic spinal cord injury

QoL – Quality of life

SCI – Spinal cord injury

SD – Standard deviation

SHC – Secondary health complication

TSCI – Traumatic spinal cord injury

USA – United States of America

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Chapter 1: Introduction

1.1. Introduction

Spinal cord injury is a significant, life altering health condition, no matter its nature or origin. Spinal cord injury (SCI), both traumatic and non-traumatic, can cause significant physical impairments such as loss of motor and sensory function and loss of bowel and bladder function, leading to a decline in quality of life (QoL) (Cheng *et al.*, 2017), as well as increased burden of care (Turner-Stokes *et al.*, 2016). These factors are indicators for the use of specialized rehabilitation services following SCI (Cheng *et al.*, 2017).

The global incidence of SCI has been increasing over time as people have been engaging more and more in activities which contribute to these injuries. A study by Kang *et al.* (2017) showed that the incidence of SCI is higher in low-middle income countries, and that motor vehicle accidents (MVA) and falls are among the most common causes of traumatic spinal cord injury (TSCI). Similar findings have been reported in Cape Town, South Africa by Sothmann *et al.* (2015), with incidences of violence also added to the list. The incidence of non-traumatic SCI (NTSCI) is not well reported (Joseph *et al.*, 2017). A review of literature from Sub-Saharan Africa by Draulans *et al.* (2011) found that the most commonly reported causes of NTSCI in this region were tuberculosis, neoplasms, degenerative conditions and myelitis. While research in the field of the treatment of SCI has advanced (Rouanet *et al.*, 2017), there is still no cure for SCI (Jazayeri *et al.*, 2015). This highlights the significant role played by inpatient rehabilitation in the recovery following SCI and in the optimization of function, as well as in the improvement in participation in the community (Cheng *et al.*, 2017).

Rehabilitation following SCI should be through a multidisciplinary team (MDT) of health professionals and should empower patients to optimize their independence, transition to home, return to productive life and to manage their own medical requirements as far as possible (Du Plessis *et al.*, 2018; Pefile, Mothabeng and Naidoo, 2019). A scoping review of models of care for patients with SCI revealed that there is no one

universally applied model of care for SCI. In addition, there were several corresponding themes across the reviewed models of care including the value of an SCI specialized MDT at all stages following injury and the delivery of SCI care in rural settings (Ho *et al.* 2021).

The World Health Organization has initiated a global agenda to strengthen rehabilitation care by 2030. Rehabilitation should be available and accessible to anyone who sustains an SCI to allow survivors of the condition to continue to participate in societal activities such as receiving education, being employed and participating in family roles and productive life (World Health Organization, 2013). The Rehabilitation 2030 initiative brings focus to the fact that there is a need to provide quality rehabilitation services for all people of all ages; to bolster entire health systems with the view of adding more rehabilitation services; and that rehabilitation is an indispensable health service necessary for global health (World Health Organization, 2017).

Rehabilitation care is limited in South Africa. In Sub-Saharan Africa, there are only 24 specialized rehabilitation units for SCI, 16 of which are in South Africa (Southern African Spinal Cord Association, 2020). These specialized rehabilitation units, however, are largely in urban areas and mostly privately funded (Pefile, Mothabeng and Naidoo, 2019). Services in the South African public health sector provide for roughly 80%-84% of the population (Mayosi and Benatar, 2014), are often under-resourced, and are not geographically and financially accessible for everyone. Other challenges in the public health sector include the high patient to health worker ratio, as well as inadequate knowledge on disability needs among healthcare workers (Sherry, 2015; Joseph *et al.*, 2017; Morris *et al.*, 2021). These challenges influence care for people with disabilities including spinal cord injured patients.

Care during acute phase can influence long-term outcomes. The Integrated Disability Management and Rehabilitation Pathway of Care document states that patients with SCI should receive 15 to 90 days of high-intensity rehabilitation following the initial

acute treatment stage (Joseph *et al.*, 2017). However, in South Africa it is common that patients who have been admitted to acute hospital emergency departments with a disabling condition are discharged home within 4 days of admission, and may not be referred for rehabilitation services at all (Morris *et al.*, 2021). A study done in Cape Town, South Africa found that the mortality rate of patients with TSCI 4 years after injury was 24%, and of those still remaining, there was a high rate of secondary complications such as pain, pressure sores and urinary tract infections (Madasa *et al.*, 2020). This begs the question, is rehabilitation that **is** occurring in South Africa adequately preparing patients with SCI for a safe transition to home, as well as for optimal reintegration into society?

1.2. Problem statement

In the high-income countries, there is much work being done to investigate the role of rehabilitation in SCI (Ho *et al.*, 2021). However, in low-middle income countries such as South Africa, information on rehabilitation care for SCI is limited (Morris *et al.*, 2021). Most of the evidence on models of SCI care comes from Australia, the United States, Canada and the Netherlands, and there is only a small percentage of evidence pertaining to low-middle income countries (Ho *et al.*, 2021). South Africa has a myriad of social and financial challenges to overcome, and these have a massive impact on the healthcare systems, both publicly-, and to a lesser extent, privately-funded. It is therefore impossible that the available data from high income countries can accurately be extrapolated and applied to the low-middle income world. This highlights the need for information that provides a more accurate view of the situation within the local context.

The responsibility of rehabilitation units to assist patients with SCI to transition to a safe and fulfilled life is high, and it is essential for these facilities to prepare patients for their transition to home as well as for community reintegration, not only to teach them how to manage within a largely adapted institution. While in the hospital setting, the physical environment may be easy to navigate; the “community” members are also patients with disability; and there is access to round the clock medical care. This experience during in-patient rehabilitation may cause patients to misjudge their readiness to return home and back to their communities (Du Plessis *et al.*, 2018), and

once they are discharged and “reality sets in,” this misconception may be quickly thwarted. There is a dearth of information on the role of rehabilitation care within the in-patient setting in preparing people with SCI to self-manage and transition to community living.

1.3. Research question

How do the experiences in inpatient rehabilitation influence the transition to home among people with SCI?

1.4. Aim of study

To explore how inpatient rehabilitation experiences influence the transition to home among people with spinal cord injury.

1.5. Objectives

1.5.1. To explore the inpatient rehabilitation experiences of people with SCI.

1.5.2. To explore how the experiences of inpatient rehabilitation influence the transition to home among people with SCI.

1.5.3. To explore the needs of people with SCI when transitioning from inpatient rehabilitation to home.

1.6. Significance of study

Given that there is little documented on the inpatient rehabilitation experience among patients with SCI in South Africa, learning more from patients who have received treatment at one of the few specialized spinal rehabilitation units in the country and who have already made the transition to home may provide important insights into the gaps in services, as well as into aspects that are working well. It may also provide information towards improving these services within specialized units in the developing world, as well as assisting non-specialized units to provide better care. Understanding the needs and current successes may aid in achieving better outcomes for these patients, and more successful home transitions and community reintegration, as well as prevention of secondary complications. The knowledge gained from this study could also assist with making recommendations relating to health and disability policies and opportunities for further research in the field.

Chapter 2: Literature Review

2.1. Introduction

In this chapter, literature on the experience of rehabilitation will be reviewed. Literature on the experience of people with SCI, as well as of health care professionals and family members, will be included. The "experience" includes the physical rehabilitation environment, health care professionals, the emotional experience, the process of rehabilitation and acquisition of skills, acquisition of information, spinal cord injury care needs, and discharge. Themes identified in the literature have been categorized and subcategorized. Only literature published between 2013 and 2023 has been included.

Search engines: Pubmed, Google Scholar, ClinicalKey, PEDro

Keywords: spinal cord injury, experience, rehabilitation, inpatient, home transition, discharge, specialized

2.2. Spinal cord injury prevalence and incidence

The occurrence of SCI has been on the rise globally due to an increase in engagement in activities leading to SCI. The incidence of SCI appears to be higher in low-middle income countries, ranging from 13 to 220 per million people, while in high income countries it ranges from 13 to 163 per million people (Kang *et al.*, 2017). Globally, motor vehicle accidents and falls appear to be the most common causes of traumatic cases of SCI (Kang *et al.*, 2017). In South Africa, this data is on par, with a study done in Cape Town finding similar results, in addition to instances of violence (Sothmann *et al.*, 2015). The incidence of NTSCI in South Africa as a whole is not well known (Joseph *et al.*, 2017), however a study done in Durban found that NTSCI accounted for 54% of SCI admissions, with a significant association with HIV (Pefile, Mothabeng and Naidoo, 2019). A review by Draulans *et al.* (2011) found that the most common causes of NTSCI in Sub-Saharan Africa were tuberculosis, cancer, degenerative conditions and myelitis. The study by Kang *et al*. (2017) found that prevalence of SCI is not well reported. In high income countries, prevalence of SCI was noted by three articles to be between 490 per million to 526 per million, while the prevalence in low-middle income countries was reported by only one article to be approximately 440 per million people (Kang *et al.*, 2017).

2.3. SCI management and continuum of care

2.3.1. Rehabilitation

Rehabilitation following SCI is imperative to optimize function and improve participation in life activities (Cheng *et al.*, 2017), especially considering that there is no cure (Jazayeri *et al.*, 2015), despite the advancement of research in the field of treatment of SCI (Rouanet *et al.*, 2017).

The World Health Organization defines rehabilitation as "a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment" (World Health Organization, 2017). Rehabilitation includes methods and modalities which address impairments, activity limitations and participation restrictions, as categorized by the International Classification of Functioning, Health and Disability (ICF), and should take into account the person's preferences, goals and health condition to keep the person at the centre of it (World Health Organization, 2017). Following SCI, rehabilitation should be executed by an MDT of health professionals. The aim should be for people with SCI to be empowered in their independence, management of their own medical requirements, and in their return to productive life, as far as possible (Du Plessis *et al.*, 2018; Pefile, Mothabeng and Naidoo, 2019).

2.3.2. Rehabilitation in South Africa

In South Africa, rehabilitation following injury or disease is not prioritized. There are 24 specialized SCI rehabilitation units in Sub-Saharan Africa, and 16 of these are in South Africa (Southern African Spinal Cord Association, 2020). Most of these units are in urban areas and privately funded (Pefile, Mothabeng and Naidoo, 2019), which makes them inaccessible to the 80-84% of the population using public health services (Mayosi and Benatar, 2014). Furthermore, services in the public sector are often under resourced, with inadequate expertise on disability care among health workers. They also have a high patient to health worker ratio and are not geographically and financially accessible for everyone (Sherry, 2015; Joseph *et al.*, 2017; Morris *et al.*, 2021). The number of occupational therapists and physiotherapists employed in the public sector specifically is small compared to the number of therapists who are registered with the country's counsel for health professionals, and the ratio in general

of physiotherapists is seven per 100 000 people (Myezwa and Van Niekerk, 2013). There is also the added challenge of the looming National Health Insurance (NHI) policy in South Africa, which could further impact the way in which rehabilitation services are delivered (Myezwa and Van Niekerk, 2013) given that rehabilitation is not prioritized as much as curative and medical aspects of health (Morris *et al.*, 2019).

2.3.4. Rehabilitation environment

According to the ICF, environmental factors are important determinants of health. Environmental components include attitudes of people, physical or architectural environment, and law (World Health Organization, 2002). The rehabilitation environments in South Africa are largely within hospital settings (Southern African Spinal Cord Association, 2020). This implies that the environment is controlled and clinical relative to home and the community, and the expectation is that there are health professionals on hand at all times. In the ward environment where patients do many of their activities of daily life during their rehab stay, there may be mechanically adjustable hospital beds and wheelchair-friendly bathrooms. In addition, domestic tasks are completed for patients: beds are made by nurses, food is prepared and served entirely by catering staff, and ward environments are kept clean by hospital staff. Since there is no one universally used model of care for SCI rehabilitation (Ho *et al.*, 2021), it is possible that there may not yet be an optimal rehabilitation environment. Even in high-income countries, where it is assumed there may be more resources, there may still be positive and negative aspects. Research on the impact the environment on SCI health outcomes is needed.

2.3.5. Physical rehabilitation environment

The physical hospital environment can affect the patients' future outcomes. A qualitative study conducted with patients with SCI in a rehabilitation center in New Zealand by Bourke *et al.* (2014) noted that participants described the rehabilitation environment as safe, secure, and geared for people in wheelchairs, which was different to their homes. Reiterating this point, Nunnerley and Dean (2013), whose study was also done with patients with SCI in New Zealand, found that participants who had been discharged from the rehabilitation unit had difficulties navigating the

change between the unit and the environment they experienced in the community, which they described as “unfamiliar and unsympathetic.” They had difficulty applying the skills they had learnt in rehab to the more challenging community environment, which they also found to be inconsistent even in supposedly wheelchair-friendly spaces (Nunnerley and Dean, 2013).

The physical environment in these hospitals can have an impact on the emotional state of the patients in hospital. A systematic review of qualitative literature on the experiences of people with SCI found that having access to nature or the outdoors was associated with positive emotional experiences such as peace, calm, connection, laughter and fun (Simpson, Villeneuve and Clifton, 2020). The fact that patients at many rehabilitation facilities are accommodated in wards or shared rooms may also impact the experience. Nunnerley and Dean (2013) found that some of their participants felt that they did not have privacy when performing personal care tasks and felt exposed. Colley, Zeeman and Kendall (2018) explored the role of corridors in rehabilitation centres and their impact on the experience of people with SCI and acquired brain injuries (ABI), as well as how the staff working at the centres perceived them. The study reported that some staff members felt that maintaining privacy and dignity was a challenge in the rehabilitation space. They expressed concerns about the fact that conversations about, or with, patients in corridors were often overheard. They also noted that patients had to move or be transferred through corridors to go between their rooms and the bathrooms, which meant that at times they were not adequately dressed when in the more public areas (Colley, Zeeman and Kendall, 2018).

The physical environment can be physically challenging for patients. Colley, Zeeman and Kendall (2018) found that people with SCI struggled with various aspects of navigating the hospital physical environment, especially while learning wheelchair skills. The patients reported difficulties navigating tight sections of corridors either because of obstacles or design; passing through narrow doorways; and pushing buttons on elevators. Some participants felt that they needed to manoeuvre their wheelchairs through difficult spaces before even getting to the rehabilitation rooms for sessions, and that they wasted time moving between rooms. Participants suggested

that the design of the corridors should take into account that patients have various wheelchair skill levels; and that these centres should be designed with better placement of the most frequently used rooms (Colley, Zeeman and Kendall, 2018). The availability of equipment and resources can also have an impact on the experience of hospitalization for people with SCI. A study done in Australia in non-specialized facilities found that participants had difficulty managing their bowel care due to the lack of appropriate bathroom equipment such as commodes, and limited space in bathrooms. They also noted that they did not have access to the right foods which would usually assist them in their bowel care. This lack of appropriate resources was concerning for participants (Pryor, Haylen and Fisher, 2021). Access to these resources which influence the in-patient experience and the development of self-management skills may have an impact on the transition to home.

2.4. Health care professionals

2.4.1. Availability of health care professionals

A significant difference between the inpatient rehabilitation setting and home is the availability of health professionals. In hospital, there are generally doctors, nurses and various allied professionals at the disposal of the patients to assist when needed. A theme from a study by Nunnerley and Dean (2013) was that patients had a “safety net” while in rehab since there was always access to supervision and assistance. While this may seem positive, it also meant that they had limited opportunities to be autonomous in their self-care. Du Plessis *et al*. (2018) suggested that this support in hospital may result in patients underestimating how much assistance they need, and overestimating how much support they may have on discharge.

The study by Nunnerley and Dean was done in New Zealand, a high-income country, and this may not always be the case in rehab centers in low-middle income countries. In Mongolia, for example, doctors working in this sector believe that there may not be adequate numbers of rehabilitation staff. They estimated that in urban areas, there were two to five rehabilitation doctors in tertiary hospitals and fewer in smaller centers, and in rural areas there were none. There were also very few rehabilitation physiotherapists and other professionals with specialized skills (Dorjbal *et al.*, 2019). This is also the case in the public sector in South Africa, where the ratio of

physiotherapists to the population accessing public health care is twelve to 100000, and occupational therapists is seven to 100000 (Myezwa and Van Niekerk, 2013). On the other hand, a study done in Australia, a high income country, found that while patients with SCI had access to enough nursing staff, they did not receive the time and attention they wanted, particularly for the management of their bowels, as they perceived the nurses' workloads to be too heavy (Pryor, Haylen and Fisher, 2021). Specifically with regard to their bowel care, patients perceived the assistance from nursing to be rushed as they needed to assist multiple patients, and this had a negative effect on the patients' perception of security. They also found that although they had access to health professionals who could assist, it was unclear which professionals were responsible for managing bowel care with patients (Pryor, Haylen and Fisher, 2021).

2.4.2. Skill and knowledge of health care professionals

Health professional skills and knowledge levels play a critical role in patient care. A study done on the prevention of secondary health complications (SHC) in SCI in South Africa found that patients felt that health care professionals, in and out of hospital, were not knowledgeable on SHC's or their prevention. Some noted that even when in hospital, health workers did not comply with prevention protocols that were in place (Pilusa, Myezwa and Potterton, 2021a). As this was a perspective of the participants, it is unclear why this was the case. A study done by Badenhorst *et al.* (2021) explored the experiences of people with rugby-related SCI in accessing health care in South Africa. The authors found that many of their participants had been disappointed by the quality of the rehabilitation outside of specialized units, particularly with regard to the services provided by students in the state-run facilities. The SCI participants felt that they did not receive adequate care from health professional students who were still in training compared to the qualified physiotherapists (Badenhorst *et al.*, 2021). It is important to consider here that in the South African health system, students are meant to supplement services receieved by professional staff, however this may not always be the case. Participants in this study also expressed that the qualified and experienced professionals had helped them not only within their own scope of practice, but also with knowledge and information beyond that (Badenhorst *et al.*, 2021). On the same note, in a study done in Mongolia, health professionals working with people with SCI were transparent about their knowledge limitations regarding SCI-related health

conditions, rehabilitation, prognosis, assistive devices, sexual health and fertility (Dorjbal *et al.*, 2019).

2.4.3. Attitudes of health care professionals

While access to healthcare professionals and their level of expertise is important, so too are the attitudes with which they interact with people with SCI in the inpatient setting. In one study on the experiences of people with SCI in rehabilitation in New Zealand, it was found that the participants' feelings of control were impacted by the attitudes and approaches of staff: feelings of control were positively impacted when healthcare professionals showed commitment to their roles, were supportive and provided motivation, as this added to participants' feelings of value and respect. On the other hand, when healthcare professionals approached participants in a rushed or uncaring way, were negative about the future, or were inattentive, participants felt less of a sense of control (Bourke *et al.*, 2014). This negative impact was also highlighted in a study done in Italy, where it was found that participants experienced distress and disorientation when healthcare professionals' approach was rigid, rushed, and when scheduling was not based on the participants' needs, but rather on the needs of the organization or bureaucratic influences (Conti *et al.*, 2020). While the attitudes of health care professionals in the rehabilitation setting clearly impact the overall experience, these studies do not explore how this impacted the transition to home.

2.5. SCI and emotional impact

2.5.1. Emotional impact

There is a link between physical and emotional health. In New Zealand, Nunnerley and Dean (2013) found that SCI participants felt that the main focus in rehabilitation was their physical recovery, and that their emotional needs were not made a priority, despite them identifying changes in their physical, psychological and spiritual well-being (Nunnerley and Dean, 2013). This finding was corroborated by Bourke *et al*. (2014), who found that some patients with SCI felt that they were well prepared and cared for from a physical perspective, but that the psychosocial side of transitioning back to home was not very well addressed, and this included dealing with the way in which other people interacted with them following their rehabilitation.

2.5.2. Patient involvement during rehabilitation

Person-centred care promotes patient involvement in care to empower the patients. Recognizing patients as core participants in their care was also highlighted by Lindberg *et al.* (2013) in their study done in Sweden. Participants with SCI voiced that they felt it was necessary for staff to become acquainted with them as individuals and to treat them as such, including recognizing their individual needs and preferences. When this did not occur or when staff members did not listen to them, participants felt that staff members were insensitive. This had an impact on participants' feelings of integrity and being respected by staff (Lindberg *et al.*, 2013). Nunnerley and Dean's study (2013) highlighted the importance of the patient-centred approach, as their participants perceived that the structured system of rehabilitation was not flexible enough to accommodate individual needs.

People with SCI need to be able to participate in making decisions in their lives. Lindberg *et al.* (2013) also found that their participants thought it was essential that they be involved in conversations around their rehabilitation plans; that their opinions be considered; and that they have opportunities to make their own decisions after receiving all the relevant information. They also noted that their active participation in decision making may be influenced by their medical condition: in the early stages after their injuries, they may have chosen to have decisions made for them, however as they became stronger, they placed more value on being able to participate (Lindberg *et al.*, 2013). In the United States of America (USA), a study exploring the narratives formed by married people after SCI found that their participants had trouble thinking about the future and making decisions because they felt they were "in transition", and they required information from others to do so (Bender and Burgess, 2020). A study done in New Zealand found that participants' feelings of control of their lives lay in them learning that they could still take responsibility for making decisions (Bourke *et al.*, 2014), and a systematic review done in 2020 had similar findings, with participants describing more feelings of control over various aspects of their lives (including their health, bodies and recovery) as the facility interventions facilitated improved participation in tasks that allowed them to plan and decide on aspects of their lives (Simpson, Villeneuve and Clifton, 2020).

2.6. SCI care needs

2.6.1. Activities of daily living and self-management

Independence (as far as possible) in self-management and activities of daily living is one of the objectives of inpatient rehabilitation in SCI. This has been noted to be one of the challenges for people with SCI (Machida, Irwin and Feltz, 2013) and one study done in the Netherlands found that participants with SCI felt that while in the rehab facility their loss of independence was taken too lightly, and that it was more of a challenge to manage on their return to the community than they expected it to be (Van Diemin *et al.*, 2017). Independence and self-management complex as it may depend on each individual's level of injury.

Many people with SCI do not reach full independence, and thus often require a care giver to assist them with their activities of daily living. A study in Italy found that participants relied totally on others to complete their basic self-management tasks, and often more so than they actually needed to due to the fear of injuring themselves or failing (Conti *et al.*, 2020). This study also found that many participants experienced feelings of guilt for having to depend on another person for these tasks (Conti *et al.*, 2020). Rehabilitation care can minimize these experiences. Participation in self-management tasks, even in small ways, can improve autonomy, self-reliance and participation in meaningful activities, community activities, life roles, as well as in obtaining information and making decisions (Simpson, Villeneuve and Clifton, 2020).

2.6.2. Bowel and bladder management

One important, and specialized, aspect of SCI rehabilitation is bowel and bladder management. A study done in the USA to investigate associations between different bladder management techniques and demographic, neurological and urologic factors found that the most commonly used methods in their population were clean intermittent catheterization, the Crede maneuver, the use of adult continence pads, spontaneous emptying, and indwelling catheters. This population was predominantly male, however, and this may not be the case in a female population with SCI (Morin *et al.*, 2019). Bladder and bowel management is an important aspect of self-management, and the failure of a person with SCI to manage their bowel and bladder correctly could lead to secondary complications.

In Australia, a study was done to investigate the challenges of people with SCI relating to bowel care when in non-specialized medical settings (Pryor, Haylen and Fisher, 2021). The study found that people with SCI, when admitted to a hospital setting not specifically equipped for spinal patients, experienced several problems when it came to managing their bowels. Firstly, the hospitals were fast-paced, and the staff were often changing and had high workloads. This made it difficult for the patients to implement their bowel management methods in their usual ways, which required a slower, consistent, and individualized approach. Secondly, patients noted difficulty with the availability of staff, as well as the quality of the assistance they were receiving. It was also noted that no one staff member was able to provide all aspects of bowel care (Pryor, Haylen and Fisher, 2021). This study highlights the need for SCI patients to be cared for in hospital by specially trained staff who are part of an MDT. Bowel and bladder care also needs to be done in conjunction with mastering physical skills such as commode or toilet transfers.

2.6.3. Sex and fertility

Education on sex and fertility should be part of rehabilitation following SCI. A study conducted by Barret, Ho and Finlay (2022) in the United Kingdom explored the perceptions of health care professionals on the barriers and facilitators in supporting sexual function following SCI. The participants highlighted the lack of reading material on sex following SCI in the spinal unit in comparison to the abundance of material on other SCI rehabilitation topics. They also emphasized the importance of recognizing the effect of SCI on the patient's partner/spouse with regard to sex and intimacy; and they expressed that the partner was often overlooked by health professionals (Barrett, Ho and Finlay, 2022). People with rugby-related SCI in South Africa identified the need for information and support on sex and fertility following SCI (Badenhorst *et al.*, 2021). It is worth noting that information regarding sex and fertility may not be relevant or meaningful for all people with SCI at different stages in their lives, depending on their relationship status and sexual activity.

Health care professionals participating in the study by Barret, Ho and Finlay (2022) identified various limiting factors in their ability to provide support on sex: firstly, they felt that there was a lack of education and support on the topic for the health

professionals themselves; and secondly, they felt that their own beliefs and cultural norms impacted their interactions on the subject. Even so, they noted that the conversation with patients should be open, regardless of whether the health professional was an expert on the topic or not, and that it should be approached as a multi-disciplinary team (Barrett, Ho and Finlay, 2022).

2.6.4. Leisure

Following SCI, a person's ability to participate in premorbid leisure activities is compromised. Clifton described his own experience following SCI as follows:

"I also struggled to work out how to enjoy myself. Prior to my injury I was a passionate surfer and played golf regularly, and also diligently jogged and swam to keep fit. Without these endeavors, I didn't know how to fill my time, spending most of my day and weekend staring at the computer screen" (Clifton, 2014, p 1826). A study which conducted a meta-synthesis of qualitative data on leisure time in people following SCI found that there were various factors which were barriers to participating in leisure activities following SCI. These included subjective well-being like depression and low self-confidence; poor social well-being such as social exclusion and attitudes of the community; and environmental factors such as community access and financial access to accessible sports (Williams, Smith and Papathomas, 2014).

People with SCI who participated in wheelchair rugby following their in-rehabilitation expressed that that engaging in sport was a positive driver of their recovery. This study found that participants felt a sense of achievement through sport, and that it gave them the opportunity to be active, driven and to work through some emotions related to their SCI (Machida, Irwin and Feltz, 2013).

This finding is in line with a literature review on the well-being of people with SCI which found that previous leisure tasks were important. Some people with SCI expressed the need for finding new leisure pursuits that are appropriate within the new limitations. Engaging in social leisure activities has been found to improve well-being through motivation, encouragement, acceptance, experiencing fun, and being part of a community. Some people with SCI also felt that leisure tasks were not adequately addressed in rehabilitation (Simpson, Villeneuve and Clifton, 2020). How this experience impacted the transition home is not known.

2.7. SCI-related education

2.7.1. Acquisition of information

Adjusting to and living with SCI requires education. People with SCI have described the acquisition of information as vital to being able to participate and advance in their rehabilitation journeys (Lindberg *et al.*, 2013; Conti *et al.*, 2020).

Three different studies found that while participants felt the acquisition of information was very important, the way in which it was delivered, by whom, and the timing of the delivery of the information was also important (Lindberg *et al.*, 2013; Bourke *et al.*, 2014; Badenhorst *et al.*, 2021). Participants in a study in Sweden expressed that they wanted to receive all the information about their condition and prognosis, even if it was negative. They also wanted health professionals in the rehabilitation facility to listen to them, answer their questions, as well as give the information in a way that was individualized according to each patient's needs (Lindberg *et al.*, 2013). A similar study done in New Zealand found that participants got their information from two main sources: staff and other people with SCI (including in-patients and peer supporters). The information given by staff was perceived as more or less credible based on the amount of SCI experience of the staff, and it was also perceived as positive or negative based on the way in which the information was delivered (Bourke *et al.*, 2014). In South Africa, participants with rugby-related SCI who had been managed in public and private sectors identified the information they received on their conditions throughout their recovery was lacking (Badenhorst *et al.*, 2021).

Participants in a study in the USA shared that the timing of receiving information was important (Machida, Irwin and Feltz, 2013). During the initial hospital phase, they expressed that they were confused, distressed, and overwhelmed, and this made it difficult to take in and grasp information about their condition. They also noted that even information received in the early rehabilitation phase was under-valued at the time. The authors found that psychological stability in these participants was essential for being able to absorb educational content, and that participants often felt pressured to take in all the information presented to them. Aside from the emotional barriers, participants also felt that their fatigue, pain and feelings of physical weakness in the initial phases were also limiting their ability to engage with the new information (Machida, Irwin and Feltz, 2013). These contradicting findings show that care needs

to be taken to share the right information at the right time within the rehabilitation journey.

2.7.2. Family / caregiver involvement

Many patients with SCI require assistance of a caregiver or family member on discharge from rehabilitation due to their limitations in independence, and the burden of care may be higher in those with higher-level injuries. It is therefore important for caregivers to be educated and trained prior to discharge. A study done in Mongolia, a low-middle income country, which explored the perspectives of medical doctors working with people with SCI, found that there is poor awareness on SCI and the importance of long-term SCI rehabilitation among people with SCI and their caregivers; and they believe that this is largely due to the lack of basic health education in general, making it challenging for them to grasp more complicated SCI concepts. Another challenge is that, while the medical staff attempt to conduct caregiver trainings regularly, caregivers often alternate, and this makes it difficult for any to receive all the information and training (Dorjbal *et al.*, 2019). A study done in South Africa found that it was important for family members and caregivers to be educated on SCI, particularly on discharge, so that they can support the prevention of secondary health complications (Pilusa, Myezwa and Potterton, 2021a).

In Sweden, some patients with SCI in rehab expressed how important it was to involve their spouses or family members in the decision-making process regarding their care, and that the SCI had a big effect on their family members as well. On the other hand, within the same study, some participants did not want to involve their families in their rehabilitation as they believed it was not beneficial, and that the process was predominantly to do with themselves and the rehabilitation staff (Lindberg *et al.*, 2013).

2.7.3. Peer support

While gaining information from health care professionals in rehabilitation is necessary, people with SCI could also learn from others who have had similar experiences. Participants in a study in New Zealand expressed that interacting with peers with SCI was a valuable source of learning about experiencing life with SCI and using a wheelchair. They felt that their peers could empathize and understand more so than others who were offering support or information. Some participants preferred to work

with “independent living coaches,” who were peers with SCI, rather than staff when doing activities such as preparing a meal (Bourke *et al.*, 2014). This is in line with the findings of a review of the literature on well-being in SCI, which found that information obtained from formal peer support services had more validity due to the shared experience, and that people with SCI found it easier to have conversations about personal topics such as bladder management and sex with their formal peers (Simpson, Villeneuve and Clifton, 2020). In the USA, participants in a study exploring the influence of sport on the experiences of people with SCI found that participants felt that it was important for them to meet people with disabilities to which they could relate, and this happened through interacting with the rugby team on which they played, or through support groups or rehabilitation programs. These people with SCI described that it encouraged their own need to change when they see others who had worse injuries adapt successfully and be independent (Machida, Irwin and Feltz, 2013).

2.8. Readiness for discharge

2.8.1. Perceived readiness for discharge

The ultimate goal of rehabilitation in SCI is home discharge and eventually full participation in life events, and it is important for patients to feel prepared for this. A study done in a government facility in South Africa in 2018 found that there was a discrepancy between how ready patients with SCI felt they were for discharge compared to how ready their therapists thought they were (Du Plessis *et al.*, 2018). While most of the participants thought that they would need help at home, they also perceived themselves to be able to manage self-care tasks, their medical requirements and their everyday needs. Their physiotherapists, on the other hand, did not believe that the patients were ready to manage these tasks (Du Plessis *et al.*, 2018).

Another study in New Zealand in 2014 found that participants felt that the difference between simply considering their move from the spinal unit to their discharge destination versus actually making the move elicited a sense of “shock.” One participant felt unprepared with certain elements, such as having a carer in his personal space at home, which was something he had never had prior to his SCI. This participant also expressed feeling unprepared to meet people and explain his injury

outside of the environment of the spinal facility. Some participants felt that the spinal facility did not provide a realistic benchmark of how their injuries would impact their lives at home. This is because the facility environment was so different to that of the participants' homes. The home environment which, before the participants' injuries was familiar, becomes new (Bourke *et al.*, 2014). Home trials may be a solution to this problem, however there is a dearth of literature on this subject.

2.8.2. Discharge destination

One factor that may indicate the success of the outcomes in rehabilitation is the discharge destination following SCI. A study done in Canada in 2017 investigated whether specialized rehabilitation had an impact on the discharge destination, and what the other factors were that influenced this (Cheng *et al.*, 2017). When comparing a group which received specialized rehabilitation with another group which did not receive rehab, it was found that the rehabilitation group was three times more likely to return home, rather than to another facility. It is necessary to note, however, that the rehabilitation group was younger than the group which did not receive rehab, and this may have also influenced the discharge destination. In addition, while the discharge destination itself was known, the study did not investigate *how* the participants coped at that discharge destination (Cheng *et al.*, 2017). A study done within the public health system in South Africa found that most participants with SCI were discharged from rehabilitation to private residences, and that discharge was achieved most successfully in participants with TSCI compared to those with NTSCI (Alves, Pilusa and Mashola, 2023).This study also did not investigate how participants coped following discharge.

2.8.3. Continuity of care

SCI care needs extend well beyond the acute and initial rehabilitation phase of recovery. In Italy, Conti *et al.* (2020) found that participants with SCI were unsure how to use the skills they had developed during their inpatient rehabilitation once they were discharged, and were unsure whether they had been given all the required information. They felt that there was a disconnect between the rehabilitation facilities and the community facilities and health care providers. They felt that the community providers did not have enough knowledge on their conditions, which led them to feel that the

rehabilitation facility was their only option when they needed care post-discharge (Conti *et al.*, 2020). This sentiment was echoed by participants with rugby-related SCI in South Africa, who felt that there were not enough health professionals in the community, particularly rehabilitation professionals such as physiotherapists and occupational therapists, who could assist them in continuing with their physical rehabilitation. One participant who had been rehabilitated in a state facility noted that on his discharge from hospital, he was still unable to complete any functional tasks on his own, and would have benefited from more rehabilitation services in the community (Badenhorst *et al.*, 2021). Another study done in South Africa found that rehab therapists expressed that there was not enough emphasis during in-patient rehabilitation on empowering patients to manage their own secondary health complication prevention following discharge (Pilusa, Myezwa and Potterton, 2021a).

In Mongolia, barriers to rehabilitation and the continuity of care were related to limitations in knowledge and awareness regarding SCI within all areas of their health system, from health professionals on the ground to policy makers, as well as in the community. They felt that compared to other areas of medicine, SCI-related conditions receive fewer recognition and resources, which limits the strength of rehabilitation services in the country (Dorjbal *et al.*, 2019).

2.9. Conclusion

Most of the literature exploring the perspectives of people with SCI, particularly regarding inpatient rehabilitation, has been done in high income countries. These studies, therefore, cannot be used to accurately describe the experience of people with SCI in low-middle income countries like South Africa. Having said that, the existing literature is insightful, and can guide current and future investigations on the experiences of people with SCI.

Chapter 3: Methodology

3.1. Introduction

This chapter discusses the study design, study setting, population, data collection procedures including ethical clearance, as well as the pilot and main study procedures.

3.2. Study design

This research project was an exploratory qualitative study. This design was the most appropriate as it allowed the authors to be flexible and open-ended within the data collection process. It was the best design to achieve the objectives of the study, and to provide a framework for future research (George, 2023).

3.3. Study Setting

The study was based at the spinal unit at a rehabilitation hospital in Johannesburg, South Africa. The hospital is a private in- and outpatient hospital offering rehabilitation care for patients with SCI, stroke, orthopaedic polytrauma and acquired brain injury. The hospital offers care provided by a multi-disciplinary team including doctors, nurses, physiotherapists, speech therapists, occupational therapists, social workers and psychologists. Services provided include wheelchair and assistive device assessments and procurement, condition-specific education, group therapy, hydrotherapy, gait retraining with unweighing systems, and a robotic gait trainer. A private institution was chosen as the first author works in the private sector, and there is a need for insight into the experience in both private and public sectors.

3.3. Study Population

The study population included patients with SCI.

3.3.1. Inclusion criteria:

Patients older than 18 years who have sustained any SCI, whether traumatic or non-traumatic, and who had received inpatient rehabilitation at the Rehabilitation Hospital.

3.3.2. Exclusion criteria:

Participants were excluded if they had had any rehabilitation stays prior to this admission; they were admitted with secondary complications such as pressure sores; had a length of stay less than six weeks; and/or had sustained any other injury or event resulting in severe cognitive fallout.

3.3.3. Sample size and selection:

Participants were selected from a data base of patients who were admitted to the spinal unit in the rehabilitation hospital, and who were in the final week of their rehabilitation stay, or who had been discharged within 1 month prior to data collection.

Eleven participants were recruited with assistance from an employee at the rehabilitation hospital. Interviews were conducted until no new themes were emerging and saturation was reached (Morse, 1995; Saunders *et al.*, 2018).

3.4. Data collection procedures

3.4.1. Interview guides

An interview guide was developed by the authors based on previous literature (Nunnerley and Dean, 2013; Bourke *et al.*, 2014), and was used to facilitate the semi-structured interviews (Appendix A). Section A of the interview guide included demographic data and Section B included open-ended questions with probes. The probes were chosen using the ICF framework to break down the “hospital environment” into several factors including physical ward environment, therapy environment, psychological support, and personnel involved.

3.4.2. Pilot study

A pilot interview was conducted to refine the interview guide, as well as for the author to practice her interview skills. Due to recruiting limitations (limited patients who met the inclusion and exclusion criteria, and who agreed to participate) at the time of the pilot interviews, only one participant was included in the pilot study. The participant used in the pilot study was recruited prior to his discharge, and he was provided with an information sheet on the purpose and procedure of the study. Written informed consent was obtained. The interview was conducted telephonically following his discharge from the spinal unit at the rehabilitation hospital and the interview was audio recorded. The interview was conducted telephonically one week after discharge as the participant, who had agreed to participate in the study while still in the hospital, was discharged prior to the original discharge date. The data was included in the main study, however the data collected may not have been as in depth due to the telephonic nature of the interview. The demographic questionnaire was completed, and this was followed by a discussion led by the semi-structured interview guide. Notes were kept during the interview, and these were discussed with an experienced academic in the

field following the interview. The interview guide was refined: some questions were made to be more open-ended, and the categories were further broken down to include specific elements of the “environment.” The interviewer’s experience was discussed, and suggestions were made to improve the author’s interview skills.

3.4.3. Main study

Interviews for the main study were conducted in person at the rehabilitation hospital in the ward, the garden or in a cafeteria area, as chosen by each participant. A therapist employed at the rehabilitation hospital assisted with introducing the authors to the participants, and the interviewer then discussed the information sheet and obtained informed consent. Eight interviews, including the pilot interview, were conducted by the first author in English, and the other three interviews were conducted by the second author in Zulu to ensure interviews were done in the language of the participants’ choice. The main study interviews were all done within the final week of each participants’ rehabilitation stay. All interviews were audio recorded, field notes were kept, and an interview journal was kept. Trustworthiness of the data was ensured by using the following approaches (Krefting, 1991; Nowell *et al.*, 2017). Credibility was upheld by maintaining the inclusion criteria and only including participants who could clearly dictate their experiences, and by conducting regular discussions with the co-author about the data collection process, results and analysis. Triangulation of the methods was done during the initial coding process. Dependability was ensured by analysing a portion of the same data twice and comparing the findings. The participants’ demographic data was included for transferability, and the interviews were audio recorded to assist with confirmability of the data.

3.5. Data analysis

Once the interviews were completed, the data was transcribed verbatim. Interviews conducted in Zulu were translated into English and transcribed by an external translator and transcriber, and the English interviews were transcribed by the author. The transcribed subject matter was studied, and general ideas were consolidated, following which smaller “meaning units” were identified. These were then arranged into themed and encoded (Erlingsson and Brysiewicz, 2017). The data was analysed manually and inductively.

3.6. Ethical considerations

Ethical clearance was granted by the University of Witwatersrand Human Research Ethics Committee (Appendix B), as well as by the hospital group Research Operations Committee (Appendix C). The hospital group was kept anonymous in the research report in adhering to their Research Operations stipulations. Information sheets explaining the purpose and details of the study were given to all prospective participants (Appendix D) and each participant gave verbal or written informed consent (Appendix E) to participate. Participants took part in the study of their own accord and were not penalised for leaving the study at any time. The identities and demographic information of the participants remain confidential and were used for the purpose of the study only. Participants were given participant codes and pseudonyms to maintain anonymity when using quotes in the results section. The participants did not incur any costs by participating in the study, and the interviews did not interfere with their therapy schedule. Data was kept in a password protected folder on the first author's hard drive, and physical consent forms were kept in a secure location by the first author. The data and forms will be destroyed after 6 years, in accordance with the University regulations.

3.7. Summary

In this chapter the methodology of the study was outlined. In the next chapter, the results will be presented.

Chapter 4: Manuscript

In this chapter the results will be outlined. The results will be presented as a manuscript, titled: **Influence of Inpatient Rehabilitation Experience on the Readiness to Transition to Home Among People with Spinal Cord Injury in South Africa: A Qualitative Study.**

Journal name	South African Society of Physiotherapy Journal of Physiotherapy for review.
Authors	Cleopatra Floudiotis, Sonti Pilusa
Contribution of the authors	Cleo Floudiotis: Conceptualization, Data collection, Data curation, data analysis, funding, visualization and writing the manuscript. Sonti Pilusa: Conceptualization, supervision, data analysis, reviewing and editing.

Abstract

Background

The purpose of inpatient rehabilitation for people with spinal cord injury (SCI) is to empower them to return to home and community life. The patient experience during rehabilitation can influence the transition to home. Studies on this experience from the perspective of the patient are limited in low-middle income countries.

Aim

To explore how inpatient rehabilitation experiences influence the readiness to transition to home among people with spinal cord injury.

Setting

This study was set at a private rehabilitation hospital in South Africa.

Methods

We conducted eleven semi-structured interviews with patients with SCI in their final week of hospital inpatient rehabilitation. All interviews were transcribed verbatim. The transcripts were inductively analysed to identify themes and categories.

Results

Three themes emerged: “overall rehabilitation experience was good,” “factors influencing rehabilitation experience” and “unmet care needs influencing readiness for transition to home.” The inpatient rehabilitation experience and transition to home was influenced by hospital environmental factors and personal factors. The unmet care needs included the need to bridge the gap between skills learnt and skills practiced, simulation of home environment, formal and individualised psychological support, and patient-centred care with regard to involvement in decision-making and communication.

Conclusion

Rehabilitation needs to prepare patients for home. This study found multiple factors that influence inpatient rehabilitation and the transition to home. These must be considered when developing rehabilitation programmes and training health professionals.

Introduction

Rehabilitation following a spinal cord injury (SCI) is needed to address the resulting physical impairments and functional limitations which can lead to poor quality of life (QoL) (Cheng *et al.*, 2017) and increased burden of care (Turner-Stokes *et al.*, 2016). According to the World Health Organization, rehabilitation should be guided by the categories highlighted in the International Classification of Functioning, Health and Disability (ICF) to optimize functioning within the person's environment, while keeping the individual's goals, preferences and circumstances at the centre (World Health Organization, 2017). Rehabilitation should be interdisciplinary, with the ultimate goals of enabling people with SCI to return to productive life and to self-manage as far as possible (Du Plessis *et al.*, 2018; Pefile, Mothabeng and Naidoo, 2019).

The World Health Organization has put forward a global action initiative to strengthen rehabilitation care by 2030. This initiative states that rehabilitation care should be accessible and available at all levels of care to all people with disabilities to allow them to participate in home and community life (World Health Organization, 2017). Currently, there is no one model of care for SCI that is universally used (Ho *et al.*, 2021). In addition, most of the evidence on SCI rehabilitation has been conducted in high income countries, such as Australia, the United States and Canada (Ho *et al.*, 2021). In low-middle income countries such as South Africa, however, contextual evidence on SCI rehabilitation is limited.

In South Africa, rehabilitation care for people with disability, including SCI, is not prioritized and needs strengthening (Morris *et al.*, 2021). There is a myriad of health system, social and economic challenges which impact both private and public health care systems. The mortality rate of patients with traumatic SCI in Cape Town, South Africa, is 24% four years after injury, and of those still remaining, many have secondary health complications including pressure sores, urinary tract infections and pain (Madasa *et al.*, 2020). This highlights the need for quality rehabilitation services that adequately prepare patients for home and community reintegration within the South African context. This study, therefore, explored the experiences of inpatient rehabilitation among people with SCI and how this influenced their transition to home. To the authors' knowledge, there is no other study in South Africa exploring the experiences of inpatient rehabilitation and the influence on the transition home in SCI.

Methods

Study design

This study used a qualitative design to explore the experiences of rehabilitation in people with SCI.

Study setting

This study was done at a private rehabilitation hospital which renders multidisciplinary team services for SCI, stroke, orthopaedic polytrauma and acquired brain injury. All patients receiving care at the rehabilitation hospital are funded through their own private medical aid (medical insurance), or state-lead compensation funds such as the Workmen's Compensation Fund and the Road Accident Fund. In the spinal unit, patients receive mainly physiotherapy and occupational therapy in individual and group therapy sessions. The length of stay for patients with SCI in this hospital is generally between 6 and 12 weeks. In preparation for discharge, patients are encouraged to go to their discharge destinations for weekend trials.

Study population

Patients with SCI regardless of aetiology or level of lesion; who were over the age of 18; who were within their week of discharge; and who had received inpatient rehabilitation at the spinal unit for at least 6 weeks were recruited by the first author, with the assistance of an employee at the rehabilitation hospital.

They were excluded if they were admitted with any secondary complications such as pressure sores or had sustained any other injury or event which resulted in severe cognitive fallout.

Data collection

Semi-structured interviews were conducted using an interview guide which was developed by the authors based on previous literature (Nunnerley and Dean, 2013; Bourke *et al.*, 2014). The interview guide had 2 parts: section A was a questionnaire used to gather demographic information, and section B included open-ended questions with probes, which were selected based on the ICF framework (World Health Organization, 2002). The probes assisted in categorizing the "hospital environment" into factors such as physical ward and therapy areas, staff involvement

and psychosocial support. The final questions in section B were related to the needs of people with SCI while in rehabilitation and in the transition to home.

A pilot interview was conducted with one participant telephonically. The participant used in the pilot study was recruited prior to his discharge, and he was provided with an information sheet on the purpose and procedure of the study. Written informed consent was obtained. The interview was conducted telephonically following his discharge from the spinal unit at the rehabilitation hospital and the interview was audio recorded. The interview was conducted telephonically one week after discharge as the participant, who had agreed to participate in the study while still in the hospital, was discharged prior to the original discharge date. The data was included in the main study, however the data collected may not have been as in depth due to the telephonic nature of the interview. The telephonic interview was discussed and analysed by the authors to refine the interview guide and the first author's interviewing skills. The following semi-structured interviews were conducted by the authors at the rehabilitation hospital within the final week of each participant's rehabilitation stay. The average length of the interviews was 30-45 minutes, and they were conducted from October 2023 to February 2024. Once data saturation was reached, the interview process was concluded.

Data analysis

The interviews were audio-recorded and transcribed verbatim. Interviews conducted in Zulu were translated into English for data analysis. Each participant was given pseudonym names to ensure anonymity. The data was analysed manually inductively. Thereafter the authors discussed the codes and categories.

Ethical considerations

The recruitment and data collection process were only started once permission was granted by the rehabilitation hospital group, and once ethical clearance was given by the Human Research Ethics Committee of the University of Witwatersrand (M2111137). We explained the study to the participants in English or Zulu, and they all gave written or verbal informed consent.

Results

1.1. Demographic profile

The sample in this study included eleven patients with SCI. Most of the participants were male (81.8%) and had traumatic injuries (72.7%). Most of the participants' injuries were thoracic (54.5%) and incomplete (81.8%). Table 1 and 2 show the demographic and SCI profile of the participants.

Table 1: Demographic profile (n=11)

Demographic profile		
Age in years		
Mean (SD)	45.7 (19.46)	
Range	18 - 68	
Gender, n (%)		
Male	9 (81.8)	
Female	2 (18.2)	
Race, n (%)		
Black	5 (45.4)	
White	4 (36.4)	
Coloured	2 (18.2)	
Marital status, n (%)		
Married/partnership	6 (54.5)	
Single	4 (36.4)	
Widowed	1 (9.1)	
Length of stay in weeks		
Mean (SD)	8.45 (1.44)	
Range	6 - 11	
Employment, n (%)		
	Before injury	On discharge
Employed	8 (72.7)	4 (36.4)
School-going	1 (9.1)	1 (9.1)
Retired	1 (9.1)	1 (9.1)
Medically boarded	1 (9.1)	1 (9.1)
Employed with temporary disability leave	0 (0)	4 (36.4)

Place of residence, n (%)		
Family / own home	11 (100)	8 (72.7)
Work rehab facility	0 (0)	2 (18.2)
Temporary work accommodation	0 (0)	1 (9.1)

Table 2: SCI profile

SCI profile	
Cause of injury, n (%)	
Traumatic	8 (72.7)
Non-traumatic	3 (27.3)
Level of lesion, n (%)	
Cervical	4 (36.4)
Thoracic	6 (54.5)
Lumbar	1 (9.2)
Completeness of injury, n (%)	
Complete	2 (18.2)
Incomplete	9 (81.8)

1.2. The themes which emerged were: “overall rehabilitation experience was good,” “factors influencing rehabilitation experience” and “unmet care needs influencing readiness for transition to home”. Table 3 shows the themes, categories and subcategories which emerged in the data analysis.

Table 3: Themes, categories and subcategories

Themes	Categories	Subcategories
1.2.1. Overall rehabilitation experience was good		
1.2.2. Factors influencing rehabilitation experience	Environmental	Staff attitude and knowledge
		Hospital services received
		Care approach
		Physical space
		Supportive Peers
	Personal	Emotions
		Beliefs and motivation
		Sense of responsibility
		Readiness to go home
1.2.3. Unmet care needs influencing the transition to home	Bridging the gap	
	Physical home environment simulation	
	Individualized and formal psychological support	
	Involvement in decision-making	

1.2.1. Overall rehabilitation experience was good.

The general experience of inpatient rehabilitation was positive, however there were some aspects with which the participants were dissatisfied.

> *"… I can say 98%, it was good, 2% it was bad..." – Hloni, 48, C4 incomplete*

Participants mainly found rehabilitation helpful and enjoyable, and some compared their experience in the rehabilitation hospital to the acute hospitals they had been in, expressing feeling safe, free and at home.

> *"This is a different hospital. It's so good, I know most hospitals but it's my first to see one like this. … They make us feel free..." – Lethabo, 65, T12 incomplete*

1.2.2. Factors influencing rehabilitation experience

The participants highlighted various factors influencing the rehabilitation experience and the transition home, and these were categorised into personal and environmental factors. These factors impacted each other, along with the approach to care.

1.2.2.1. Environmental factors

The factors highlighted by the participants included the hospital staff, the physical hospital environment, hospital services, peer support and the care approach.

Staff attitude and knowledge

Participants highlighted how the hospital staff treatment, attitude, and knowledge on SCI affected their hospital experiences and transition to home.

In general, participants found the health professionals to be helpful and friendly.

> *"She (the doctor) actually listens to a person, so it's nice. I'm lucky I got a nice doctor." – Amy, 56, T8 incomplete*

> *"They (therapists) made me feel at home and um, if you can't do something, they're not very hard on you in the situation because they understand what you going through. … It's just that they had humanity." – Joe, 25, C4 incomplete*

> *"Some of the nurses are nice. Some of them are not so nice. I don't say you must come and kiss me in the morning or kiss me in the afternoon. If I treat you humanly, just do the same, that's all I ask." – John, 68, L3 incomplete*

Participants expressed how some of the health workers lacked the knowledge or skills to help the patients with SCI. They wanted the staff to be aware of patients' individual needs and limitations.

> *"All of them (nurses) know how to transfer you, and all of them know how to put you on a commode. But according to them, they don't know..." – Amy, 56, T8 incomplete*

"… the staff don't quite know. … Okay so here's your food. It's like great, I can't move either of my arms, so now what? "Oh, I forgot." So those kind of things early days were very frustrating." – Mark, 48, C1 incomplete

Health services received

The participants mentioned the services they received at the hospital to prepare them for home.

The main services in rehabilitation included nursing care, medical interventions from medical doctors, rehabilitation services (physiotherapy and occupational therapy), and psychosocial services by social work and psychology. Nurses were involved particularly with teaching and assisting with bowel and bladder management.

In therapy, participants were taught skills for self-management: wheelchair mobility and transfers; gait re-education where appropriate; and activities of daily living such as toileting, showering, and dressing.

> *"They taught me to dress myself up and to change my nappy. Now I can do everything on my own. I am happy and ready to go home and practice what they taught me here to see if I can manage." – Mpho, 27, T11 complete*

Participants could see how the skills they learnt in rehabilitation would be transferrable on discharge.

> *"So, like things that I'm doing at home I can like correlate what they (therapists), the activities that they did with me. … It helped a lot to get me back to home." – Joe, 25, C4 incomplete*

Giving participants the responsibility for their own self-management in the ward helped to prepare them as well.

> *"Once you get to the point where you can turn yourself then they leave you to yourself. It's your responsibility. I suppose also preparing you for when you go home." – Jane, 66, T9 complete*

> *"When I first came there's a nurse I used to call and request her to change my nappy. She would change it and told me that I must learn to change it myself. She was clear and talking straight with me. Emphasizing that I need to learn*

because one day I will go home, and nurses won't be there to help me. … For her to be strict with me helped me a lot." – Mpho, 27, T11 complete

Participants found weekend trials at home to be very helpful in preparing them for the transition to home. Going home over weekends helped participants and their families to prepare the environment for the transition home.

"So the warm up for home is that I've been able to go home every weekend for a couple of days." – Mark, 38, C1 incomplete

"Last weekend I spent with the carer at my home. It was good. A few changes that needs to be done. We've seen it, we've looked at it. Now we gonna sort that out once I go back." – Jane, 66, T9 complete

Care approach

The participants highlighted how communication, involvement in decision making and the disjuncture in care affected their rehab experience.

Communication

Communication was an important element of participants' rehabilitation experience. Participants expressed that communication among the health care workers involved in their care was helpful for continuity of care within rehab.

"Even when your main people aren't there, there's enough of an understanding of where I am, where they can take over to probably an 80% idea of kind of stepping in, they can kind of continue with it instead of starting from scratch..." – Mark, 48, C1 incomplete

"If he's [doctor] not gonna come tomorrow, he tells you, Dr Who Who will come and visit you..." – Hloni, 48, C4 incomplete

Participants mentioned that the involvement of their families was meaningful to them and helped prepare them for the transition home.

"Sometimes they don't want family involved (in the gym), it interferes… But to me that meant a lot." – Jane, 66, T9 complete

Communication between their families and the rehab team was helpful.

"I discussed with my wife and children what I was supposed to do, and everyone understood me. The rehab hospital also explained to the children" – Siya, 61, C5 incomplete

A lack of communication within the health care team, particularly at the start of rehab, was frustrating as participants had to repeat the same information to different professionals.

"… she was one of the thirty people asking me questions when I first got here…" – Mark, 48, C1 incomplete

Communication about discharge plans was lacking in some cases, and this made participants feel uncertain and unprepared for their discharge.

"It was actually a shock when they told me, you are leaving end of December…" – John, 68, L3 incomplete

Some participants felt that health professionals did not listen to them.

"She (the doctor) used to tell me things that I didn't like, but I managed to tell her that the words that she's using to me, it's not nice. … can't say that whenever I'm telling I've got a pain somewhere, and you are refusing that I don't have pain." – Thapelo, 21, T5 incomplete

"They don't check on you or listen to your heart or feel, you've complained of a pain, let's feel where the pain is, let's see what it's looking like. Until eventually I said, 'You need to look at this.'" – Jane, 66, T9 complete

Decision-making

Participants felt they were not able to be involved in decision-making, particularly with regard to medical care.

"And she told me that, 'You are not a doctor, you must do what I tell you.' – Thapelo, 21, T5 incomplete

Having the opportunity to make decisions was important for participants who wanted to uphold cultural beliefs.

"I am a black person and part of my culture does not allow me to be cut any how in certain areas of the body. … I then discussed with my family, and we made a decision … I told the doctor about our decision, and the doctor was not happy about it. (Doctor) was furious that we continue talking about the same issue and I don't want to do what (doctor) wants even though it will help me. Yes, it helps me, but tomorrow it might not be good for me. The doctor does not know what will happen in future. So, we ended up not seeing eye to eye with the doctor." – Siya, 61, C5 incomplete

Disjuncture in care

Some patients' experiences showed that there was no cohesion in care between the different disciplines, emphasising the need to bridge the gaps within the entire team and the services provided.

There was inconsistency when it came continuity of care in the wards, as expressed by Jane and Amy. They did not always get a chance to practice newly learnt skills related to activities of daily living.

"I hardly went to the bathroom here. They would never let me shower. … Bed baths all the time. For 8 weeks. It's hectic." – Jane, 66, T9 complete

"…I didn't really go to the bathrooms. Because here the nurses are too scared to take you there. So you've got your OT, she teaches you everything. … But in the ward they are too scared to take you to the bathroom. ... and I asked the sister and he said, no, he's not doing it, it's an OT's job. … I said, "No, the OT is there to teach me to do it. You are there to assist me to do it." He said, no, it's not his job." – Amy, 56, T8 incomplete

Another issue was that some nurses had expectations of participants to do their own self-management prior to having been taught the skills.

"'Cause she said to me, "You are here to learn." I understand I'm here to learn, but if I haven't been taught, I can't do it." – Amy, 56, T incomplete

Physical hospital space

The ward and the gym were the two areas where participants spent most of their time. Participants found the ward environment clean and spacious, but it was also noisy.

> *"The bottom line is, you don't sleep properly here, ever. … I think that's really one of the biggest bug bares. You working hard downstairs …, and your body is still trying to recover. You are pretty much getting to sleep at maybe 10, 10:30, and you will be awake at about 4, excluding anything else that might happen in the night. And the general ward is obviously worse." – Mark, 48, C1 incomplete*

Participants also found that the bathrooms were difficult to access. In addition, bathroom equipment, commodes in particular, was in poor working order and sparsely available.

> *"So when you get a commode, you either get a commode that's got no footrests, so your feet are dangling … 90% don't even have working footrests. … And then last night's one, you got one footrest, and the other one is hitting everywhere. And I say to (nurse), "My feet. My feet are important to me, I can't go hitting them anywhere."" – Amy, 56, T8 incomplete*

Participants were satisfied with the gym environment, despite it being cramped at times.

Supportive Peers

Being in an environment among other patients with SCI, with whom they could share their experiences, made participants feel more comfortable and less isolated:

> *"I feel more comfortable here because there's people in wheelchairs. It's not the same like at home." – Michael, 18, T3 incomplete*

Peers with SCI were also encouraging towards one another, which made participants feel supported. Being exposed to other people with varying levels of disability gave participants perspective on their own injuries.

"They (patients in ward) keep encouraging me that I should not give up, I will be able to walk again. I am not the only one, there are many more. I am not the first person to experience this situation…" – Mpho, 27, T11 complete

1.2.2.2. Personal factors

The participants expressed how they played a part in preparing for home. The personal factors which influenced their experiences were their emotions, beliefs and motivation, and the perceived readiness for discharge.

Emotions

Participants expressed that their emotional states throughout the care continuum affected their experience. Some had to deal with and overcome the trauma of their injuries or acute hospital experiences.

"In the beginning it was a little bit difficult ... Because even, even with my injury I also had the trauma of my mom being involved as well." – Joe, 25, C4 incomplete

Some explained that they felt uncertain and hopeless at the start of their rehabilitation journeys, but with encouragement and learning skills, they felt more confident.

"I mean, in the beginning when you get here, you're like, lost. You don't know like, what you're gonna do. … But afterwards your confidence comes, and you just learn." – Amy, 56, T8 incomplete

"First of all, when the first time I got injured, when I came here, I had given up. But when I came here, they told me, 'You must never give up, you are still young, you can make it.'" – Thapelo, 21, T5 incomplete

Beliefs and motivation

The participants' own beliefs and attitudes had a big impact on their experience in rehabilitation. They expressed the need to believe that they would get better, and that having internal and external motivation was important. The participants used acceptance, spirituality, and self determination to encourage themselves. Acceptance of the current situation made the experience easier and taking responsibility for their

own rehabilitation was important in achieving goals and becoming independent: *"I made my heart and mind understand that my situation has change and this is my present situation." – Mpho, 27, T11 complete*

> *"… even the doctors here, even the doctor there (acute hospital), he used to tell me that ah, you will never be able to walk again. And now look. I told myself that, ah, one day is one day. But here I am." – Thapelo, 21, T5 incomplete*

> *"Here it is up to you… … It is up to you to decide if you are going to continue do the exercises…" – Siya, 61, C5 incomplete*

Readiness to go home

Participants had mixed emotions when it came to being discharged from the rehabilitation hospital. They felt prepared and positive about going home, however also apprehensive*:*

> *"I feel confident. … I am a bit scared. When I go home and it's a different life … You know I like to just get up and go and do and run and… and now I can't." – Jane, 66, T9 complete*

Part of what made patients apprehensive about going home was reintegration into the community, and the attitudes of the people they would face.

> *"People's reactions in the township. They know me being able to walk by myself, now I … am using a wheelchair, I'm worried about what they will say. I am embarrassed about it." – Mpho, 27, T11 complete*

> *"… Emotional, because I know they also don't know how to face me. It's not only me. … But in a group where there's a lot of people that you know that haven't seen me and know your condition… That is something I'm not looking forward to. … Look, I've had people come here and visit me, but it still hasn't prepared me." – Jane, 66, T9 complete*

1.2.3. Unmet care needs influencing the transition to home

There is a need to bridge the gap between the skills learnt and information received in the therapy spaces and what is practiced in the ward to prepare patients more adequately for SCI-specific self-management before they are discharged.

"Also, you know you're doing the bowel regime. … The suppository, I would not get it in time. … To put you on the commode, never happened. You supposed to have it and then half an hour, an hour later, go to the commode, go to the bathroom. That never happened. They would never bring it, there was always an excuse, and they just left you. … to the point that I haven't got into a routine yet." – Jane, 66, T9 complete

There is also a need for the ward environment to simulate a real-life home environment more closely, or for patients to have access to similar environments at the hospital or on weekend trials.

"But if my space is not the same at home as here, then I can't compare the two..." – John, 68, L3 incomplete

There is a need for psychological intervention or counselling to be more individualised and more formal.

"They definitely need to be setting more formal things. Can't have sitting down and, 'Ah we gonna have a heart to heart,' at random times, random days… I mean, (psychologist) came and sat down here the other day at 8 o'clock in the evening. I hadn't seen her for 2 weeks…" – Mark, 48, C1 incomplete

"… so if it (psychology) was just a little but more specific on what I can expect and what I can control when I get here (home) then it would have been better." – Joe, 25, C4 incomplete

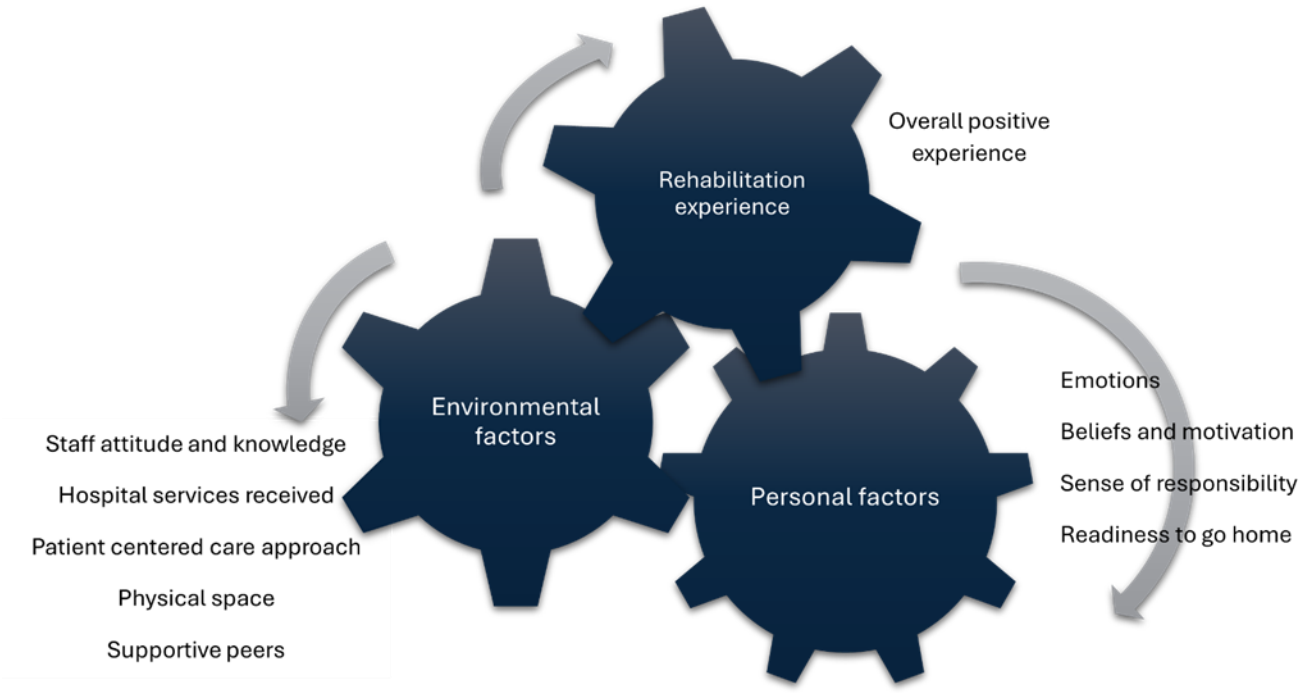


Figure 1: Factors influencing the rehabilitation experience.

Discussion

This study aimed to explore the experiences of inpatient rehabilitation among people with SCI, and how this affects their transition to home. To the authors' knowledge this is the first study to explore the experience of home transition for people with SCI in South Africa. Three themes emerged, namely "overall rehabilitation experience was good," "factors influencing rehabilitation experience" and "unmet care needs influencing readiness for transition to home".

The rehabilitation experience was generally positive and helpful, and it prepared participants for the transition to home. There were, however, aspects of rehabilitation and the transition with which they were dissatisfied. This study findings are similar to previous studies. Studies by Moran, Barclay and Lannin (2022) and Nunnerley and Dean (2013) looked at the experiences of people with SCI following discharge from rehabilitation and found that participants were prepared by rehabilitation, but still experienced physical and psychosocial challenges on returning home.

This study was set in one of the specialized, privately funded rehabilitation hospitals in South Africa. Most specialized SCI rehabilitation units in the country are privately funded and in urban areas, meaning that some patients with SCI may not receive specialized rehabilitation care (Joseph *et al.*, 2017) as the majority of the South African

population does not have private health insurance (Mayosi and Benatar, 2014). The rehabilitation experience could be different for patients accessing public rehabilitation hospitals because the public health system is overly burdened, and many health facilities are understaffed, mismanaged and underfunded (Mayosi and Benatar, 2014). A study by Mothabeng *et al.* (2007) found that during rehabilitation following SCI in South Africa, the factors which influenced the inpatient rehabilitation experience were emotions, dependence on health professionals, and insight into their health conditions. Another study was conducted in the United Kingdom on the experiences of women with SCI, and findings were similar in that the psychosocial factors played a large part in the rehabilitation experience (Samuel *et al.*, 2007), albeit these studies were conducted almost two decades ago. There is a need for more current research to understand the experiences of patients in the private and public health system, which will assist in evaluating and updating rehabilitation systems (Mji *et al.*, 2013).

There were various factors that influenced readiness to go home. In agreement with previous studies, the rehabilitation environment can influence the patients' experiences and their outcomes (Nunnerley and Dean, 2013; Bourke *et al.*, 2014; Colley, Zeeman and Kendall, 2018; Simpson, Villeneuve and Clifton, 2020). While there were various minor issues related to the physical environment, the main theme that emerged regarding the physical environment was that the ward did not simulate the participants' home environment closely enough. This finding was corroborated by Nunnerley and Dean (2013), Bourke *et al.*, (2014) and Moran, Barclay and Lannin (2022), who found that the rehabilitation units were safe and sensitive to wheelchair users. Although the safety of the environment is important for patients care, ensuring that there are spaces in the hospital that simulate life after hospitalization is important in helping the patients to be ready for home transition. Participants in the present study who were able to go on home trials prior to discharge felt that this was helpful in feeling ready to make the transition to home following discharge as they knew what to expect on returning home.

The health care workers involved in the care and rehabilitation of people with SCI in the inpatient setting can have a significant impact on the overall experience, as well as on outcomes (Conti *et al.*, 2020; Pryor, Haylen and Fisher, 2021; Moran, Barclay

and Lannin, 2022). In the present study, health professionals were generally found to be helpful, friendly and knowledgeable, however there were some whose attitudes, and perceived lack of skills and knowledge on SCI negatively impacted the participants. Pryor, Haylen and Fisher (2021) had similar findings. There is a need to ensure regular training for health professionals on patient-centred care to ensure a conducive environment for patients. Specialized care does not only involve having SCI-related knowledge or skills: participants in the current study expressed the need for all staff in rehabilitation environments to understand their roles and be trained on how to interact with patients who are amid a profound change in their lives. Other qualitative studies' findings have supported this notion: staff attitudes have an impact on achieving self-management tasks, and the patients' feelings of control (Bourke *et al.*, 2014), and continuous development programs are encouraged on topics such as self-management and patient-centred care (Krysa *et al.*, 2022).

Patient care approach was highlighted as one of the barriers that patients experienced. Some of the participants felt that they were not listened to; not involved in decision-making; and that their opinions and beliefs were not taken into consideration. People with SCI want to feel heard (Pilusa, Myezwa and Potterton, 2021a). In addition, patients with SCI want to have a sense of control, especially when transitioning back into their lives, and being given the opportunity to make decisions can help with recognizing that they still have autonomy and responsibility in their lives (Lindberg *et al.*, 2013; Bourke *et al.*, 2014). Patient-centred care should be part of the rehabilitation care approach and it needs to be emphasised in training all staff involved in SCI rehabilitation. In this hospital, there are staff with varying levels of qualifications, and this may have an impact on the care approach.

Having an SCI does not just have a physical impact, but an emotional and psychological impact as well. People with SCI, including those in the present study, experience trauma, confusion, grief and distress in the acute and sub-acute phases following their injuries (Machida, Irwin and Feltz, 2013; Nunnerley and Dean, 2013; Bourke *et al.*, 2014; Clifton, 2014; Joseph *et al.*, 2016; Bender and Burgess, 2020). While participants in the present study felt motivated and supported by various staff

members at the rehabilitation hospital, they did not feel that their psychological needs were adequately met. In addition, the participants felt that, while they were physically prepared for discharge, they were not psychologically prepared for returning home or to the community with their disabilities. Bourke *et al*. (2014) also highlight this gap in psychological support around navigating community members' attitudes. The person with SCI's psychological state can have an impact on their choices to participate in social or community activities (Joseph *et al.*, 2016). Clifton (2014), in his autoethnographic paper following his own SCI, described SCI as a "body/mind separation" (p1825) and a deeply personal loss. Joseph *et al.* (2016) also found that people with SCI needed to learn to deal with their "new self" (p1376). This requires interventions which help people with SCI to rebuild their personal and new life narratives (Clifton, 2014). Given the above, it could be argued that psychological intervention such as regular individual psychology sessions, support groups and counselling should be a formal and structured part of any rehabilitation programme following SCI.

There were some limitations of this study. Only one rehabilitation hospital was included in the study, and it was a privately funded hospital, therefore the findings cannot be generalised to other settings, especially those in the public sector. There may have been responder bias due to the sample being purposive. Most of the participants were male and had traumatic SCI, which is in keeping with local studies on SCI, however it limits the transferability of findings to this group only. More females and people with non-traumatic SCI should be included in future studies. Most participants also had incomplete SCI, which may have impacted their experience and readiness for home compared to those with complete SCI. Most participants' injuries were also thoracic-level, and their experiences may not be on par with people with higher-level injuries as the impairments, functional limitations and participation restrictions in the two groups can be different. In future, participants with higher-level and complete injuries should be included.

Conclusion

With no contextual SCI model of care, understanding the experiences and outcomes of those undergoing SCI rehabilitation in private settings can be valuable in developing

this specialized area of health and disability. The findings of this study highlight the need for specialized, individualized and “human-centred” rehabilitation, where patients are listened to and involved in their care. This study has highlighted the contextual factors that influence the readiness to transition to home for patients with SCI. Further research is required to develop strategies to address the influencing factors, and to explore transition to home for patients in the public health sector. This will assist in bolstering the health system in favour of promoting quality of life, reintegration, and participation.

Implications

Clinical practice

Understanding the factors which influence the experience of rehabilitation, and the transition home is useful in developing rehabilitation units. When designing rehabilitation programmes, environmental factors, personal factors and patient-centred care must be taken into account.

Declaration

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Competing interest

The authors declare that there is no competing interest, and that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

Data availability statement

The data used and analysed in this study is available from the corresponding author on reasonable request.

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These appear at the end of this report, however, are included in the manuscript which was submitted to the journal.

Chapter 5: Overall discussion

In this study we found that the general experience of rehabilitation was positive, and that participants felt prepared for the transition to home. There were, however, some aspects of rehabilitation and the preparation for home which could have been better. The factors which impacted the experience were categorized into environmental factors, personal factors, and patient-centred care. We found that there is a need to bridge the gap between the different disciplines involved in SCI-related care; for the physical environment in rehabilitation to simulate the home environment more closely; for more formal and individualized psychological support; and for patients to be involved in decision-making regarding their own rehabilitation and care.

Rehabilitation care for SCI continuum

Given that there is no cure for SCI (Jazayeri *et al.*, 2015), rehabilitation should be prioritized and optimized in order to empower people with SCI to participate in home and community life (Cheng *et al.*, 2017). SCI rehabilitation should be specialized and patient-centred, given the unique acute and long term needs of people with SCI (World Health Organization, 2013). Following a review of literature on current SCI models of care, Ho *et al.* (2021) determined that there are many different models of care used in different settings. In South Africa, rehabilitation care following disease or disability is not prioritized, but the model of care has changed over time from a medical model to a more biopsychosocial model (Mji *et al.*, 2013). According to the ICF, there are various factors which form part of the lived experience of people with disability (World Health Organization, 2002). The themes which emerged in this study are in accordance with this, and the need for care to be specialized and patient-centred was strongly emphasized. While this study only looked at how the experiences of inpatient rehabilitation can influence the transition to home, the experiences can also impact longer term health and quality of life (Nunnerley and Dean, 2013; Bourke *et al.*, 2014; Pilusa, Myezwa and Potterton, 2021b).

In South Africa, there are some challenges related to rehabilitation, and disability care is not prioritized. There are only 24 specialized SCI rehabilitation units in Sub-Saharan Africa (Southern African Spinal Cord Association, 2020). Sixteen of these are in South Africa (Southern African Spinal Cord Association, 2020), however most of them are privately funded and in urban areas (Pefile, Mothabeng and Naidoo, 2019), and this

makes them out of reach for the 80-84% of the population who use the public health system (Mayosi and Benatar, 2014). Facilities which do exist in the public sector may face a lack of resources, high patient to health worker ratios, and a lack of specialized knowledge and skill on disability needs among health workers (Sherry, 2015; Joseph *et al.*, 2017; Morris *et al.*, 2021). According to the Integrated Disability Management and Rehabilitation Pathway of Care report, a document set out by the South African government in 1997, patients with disability should receive intensive rehabilitation in various settings (The Office of the Deputy President, 1997; Joseph *et al.*, 2017). However, according to Morris *et al.* (2021), many patients with disabling health conditions are discharged soon after their initial admission to acute care, and do not receive rehabilitation at all. In Cape Town, 24% of patients with traumatic SCI demise within four years after injury, and those who remain have a high incidence of secondary complications (Madasa *et al.*, 2020). This highlights the notion that rehabilitation for disability, and particularly SCI, is in need of bolstering to adequately prepare patients with SCI to self-manage and integrate into their homes and communities. This study was based in a specialised, private rehabilitation hospital where patients have access to private medical funding. The experiences of patients in public facilities need to be explored as they may differ due to challenges related to staffing, resources and access to long-term SCI care.

Contextual factors influencing care

The use of the ICF in the health system can help practitioners and policy makers frame health and disability in a holistic way. The factors which influence the rehabilitation experience and the transition to home are categorized into environmental factors, personal factors, and care approach factors.

Environmental factors

The environmental factors that influenced the experience of inpatient rehabilitation and the transition to home included the health professionals' SCI-related knowledge, attitudes and availability; the physical environment; the services provided; peer support; and the care approach.

The staff involved in the rehabilitation setting can have an influence on the experience and outcomes for people with SCI (Conti *et al.*, 2020; Pryor, Haylen and Fisher, 2021;

Moran, Barclay and Lannin, 2022). This study highlights this notion. While most health professionals and hospital staff were friendly, knowledgeable, and helpful, the few who did not possess these characteristics had an impact on the participants' experiences as well. The main areas where participants felt ward staff lacked skills and knowledge were related to bowel and bladder management, and commode transfers. This is consistent with the findings of a study by Pryor, Haylen and Fischer (2021). Developing bowel and bladder routines can be a slow and challenging process for people with SCI, and health professionals require specialized knowledge and skills to assist with this (Pryor, Haylen and Fisher, 2021). Participants perceived that staff were unwilling to assist with bowel and bladder care routines. Underlying this may be a lack of skill or understanding of the importance of these routines in SCI. The staff involved in SCI rehabilitation need to have the right approach to care: their attitudes also play a role in the experience, as participants in the present study expressed. The attitudes of rehabilitation staff can impact the achievement of goals, especially those related to self-management (Bourke *et al.*, 2014).

The attitudes of staff also affect communication with patients, and how patients' feelings, opinions and beliefs are considered. In the present study, participants felt that they were not listened to, and they were not able to be involved in decision-making with regard to their medical care and their discharge planning. People with SCI want to be involved in decisions regarding their own health, and they want to be listened to (Lindberg *et al.*, 2013; Bourke *et al.*, 2014; Pilusa, Myezwa and Potterton, 2021a). Health professionals involved in rehabilitation care need to acknowledge the experiences and capabilities of people with SCI themselves (Mji *et al.*, 2013).

The results of this study highlighted that the continuity of care within the rehabilitation setting is lacking. Skills and information learnt in therapy did not always translate to the ward environment as some ward staff were unclear on their roles; had not had opportunities to see the patients performing mobility or self-care tasks in the gym setting; or were simply unavailable to assist.

Personal factors

While the environment plays a large role in the experience of rehabilitation and the transition to home, there are various personal factors which have an impact as well.

These are emotions, beliefs and motivation, the sense of responsibility, and the perceived readiness to go home.

SCI comes with significant emotional and psychological impacts which require support and intervention (Clifton, 2014; Simpson, Villeneuve and Clifton, 2020). People with SCI, including those in the present study, experience trauma, grief, uncertainty, and distress in the acute phase and during rehabilitation (Machida, Irwin and Feltz, 2013; Nunnerley and Dean, 2013; Bourke *et al.*, 2014; Clifton, 2014; Joseph *et al.*, 2016; Bender and Burgess, 2020). The participants in the present study expressed that having their own internal motivation, beliefs for recovery, and spirituality were important in managing these emotions and making their experience easier. Although they had this internal motivation, and while they did receive some psychological support during rehabilitation, many felt that they were not psychologically prepared for the transition to come and to the community. This finding was corroborated by Bourke *et al*. (2014), who found that the physical preparation for discharge was the main focus, but the psychological support regarding the transition into the community especially was lacking. Psychological support is important because the person with SCI undergoes a significant personal upheaval, including changes in body image (Van Diemin *et al.*, 2017). Changes in their personal narratives can influence how they relate to other people in their lives (Bender and Burgess, 2020), and their mental and emotional states can have an impact on how they choose to engage in social or community activities (Joseph *et al.*, 2016). Given this, formal and individualized psychological support should be prioritized during rehabilitation.

Chapter 6: Conclusion and recommendations

In this study we explored the experiences of inpatient rehabilitation among people with SCI, and how these experiences influenced the transition to home. We also explored the needs of people with SCI when transitioning from inpatient rehabilitation to home.

Recommendations

Practice

There is a need to strengthen the practice of self-management in the inpatient rehabilitation programme. It is not enough to teach patients how to self-manage; they must also practice these skills within the rehabilitation setting, especially within the wards. The practice of skills in the ward environment should start early in the programme and can be graded as the patients become physically stronger and more confident. This will ensure that patients can self-manage by the time they transition to home, particularly regarding wheelchair skills, transfers, self-care and bowel and bladder management.

Training of staff

All staff in the SCI rehabilitation space, whether clinical or non-clinical, should be trained regularly on the purpose of SCI rehabilitation, and their roles within that environment. More importantly, staff should be trained and assessed regularly by the institution on the importance of patient-centred care: listening to patients, involving them in decision-making, and respecting the feelings and opinions of patients.

Research

More research is needed on the experiences of people with SCI within rehabilitation. Further research is needed to understand the experience of the transition to home and into the community post-discharge from rehab within the varying socio-economic environments in the South African context, both within the public and private sectors, and within urban and rural environments. Comparisons between specialized and non-specialized units could also assist in gaining valuable insight into the benefits of specialized SCI care, which could guide the development of SCI rehab protocols and policies.

Limitations

There were limitations to this study. There was only one rehabilitation hospital included in the study, and it was privately funded. The findings of this study, therefore, may not be relevant in other settings, particularly in the public sector. The sampling was purposive, therefore there may have been responder bias. Most of the participants in the study had incomplete SCI, which may have also been a factor influencing the experience and the perceived readiness for home. These may be different to the experiences of people with complete SCI. Most of the participants' lesions were thoracic level, which means that the findings may not be transferrable to people with higher level injuries, given the differences in functional limitations between the two groups. In keeping with local studies on SCI, most participants were male and had traumatic SCI (Sothmann *et al.*, 2015; Joseph *et al.*, 2017). The findings may not accurately reflect the experiences of females and those with non-traumatic SCI. Further research which is more inclusive of all injury levels and genders should be conducted.

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Appendix A: Interview guide

Section A: Demographic information

Identifier code:	P	
Age		
Gender		
Race		
Date of injury		
Date of admission to rehab		
Length of stay in rehab		
Aetiology of SCI		
Level of lesion		
Completeness of level		
Functional level		
Assistive device		
Employment status	At time of injury	Current
Marital status		
Residence	At time of injury	Current/At discharge

Section B: Open-ended questions

Disability	Can you tell me about your disability? (Probe: Can you tell me how/when it happened?)
Hospital and rehabilitation experience	Can you share your experience of rehabilitation care while you were in the rehab hospital? Probe: when were you admitted? Probe: tell me about the services you received during your rehabilitation. Elaborate of the more about the therapy received.
Personal and hospital environmental factors.	What made your experience at the rehab hospital easier? Harder? Probes: can you tell me how the hospital environment helped you? **Ward** Probes: What were your experience/thoughts of the ward in which you stayed while in the rehab hospital? Probe: How did the ward environment help in preparing you for your home environment? **Therapy area** What was your thoughts/experience of the environment in which you received therapy while in the rehab hospital?

	Were there any changes you would have made to the physical environment to improve your experience of your rehabilitation? **Personnel** What was your experience of the professionals involved in your care at the rehab hospital? What was your experience of the nurses in the ward? What was your experience of the doctors? What was your experience of the therapists? Probe: how did they equipped you to manage your disability? **Psychological support** What was your experience of any psychological support you may have received? How did your rehabilitation stay prepare you to return home? How did your rehabilitation stay prepare you to go back into the community?
Needs	Was there anything you felt you needed while you were in the rehabilitation hospital that you may not have received? Please elaborate on this. Probe: Were there any services/experiences/aspects of recovery you feel you needed? Elaborate. Probe: is there anything the rehabilitation hospital could have done to help you manage at home?

	Do you have any suggestions that could improve the rehabilitation services offered at the rehab hospital?

Appendix B: Ethical clearance certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research and Innovation)

TO:	Ms C Floudiotis School of Therapeutic Sciences Department of Physiotherapy Medical School University E-mail: cleofloudi@gmail.com
CC:	Supervisor: Dr S Pilusa <Sonti.Pilusa@wits.ac.za> and <HREC-Medical Research Office@wits.ac.za>
FROM:	Mr Iain Burns Human Research Ethics Committee (Medical) Tel: 011 717 1252 E-mail: Iain.Burns@wits.ac.za
DATE:	2022/05/09
REF:	R14/49
PROTOCOL NO:	**M2111137** (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)
PROJECT TITLE:	*The influence of the inpatient rehabilitation experience on the transition to home amongst people with spinal cord injury in South Africa: A qualitative study*

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to Government funding of the University.



MSWorks2000/Iain0007/Clearscan.wps

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R49 Ms C Floudiotis

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M2111137

NAME: (Principal Investigator)	Ms C Floudiotis
DEPARTMENT:	School of Therapeutic Sciences Department of Physiotherapy Medical School University
PROJECT TITLE:	*The influence of the inpatient rehabilitation experience on the transition to home amongst people with spinal cord injury in South Africa: A qualitative study*
DATE CONSIDERED:	2021/11/26
DECISION:	Approved unconditionally
CONDITIONS:	
NOTE:	If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>
SUPERVISOR:	Dr S Pilusa
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2022/05/09

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

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 submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **November** and therefore reports and re-certification will be due in the month of **November** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator _____ Date _____

Appendix C: Hospital permission letter

RESEARCH OPERATIONS COMMITTEE FINAL APPROVAL OF RESEARCH

Approval number: UNIV-2022-0025

Ms Cleo Floudiotis

E mail: cleofloudi@gmail.com

Dear Ms Floudiotis

RE: THE INFLUENCE OF THE INPATIENT REHABILITATION EXPERIENCES ON THE TRANSITION TO HOME AMONG PEOPLE WITH SPINAL CORD INJURY IN JOHANNESBURG, SOUTH AFRICA: A QUALITATIVE STUDY

The above-mentioned research was reviewed by the Research Operations Committee's delegated members and it is with pleasure that we inform you that your application to conduct this research at private Hospital, has been approved, subject to the following:

i) Research may now commence with this FINAL APPROVAL from the Committee.

ii) All information regarding the Company will be treated as legally privileged and confidential.

iii) The Company's name will not be mentioned without written consent from the Committee.

iv) All legal requirements regarding patient / participant's rights and confidentiality will be complied with.

v) All data extracted may only be used in an anonymised, aggregated format and for the purposes of this specific study as specified in the proposal. The data may under no circumstances be used for any other purpose whatsoever.

vi) The research will be conducted in compliance with the GUIDELINES FOR GOOD CLINICAL PRACTICE IN HUMAN PARTICIPANTS IN SOUTH AFRICA (2016).

vii) The Company must be furnished with a STATUS REPORT on the progress of the study at least annually on 30th September irrespective of the date of approval from the Committee as well as a FINAL REPORT with reference to intention to publish and probable journals for publication, on completion of the study.

viii) A copy of the research report will be provided to the Committee once it is finally approved by the relevant primary party or tertiary institution, or once complete or if discontinued for any reason whatsoever prior to the expected completion date.

ix) The Company has the right to implement any recommendations from the research.

x) The Company reserves the right to withdraw the approval for research at any time during the process, should the research prove to be detrimental to the subjects/ Company or should the researcher not comply with the conditions of approval.

xi) APPROVAL IS VALID FOR A PERIOD OF 36 MONTHS FROM DATE OF THIS LETTER OR COMPLETION OR DISCONTINUATION OF THE TRIAL, WHICHEVER IS THE FIRST.

We wish you success in your research.

Yours faithfully

19/4/22

Prof Dion du Plessis
Full member: Research Operations Committee & Medical Practitioner evaluating research applications as per Management and Governance Policy

Dr Shannon Nell
Chairperson: Research Operations Committee
Date: 24/5/2022

This letter has been anonymised to ensure confidentiality in the research report. The original letter is available with author of research

Appendix D: Study information sheet

Participant's information sheet and informed consent form

Participant number: _____

Study Topic: The Influence of the Inpatient Rehabilitation Experiences on the Transition to Home Among People with Spinal Cord Injury in Johannesburg, South Africa: A Qualitative Study.

Investigator: Cleopatra Floudiotis

Institution: University of the Witwatersrand

Introduction

Good day

My name is Cleo Floudiotis and I am a physiotherapist and Masters student at the University of Witwatersrand. As part of my postgraduate degree, I am doing a study to explore how the experiences in inpatient rehabilitation following a spinal cord injury (SCI) influence the transition to home. The objectives of the study are:

1. To explore the inpatient rehabilitation experiences of people with SCI.

2. To explore how the experiences of inpatient rehabilitation influence the transition to home among people with SCI.

3. To explore the needs of people with SCI when transitioning from inpatient rehabilitation to home.

I would like to invite you to participate in this study, which entails an in-depth interview conducted by me. With your permission, the interview will be audio recorded. The interview will be about your experience of rehabilitation in the specialized spinal unit and how this influenced your transition back to home. It will take approximately 1 hour. It will be conducted telephonically or in person. This information sheet is to assist you to make an informed decision on whether you would like to take part in the study. It is important that you understand fully what your involvement would entail before you agree to participate. Your participation in this study is voluntary, and you are free to withdraw from the study at any time without any penalties. If you would like to participate, you will be asked to sign the consent form below, which means that you

understand and agree to the information provided in this leaflet. A copy of this will be given to you.

The purpose of this study is to explore how the experiences of inpatient rehabilitation may influence the transition back to home following a spinal cord injury in South Africa. By participating in this study, you will have the opportunity to reflect on aspects of your rehabilitation stay that you thought were successful in preparing you to transition from rehab to your home, and aspects that you felt did not prepare you enough. The benefits of this study are that the information obtained will provide a better understanding of gaps in rehab, services and, also into what is working well. This will help to improve specialized spinal services, leading to better outcomes for patients making the transition home in the future. The findings may also help to make recommendations for future research on spinal cord injury rehabilitation, as well as policies on rehabilitation in South Africa.

There should not be any risks of participating in this study, and all identifying information will remain confidential. Your name will not be included anywhere in the study and the results of the interviews will be presented in the study only after being coded. Only the researcher will have access to the interview questionnaires and hospital files. If you agree to participate in the study, you may still withdraw at any time without any penalties.

If you have any further questions, please feel free to contact me on 0725483381 or at cleofloudi@gmail.com. If you have any concerns regarding the way this study is being conducted, please contact the Chairperson of the Witwatersrand Human Research Ethics Committee, Professor Clement Penny, on 011 717 2301 or via email at clement.penny@wits.ac.za.

Appendix E: Informed consent and permission to record interview

Participant number: _____

Study Topic: The Influence of the Inpatient Rehabilitation Experiences on the Transition to Home Among People with Spinal Cord Injury in Johannesburg, South Africa: A Qualitative Study.

Investigator: Cleopatra Floudiotis

Institution: University of the Witwatersrand

I hereby confirm that I have been informed by the study investigator, Cleopatra Floudiotis, about the purpose, procedure, benefits, and risks of the study. I have also read and understood the information leaflet above. I understand that my personal identifying information will remain confidential and that I am allowed to withdraw from the study at any time without consequences. I have been given the opportunity to ask questions and I am prepared to participate in the study.

Participant's name: _____Date: _____

Participant's signature_____

I, Cleopatra Floudiotis, confirm that the above participant has been fully informed

about the purpose and considerations of the above study.

Signature: _____ Date: _____

Permission for audio recording

With your permission, the interview conducted in this study will be audio recorded. I agree that the researcher, Cleopatra Floudiotis, may audio record my interview. I am aware that my name and identifying information will not be included in the transcription of these recordings.

Name:_____ Date: _____

Signature: _____

Appendix F: Plagiarism declaration

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I _Cleopatra Floudiotis____ (Student number: __2507835__) am a student

registered for the degree of _Masters in Physiotherapy__ in the academic year _2024_.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission

  and/or without acknowledging the original source) is wrong.

- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.

- I have followed the required conventions in referencing the thoughts and ideas of others.

- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.

- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: _____ Date: 11 October 2024

Appendix G: Turnitin report