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Prevention care for secondary health conditions among people with spinal cord injury in the Tshwane metropolitan area

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PREVENTION CARE FOR SECONDARY HEALTH CONDITIONS AMONG PEOPLE WITH SPINAL CORD INJURY IN THE TSHWANE METROPOLITAN AREA



Sonti Imogene Pilusa

A thesis submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Doctor of Philosophy Johannesburg, South Africa.

April, 2021

DECLARATION

I, Sonti Imogene Pilusa, declare that this Thesis is my own, unaided work.

It is being submitted for the Degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg.

It has not been submitted before for any degree or examination at any other University.

I confirm lead authorship of the published articles included in this Thesis.

_____

Sonti Imogene Pilusa

_____day of_____20_____in_____

DEDICATION

This work is dedicated to Abu Nayiluma. You left too soon. I now understand how you felt about disability. Living with a spinal cord injury is not easy. Rest in peace.

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ACRONYMS AND ABBREVIATIONS

Acronyms	
ASIA	American Spinal Injury Association
CBR	Community-based rehabilitation
CRediT	Contributor Roles Taxonomy
ECCM	Expanded Chronic Care Model
FSDR	Framework and Strategy for Disability and Rehabilitation
ICF	International Classification of Function, Disability, and Health
MVA	Motor Vehicle Accidents
NTSCI	Non-traumatic Spinal cord injury
OPD	Outpatient Department
PRISMA	Preferred reporting Items for Systematic Reviews and Meta-analysis
PU	Pressure Ulcer
RAF	Road Accident Fund
SCI	Spinal Cord Injury
SDG	Sustainable Development Goal
SHCs	Secondary Health Conditions
TSCI	Traumatic Spinal cord injury
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UTIs	Urinary Tract Infections
WHO	World Health Organization

DEFINITION OF TERMS

- **Community-based rehabilitation:** CBR is "a strategy within community development for the rehabilitation, equalization of opportunities, poverty reduction and social integration of people with disabilities" (World Health Organization, 2004b).
- **Prevention care:** Preventing diseases is an ancient concept from health promotion, referring to measures to minimize the risk of developing a condition, its progression, and impact (Chang, Burke and Glass, 2009, World Health Organization, 1998).
- **Secondary health conditions:** Secondary health conditions are conditions (physiological and mental) that develop over time due to the presence of a primary disability but are not directly caused by the primary disability (Jensen et al., 2012).
- **Spinal cord injury:** SCI is a lesion in the spinal cord, resulting in a loss of sensory and motor function below the affected area (Zhang et al., 2013).

PUBLICATIONS AND CONFERENCE PRESENTATIONS ARISING FROM THIS STUDY

Publications

1. Pilusa, S., Myezwa, H., & Potterton, J. (2021). Experiences of secondary health conditions amongst people with spinal cord injury in South Africa: A qualitative study. *South African Journal of Physiotherapy*, *77*(1), 8 pages. doi:https://doi.org/10.4102/sajp.v77i1.1530
2. Pilusa, S., Myezwa, H., & Potterton, J. (2021). 'I forget to do pressure relief': Personal factors influencing the prevention of secondary health conditions in people with spinal cord injury, South Africa. *South African Journal of Physiotherapy*, *77*(1), 9 pages. doi:https://doi.org/10.4102/sajp.v77i1.1493
3. Pilusa, Sonti, Myezwa, Hellen, Potterton, Joanne. Prevention strategies for secondary health conditions in people with spinal cord injury, JBI Evidence Synthesis: October 24, 2019 - Volume Online First - Issue -doi: 10.11124/JBISRIR-D-18-00015
4. Pilusa, S., Myezwa, H. & Potterton, J. Prevention care for secondary health conditions among people living with spinal cord injuries: research protocol. *BMC Res Notes* 12, 179 (2019). https://doi.org/10.1186/s13104-019-4202-7

Articles submitted and under review

Manuscripts titles	**Submitted**	**Post-review corrections**
"Exploring prevention and management of secondary health conditions among people with spinal cord injury, South Africa".	*International Journal of Therapy and Rehabilitation*	√
"Prevention strategies for secondary health conditions in people with spinal cord injury": scoping review	*JBI Evidence Synthesis*	√
The environmental factors influencing the prevention of secondary health conditions	*PLOS ONE*	√
Secondary health conditions in people with spinal cord injury, South Africa: Prevalence and associated factors	*South African Medical Journal*	√
Services and interventions needed to prevent secondary health conditions throughout the life span of people with spinal cord injury, South Africa.	*African Journal of Disability*	
Views of health care users and providers: solutions to improve the prevention of secondary health conditions among people with spinal cord injury, South Africa.	*Spinal cord cases and series*	

Conference presentations

1. Tshwane Rehabilitation Hospital research day (Oral presentation): Prevention care for secondary health conditions among people with spinal cord injury. 25 February 2020
2. The Consortium of Advanced Research Training in Africa (CARTA) for Joint Advanced Seminar 4 Conference. Makerere University Uganda. Oral presentation: Factors Influencing Prevention of Secondary Health Conditions in People with Spinal Cord Injury, South Africa. March 16 2020

ABSTRACT

Promoting health and well-being for people with spinal cord injury is neglected. Spinal cord injury (SCI) is a chronic condition with complex needs and health challenges due to secondary health conditions (SHCs) such as pain, urinary tract infections and pressure sores. Secondary health conditions significantly affect the quality of life, life satisfaction and can decrease life expectancy. The reported high readmission rates due to preventable pressure sores and urinary tract infections sparked the inquiry into the experience of secondary health conditions and factors influencing these conditions' prevention. This study aimed to establish factors influencing prevention care for secondary health conditions among people with spinal cord injury in the Tshwane metropolitan area to develop a prevention model of care. Knowledge on the prevention of secondary health conditions is limited in South Africa.

This study used a mixed-method approach with eight studies to address the study objectives. A retrospective study (n=425) was conducted to determine the prevalence of SHCs and the associated risk factors. The results showed a very high prevalence of SHCs (93.7%), and the most common SHCs were pain, bowel and bladder problems. The majority of the participants had multiple SHCs, and the predictors of multiple SHCs were socioeconomic factors, SCI duration and thoracic SCI lesion. These results suggest gaps in SHCs preventive care and that people with SCI need support to prevent SHCs.

A qualitative study was conducted with care users (seventeen people with SCI, six caregivers) and care providers (twenty-one therapists) to understand the nuanced experiences of SHCs, prevention thereof, contextual factors influencing the prevention of SHCs and to identify solutions to improve preventive care for SHCs. From the analysis, SHCs impacts functioning, affects mental health, and cause significant disruption in everyday life. People with SCI used self-management, medication, assistive devices, resilience coping strategies and therapeutic approaches to prevent and manage SHCs. However, preventing and managing SHCs is challenging for people with SCI. The results suggest that people with SCI need support to prevent SHCs. Health professionals need to be proactive to empower people with SCI to maintain health and prevent SHCs. The personal factors influencing the prevention of SHCs included knowledge levels, behaviour patterns, socioeconomic factors, patient activation and owning an appropriate assistive device. The environmental factors included social support, inefficient healthcare system, inaccessible built structures and transport

system. The healthcare system's inefficiencies were due to a shortage of medical resources (medication, consumables and assistive devices), health workers lacking knowledge of SHCs prevention, and inadequate patient care approach. The factors influencing the prevention of SHCs are multifactorial and complex. The findings emphasise the importance of a whole-person approach to care, understanding personal and environmental factors shaping the experience of prevention of care. If we are to optimise health and prevent the occurrence of SHCs, targeted interventions must address the identified factors

To enhance inclusive health and develop a responsive prevention care model, we needed to listen to policymakers', service users' and care providers' views on solutions to improve the prevention of SHCs in people with SCI. The proposed services and interventions to improve the prevention of SHCs include access to adequate health care, patient-centred care, the importance of strengthening rehabilitation care throughout the continuum, promotion of health, skilled healthcare workers and access to resources such as medicine, assistive devices, disability-friendly transport and housing.

The study's findings informed the development of a patient-centred prevention care model, highlighting the importance of putting the patient at the centre of care. Understanding the experiences of SHCs and preventive care shed light on the struggle to maintain health and the support needed to minimise the occurrence of SHCs. Prevention care for people with SCI needs to be holistic and empowering with a longitudinal perspective to care.

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To my God, Creator and Helper. Thank you for your grace throughout this journey.

FORMAT OF THE THESIS

The Thesis structure follows the integrated format outlined in the University of the Witwatersrand's Faculty of Health Sciences guide for PhD thesis formats.

Chapter 1: The introduction chapter will give the background information of the study, study conceptual framework, the rationale for the study, outline the study objectives, and the study's significance.

Chapter 2: The literature review chapter will describe the epidemiology of spinal cord injury, outline the related concepts, namely prevalence of secondary health conditions, the associated risk factors, and the impact of a secondary health condition on participation, health status, and quality of life and the models of care.

Chapter 3: This chapter presents the study methodology. This chapter consists of a published paper. The paper outlines the methodology for the whole PhD study, published in *BMC Research Notes*.

Chapter 4: This chapter presents the prevalence of secondary health conditions and associated factors in people with spinal cord injury. The paper presents the prevalence of secondary health conditions and the predictors of multiple secondary health conditions. This paper was submitted to the *South African Medical Journal* and is currently under review.

Chapter 5: This chapter is presented as a published paper titled "Experiences of secondary health conditions amongst people with spinal cord injury in South Africa: A qualitative study". This paper was published in the *South African Journal of Physiotherapy.*

Chapter 6. The chapter presents a manuscript titled "Exploring prevention and management of secondary health conditions among people with spinal cord injury, South Africa". The paper was submitted to the *International Journal of Therapy and Rehabilitation* and is currently under review.

Chapter 7: The chapter presents evidence on the range of prevention strategies discussed in a manuscript titled "Prevention strategies for secondary health conditions in people with spinal cord injury". This paper was submitted to *JBI Evidence Synthesis* is currently under review.

Chapter 8: Chapter 8 is presented as a published paper titled: 'I forget to do pressure relief ': Personal factors influencing the prevention of secondary health conditions in people with spinal cord injury, South Africa, *South African Journal of Physiotherapy.*

Chapter 9: Chapter 9 presents a manuscript on the environmental factors influencing the prevention of secondary health conditions submitted to *PLOS ONE* and is currently under review.

Chapter 10: This chapter presents a manuscript on "The services and interventions to enhance the prevention of secondary health conditions in South Africa". The paper focuses on the views of different rehabilitation stakeholders on the services and interventions to enhance secondary health conditions in South Africa. This paper was submitted to the *African Journal of Disability* and is under review

Chapter 11: This chapter presents the views of people with spinal cord injury and the therapists on solutions to improve the prevention of secondary health conditions. This paper is submitted to *Spinal cord cases and series* and is under review

Chapter 12: In this chapter, the study findings are discussed. The study limitations and strengths of the study are outlined.

Chapter 13: The proposed care model is presented, and study implications are outlined.

1. CHAPTER ONE: BACKGROUND OF STUDY

This chapter will give a brief overview of the health challenges people with spinal cord injury face and the rationale for the study. The study aim and objectives will be outlined. The conceptual framework for the study will be discussed.

1.1. Introduction

Good health and well-being for people with spinal cord injury (SCI) is a neglected right. According to the World Health Organization, health is "a complete state of physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 1998). The concept of health in people with chronic conditions is viewed differently because a chronic condition such as SCI is incurable and complex; thus, the complete state of well-being might not be achieved. Health in individuals with chronic conditions focuses on coping, adapting to the chronic condition, the ability to self-manage, and participating meaningfully in life (Huber et al., 2011). People with SCI have complex needs and health challenges that compromise their health, independence and inclusion (Fuseini et al., 2019, Cao and Krause, 2021). A person with SCI needs personalised care and support to maximise functioning, self-management and prevent further disability (McColl et al., 2017). However, health care needs for people with SCI are unmet (McColl et al., 2017, Chang et al., 2017). The limited focus on health for people with SCI undermines the right to enjoy the highest standard of health (United Nations, 2006).

People with SCI experience poor health due to preventable secondary health conditions. Secondary health conditions (SHCs) develop over time due to living with a disability (Rimmer et al., 2011, Jensen et al., 2012). Examples of SHCs include urinary tract infections (UTIs), pain, pressure sores, sexual problems, respiratory problems, spasms, osteoporosis, fractures and depression (Adriaansen et al., 2016, Sezer et al., 2015). Research shows that SHCs are prevalent throughout the lifespan of people with SCI (Adriaansen et al., 2016, Madasa et al., 2020, Brinkhof et al., 2016, Wahman et al., 2019). Not only are the SHCs prevalent, but there is also evidence of SHCs occurring concurrently (2 to15 SHCs) (Brinkhof et al., 2016, Rivers et al., 2018, Wahman et al., 2019). The presence of SHCs lowers the quality of life (Park et al., 2017, Rivers et al., 2018), increases readmission rates (Mashola et al., 2019), and worsens the primary disability (Richardson et al., 2021). If unmanaged, some of the SHCs (pressure sore and UTIs) can lead to death

(Callaway et al., 2015, Øderud, 2014, Cao and Krause, 2021, Madasa et al., 2020). Despite empirical evidence on SHCs among people with SCI, there is limited research on preventive care for SHCs.

Holistic care for a person with a chronic condition, including SCI, aims to improve functioning and minimize disability. Rehabilitation is a process that includes a set of measures to enhance health, functioning and to minimize disability (World Health Organization, 2011b). It includes prevention care at all levels of diseases prevention to address risk factors that can affect health, minimise complications and further disability (McColl et al., 2017, Sherry, 2014). However, prevention care needs for people with SCI are unmet. For instance, Mashola et al. (2019) investigated readmission rates within five years of rehabilitation in a private rehabilitation hospital, South Africa. They found high readmission rates (80%) due to SHCs, and some patients were readmitted several times for preventable SHCs such as pressure sores and UTIs (Mashola et al., 2019). What could be causing individuals to be readmitted three to four times for pressures sores which are preventable? Another local study reported the mortality rate for people with traumatic SCI four years post-SCI (Madasa et al., 2020). The study found that 24% of the participants died, and the causes of death included septicaemia and pressure sores (Madasa et al., 2020). Both these studies show that preventative care is an unmet need for people with SCI in South Africa.

1.2. The rationale of the study

1.2.1. Prevalence data on secondary health conditions is limited

Research on the SHCs epidemiology in people with SCI is limited in South Africa. Joseph and Wikmar (2016) investigated the prevalence of secondary complications following traumatic SCI during acute care in a tertiary public hospital in Cape Town. They found that 50% of the participants had at least one SHCs (Joseph and Wikmar, 2016). Evidence on SHCs post-rehabilitation phase in South Africa was reported by Madasa et al. (2020). Their study reported a higher prevalence of SHCs (89%) in people with traumatic SCI four years post-injury. Although these studies identified the extent of SHCs among people with SCI, both studies focused only on traumatic SCI and were based in one region, Cape Town. Given the uniqueness of the nine provinces in population demographics, social dynamics, and access to resources and services

(Statistics South Africa, 2019), Madasa's and Joseph's findings cannot be generalised to other provinces in South Africa. Evidence on the epidemiological data on SHCs is needed to inform planning and prevention interventions. Furthermore, understanding how people with SCI experience of SHCs will enrich the prevention care response.

1.2.2. Experiences of SHCs are not known

Even though there is some evidence on the prevalence of SHCs among people with SCI in South Africa (Joseph and Wikmar, 2016, Madasa et al., 2020), none have explored the experiences of SHCs from the patients perspective. Studies that have explored the impact of SHCs have reported the negative impact of SHCs on self-care, participation, mental health and life's role involvement (Callaway et al., 2015, Fuseini et al., 2019). There is a need to understand personal illness experience related to SHCs to inform a context-based prevention care model.

1.2.3. Factors influencing the prevention of SHCs are not known

Context-based evidence of factors influencing health maintenance and preventive care is lacking. A Canadian-based study explored factors influencing the journey of care related to the prevention of secondary health conditions and found several interconnected factors at a personal, family, community and healthcare system level (Guilcher et al., 2013). Some of the reported factors include a poor transition from inpatient rehabilitation to home care, being discharged without modifying the home environment, poor access to health-promoting facilities, including rehabilitation facilities and unclear policies on rehabilitation and referral systems (Guilcher et al., 2013). Other reported factors influencing the prevention of SHCs include the lack of knowledge on SHCs among health professionals, individuals' attitudes, and beliefs (Zanini et al., 2020a, Zanini et al., 2020b). Although these studies give an ecological picture of factors influencing the prevention of SHCs, the health system context is not the same.

South Africa has a high level of socioeconomic inequalities (Statistics South Africa, 2019). Disparities in South Africa are evident in access to basic resources such as education, water, sanitation, adequate housing and livelihood (Statistics South Africa, 2019). The current

unemployed rates stand at 32.5% (Department of Statistics South Africa, 2020), and in 2014, 55.5% of the population lived in poverty (R992/month), an estimate that must have increased due to the COVID 19 pandemic (World Bank Group, 2020). Socioeconomic vulnerability is worse for people with disabilities with low education levels and employment prospects (Hanass-Hancock and McKenzie, 2017). Although people with disabilities have access to social grants, disability-related costs and household maintenance lead to economic vulnerability (Hanass-Hancock et al., 2017, Kelly, 2019). Poor socioeconomic factors are associated with poor health outcomes and lower healthcare access (Gordon et al., 2020).

South Africa's health system is overburdened and curative focused (Mayosi et al., 2012). The public health sector serves 84% of the population and manages multiple disease burdens (Maphumulo and Bhengu, 2019, Mayosi and Benatar, 2014). Human immunodeficiency virus /Acquired immunodeficiency syndrome (HIV/AIDS), ischemic heart disease, tuberculosis and injury (interpersonal and road) were the top ten causes of mortality and morbidity in 2019 (South Africa Health Data, 2019). Then again, the current health challenge from the COVID 19 pandemic has overwhelmed the health system (Mbunge, 2020), putting a strain on the limited resources and increasing the demand for rehabilitation services (Brown et al., 2020, Halpin et al., 2020). In South Africa, the focus of healthcare tends to be bio-medically oriented with less emphasis on holistic chronic care management and rehabilitation care (Brown et al., 2020, Halpin et al., 2020, Morris et al., 2021, Ned et al., 2017).

Rehabilitation and access to care for people with chronic conditions such as SCI is not prioritised (Morris et al., 2021). Previous studies have reported inadequate access to health care for people with disabilities (Vergunst et al., 2017, Maart and Jelsma, 2014, Hanass-Hancock et al., 2017). Some barriers to accessing health include inaccessible transport systems, high transport costs, long distances and shortage of medication and assistive devices (Maart and Jelsma, 2014, Sherry, 2014, Vergunst et al., 2017). Access to rehabilitation services and follow-up care is also an unmet need (Maart and Jelsma, 2014). Hospital transport logistics, hospital leadership not valuing rehabilitation care (Ned et al., 2017), and a shortage of rehabilitation health professionals are some of the reported reasons that affect rehabilitation service delivery (Tiwari et al., 2020). To address

unmet rehabilitation needs, the World Health Organization initiated the global call to action, “Rehabilitation 2030”, which emphasise the importance of context-based research data to support rehabilitation and the development of service delivery models (World Health Organisation, 2017). There is a lack of research looking at service delivery for people with SCI in South Africa.

1.2.4. Inadequate service delivery model

There are gaps in South Africa's rehabilitation care services resulting in poor health outcomes for people with disabilities (Sherry, 2014, Morris et al., 2021, Ned et al., 2017). To manage disability, South Africa developed a service delivery strategy, “Framework and Strategy for Disability and Rehabilitation (FSDR) services 2015-2020” (National Department of Health, 2015). The framework outlines access to comprehensive rehabilitation services across the lifespan based on the community-based rehabilitation (CBR) strategy. CBR is “a strategy within community development for the rehabilitation, equalization of opportunities, poverty reduction and social integration of people with disabilities” (World Health Organization, 2004b, p. 2). One of the key focus areas for CBR is the right to the highest standard of health through health promotion, disease prevention, responsive medical care at all levels of care, rehabilitation and provision of assistive devices (National Department of Health, 2015). The FSDRs duration ended in 2020, and there is no formal reported evaluation outcome on the FSDR yet. However, a review of the FSDR found many barriers that influenced the framework's implementation (El Kout et al., 2020). Some of the barriers included lack of resources, such as a shortage of health professionals, high turnover, lack of political will and resource allocation to ensure the framework's implementation (El Kout et al., 2020). In line with the Rehabilitation 2030 action area on “building comprehensive rehabilitation service delivery models to progressively achieve equitable access to quality services” (World Health Organisation, 2017), there is a need for research on a model of care to prevent SHCs in people with SCI.

1.3. Study aim

This study aimed to establish factors influencing prevention care for secondary health conditions among people with spinal cord injury in the Tshwane metropolitan area to develop a prevention model of care.

1.4. Research objectives

1. To identify the prevalence of secondary health conditions and associated factors in people with spinal cord injury.
    i. To identify secondary health conditions in people with spinal cord injury
    ii. To identify factors associated with secondary health conditions
    iii. To establish the association between secondary health conditions and associated factors
2. To identify the range of prevention strategies for secondary health conditions experienced by people with spinal cord injury.
3. To explore experiences of secondary health conditions and strategies used by people with spinal cord injury to prevent secondary health conditions.
4. To explore contextual factors (personal and environmental factors) influencing the prevention of secondary health conditions among people with spinal cord injury.
5. To develop a prevention model of care for secondary health conditions.

1.5. Conceptual framework

The foundation of good research is a clear conceptual framework that shows the linkages between concepts when describing a specific phenomenon (Jabareen, 2009, Darlaston-Jones, 2007, Sinclair, 2007). In this study, the Conceptual Model for Identifying, Preventing and Managing Secondary Conditions in People with Disabilities was used to understand how SHCs develop, their impact and strategies that can be used to prevent their occurrence (Rimmer et al., 2011). Rimmer's conceptual model incorporates the International Classification of Functioning, Disability, and Health (ICF). The ICF is, an integrative model that demonstrates the outcome of health conditions as an interaction between the body structures and function, activity and participation in life events influenced by the individuals' contextual factors (Petretto et al., 2017, World Health Organization, 2013a). Rimmers' model was developed in a high-income country (Chicago, Center on health

promotion research for persons with disabilities and the department of disability and human development). To our knowledge, the model has not been used to conceptualize SCI specific needs.

Rimmer et al. (2011) conceptual model (Figure 1.2) has two parts: Part one outlines the secondary conditions' trajectory in terms of the onset, course, and the outcome (Left-hand side). Part two outlines the prevention and intervention strategies for secondary conditions, namely rehabilitation, health promotion and assistive technology and policy (Right-hand side).

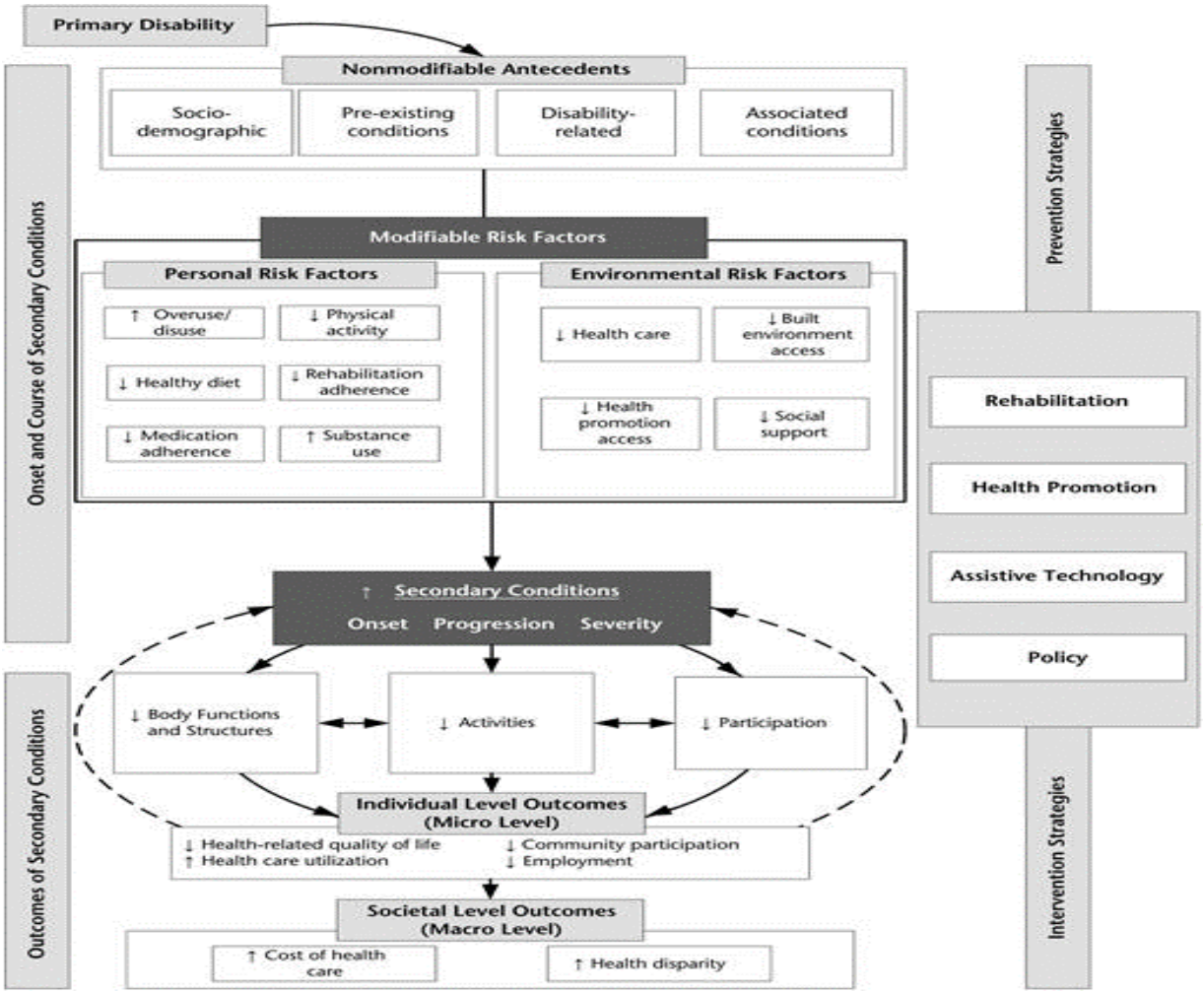


Figure 1:1: Conceptual model on onset, course, and secondary conditions outcomes in people with disabilities (Rimmer et al., 2011).

1.6. Reflexivity

I work as a lecturer in the field of public health and community physiotherapy. My previous work experience includes working as a therapist in a school for children with disabilities and a non-governmental organisation for people with disabilities. My work background has exposed me to different communities and challenges that people with disabilities experience beyond the primary disability they live with. People with disabilities experience stigma, and they have to continually fight to be part of the "normal" able-bodied society. Patients with disabilities are sent back home from inpatient rehabilitation facilities without modifying the home environment and training the family members to continue care from the inpatient rehabilitation hospital. Most communities lack rehabilitation care services at the primary healthcare level affecting continuity of care.

When conducting home-based rehabilitation (home-visit), I have observed that people with disabilities are not equipped to self-manage and take care of themselves post-discharge. The whole rehabilitation process focuses more on treatment than helping the individual with a disability to take care of themselves. In addition, the rehabilitation process does not include community integration and social inclusion. This approach to care increases vulnerability to poor health outcomes, where people die from preventable ailments. The health care system focuses a lot on curative care than health promotion and prevention of diseases in people with long-term conditions. People with a chronic condition or a disability struggle to live healthy and fulfilling lives.

My view on health and disability is informed by the biopsychosocial approach, summarized in the International Classification of Functioning, Disability, and Health. The ICF recognizes that health does not occur in a vacuum, but personal and environmental factors shape it. As such, the experience of health and wellness will be subjective depending on the contextual factors.

The ontological basis of this study is that reality is subjective. An interpretive approach unpins the journey to understand the experiences of SHCs, prevention, contextual factors, and perspectives on the solutions to improve SHCs prevention. Interpretivism relies on the narratives to understand the phenomena from the participants' perspective and the social factors shaping the experience.

1.7. Conclusion

This chapter has provided an overview of health challenges experienced by people with SCI. The rationale for the study was also discussed. The study aim and the corresponding objectives were outlined. The framework adopted to guide the study "Conceptual Model for Identifying, Preventing and Managing Secondary Conditions in People with Disabilities" was discussed. In Chapter 2, previous studies on SCI, SHCs and models of care will be reviewed.

2. CHAPTER TWO: LITERATURE REVIEW

2.1. Introduction

Spinal cord injury (SCI) is a devastating incurable injury to the spinal cord, causing disability, as well as inclusion and productivity limitations (Nas et al., 2015, O'Neill and Dyson-Hudson, 2020). In addition to grappling with the primary disability, people with SCI are prone to developing secondary health conditions (SHCs), affecting health and further disability (Stillman et al., 2017, Park et al., 2017). The reported high prevalence of SHCs points to a need for research to better understand the SHCs experiences of people with SCI and prevention care for SHCs in this population.

This chapter will review previous studies on SCI, SHCs and prevention care related to the study aim: to establish factors influencing prevention care for secondary health conditions among people with spinal cord injury to develop a prevention model of care.

The literature review consists of three sections covering the epidemiology of spinal cord injury, secondary health conditions (definition, prevalence and impact), prevention care and models of care.

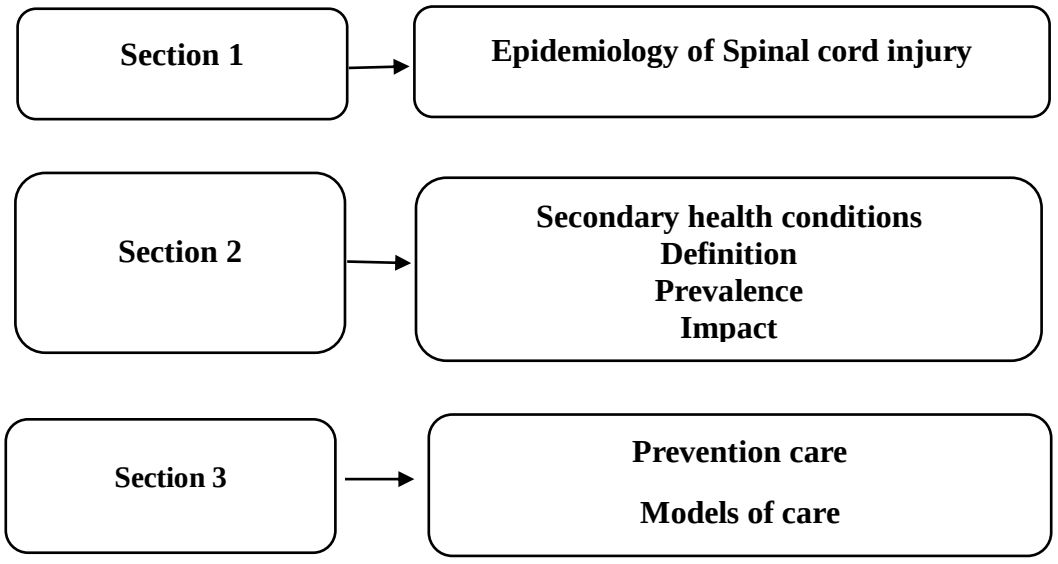


Figure 2:1: Schematic diagram outlining the sections in the literature review

This review includes published literature in English from 1998 to 2021. PubMed, Google scholar, CINHAL, and Science Direct databases were used to identify relevant literature using the following keywords: spinal cord injury; prevention; secondary health condition; secondary complications, personal factors, environmental factors, prevention and care model.

SECTION ONE

2.2. Epidemiology of spinal cord injury

Epidemiological data on SCI is scarce. A review on the global SCI epidemiology reported an SCI incidence range between 13.0 to 220 cases per million in low-middle income with a slightly lower-end range estimate for high-income countries of 163.4 cases per million (Kang et al., 2017). The estimated global incidence by Kang et al. (2017) is higher than the reported incidence in the International Perspectives on Spinal Cord Injury WHO report (2013), which reported 40 to80 SCI cases per million (World Health Organization, 2013b). The difference between the reported incidences implies an increase in SCI cases, possibly due to the growing burden of the ageing population and chronic conditions (Vos et al., 2020). The prevalence of SCI ranges between 490 to 526 per million in high-income countries and 440 per million people in low-middle countries (Kang et al., 2017). The possible reasons for the difference could be low reporting of disability outcomes, higher mortality rates and poor long-term care that increases vulnerability to poor health outcomes in low-middle income countries (Rahimi-Movaghar et al., 2013, World Health Organization, 2013b). Although the literature review by Kang et al. (2017) and the WHO report on SCI gives a global picture of SCI, the level of evidence is low. Also, the literature review by Kang et al., (2017) did not fully describe the types of studies reviewed, and only studies in English were included in the review. Therefore, it is possible that the epidemiology SCI was under-estimated. There is a need to strengthen SCI surveillance globally to inform SCI prevention interventions and future health care planning.

Reporting SCI aetiology needs to be comprehensive to inform prevention and planning for long-term care. Information on the causes of SCI is more readily available for traumatic SCI than for non-traumatic (NT) SCI (World Health Organization, 2013b). Worldwide, the estimated incidence

of traumatic SCI (TSCI) ranges from 10.5 to 16 cases per 100000 annually, and the prevalence ranges from 340 to 409 per 100 000 (GBD 2016 Traumatic Brain Injury and Spinal Cord Injury Collaborators, 2019, Kumar et al., 2018).). Leading causes of traumatic SCI include gunshot, motor vehicle accidents (MVA), sports-related injuries and falls (Draulans et al., 2011). On the other hand, epidemiological data for non-traumatic SCI (NTSCI) is limited, with the global incidence ranging between nine to 76 cases per million per year (Draulans et al., 2011, Kang et al., 2017, New et al., 2014). The prevalence data on NTSCI from only three countries, India, Canada (New et al., 2014), and Austria (Kang et al., 2017), range between 367.2 to2310 per million. Non-traumatic causes of SCI include HIV, cancer, arthritis, and Tuberculosis (TB) (Musubire et al., 2017). In low-middle income countries, the most common causes of non-traumatic SCI (NTSCI) are TB, HIV, and tumours, whereas, for high-income countries, the leading causes are degenerative conditions and tumours (Draulans et al., 2011, New et al., 2014). Given the global health challenges from the ageing population and rising infectious conditions, surveillance of NTSCI is necessary to understand disease patterns, associated risk factors and plan for resources needed for this population (Vos et al., 2020).

Context-based surveillance data and local research on SCI health outcomes are imperative to inform tailored interventions and policies. This need exists in South Africa, with no national SCI database, although a few reported epidemiological studies have been published. Data obtained from one hospital-based study in KwaZulu Natal province reported an annual SCI incidence of 12.3 cases per 100 000 from 2009 to 2015, mainly from MVA, falls, assault, infective spondylitis and neoplasm (Pefile et al., 2019). The incidence of SCI could have been under-estimated given that the study was a retrospective analysis of medical records. Two Cape Town-based retrospective studies reported SCI admissions per year (Miseer et al., 2019, Sothmann et al., 2015). The study by Miseer et al. (2019) reported 349 SCI admissions between 2016 to 2017, with the leading causes of SCI being trauma (51%), infectious diseases (24%), degenerative conditions (10%), and malignancy (7%) (Miseer et al., 2019). Sothmann et al. (2015) reported 185 admissions per year from 2003 to 2014 (Sothmann et al., 2015). It is difficult to compare these studies because the study period and population were not the same. The study by Miseer et al. (2017) included the pediatric population and the study period was over a year. The level of evidence of these

epidemiological studies is low, given that a retrospective design was used, which has limitations of missing and illegible data. Still, these studies highlight the SCI burden in South Africa and the need to invest in the SCI registry system. Considering that the causes of SCI (HIV, TB, injuries, cancer) contributes significantly to the burden of disease in South Africa, national surveys must include comprehensive disability information (impairment and types of disability) to ensure adequate planning for long term care service delivery (Pillay-van Wyk et al., 2016, South Africa Health Data, 2019).

2.3. Secondary health conditions

A distinction between SHCs and the terminology used to define co-morbidity or chronic diseases is necessary to ensure a common understanding of the terms. Co-morbidity or chronic condition is a condition that can occur any time (before the disability or after the disability), such as HIV, TB, cancer, diabetes, and hypertension (Khoury et al., 2013). Chronic conditions /co-morbidities are not caused or associated with the primary disability and occur in the general population (Khoury et al., 2013). Some studies incorrectly refer to co-morbidities and chronic conditions as secondary health conditions (Khoury et al., 2013). Secondary health conditions develop after the primary disability and are more prevalent in people with disabilities than those without a disability (Rimmer et al., 2011). A clear distinction between SHCs and co-morbidities/chronic diseases is necessary for SCI scholars and clinicians to develop tailored prevention interventions (Marge, 2008).

Different researchers use different terminologies to define complications or secondary health conditions experienced by people with disabilities such as SCI (Jensen et al., 2012, Kinne, 2008, Rimmer et al., 2011). Various authors have used secondary conditions, secondary medical problems, secondary impairments, secondary participation limitation, or secondary complications to refer to these health conditions (Khoury et al., 2013, Kinne, 2008, Sezer et al., 2015). In essence, complications such as musculoskeletal pain, depression, UTIs are health conditions (physiological and mental) that develop over time due to the SCI but are not directly caused by the primary disability (Jensen et al., 2012). Specific definitions of secondary complications can also include the impact of the environment on the disability, such as poor access or isolation, resulting in a

secondary disability due to participation restrictions (Kinne, 2008, Kinne et al., 2004). Although this definition aligns with the International Classification of Functioning, Disability (ICF), Marge (2008) and Jensen et al. (2012) argue that secondary complications cannot include these secondary participation restrictions factors. Secondary participation restrictions resulting from the SCI are considered risk factors for the occurrence of SHCs, but not SHCs per se. Aligning terminology to the ICF, using secondary disability or secondary health conditions terminology is more appropriate for defining health conditions experienced by persons with SCI. In this literature review and the current study, the term secondary health conditions will be used to describe secondary complications. There is, however, a need for researchers to reach a consensus on the definition of SHC. Clearer terminology for SHCs is needed for research, planning, and setting priorities for care.

2.3.1. Types of secondary health conditions

There is a range of SHCs affecting different bodily systems. The different types of SHCs include bowel and bladder complications; cardiovascular problems (orthostatic hypotension, autonomic dysreflexia, oedema, orthostatic hypotension); pressure sores, and respiratory complications (pneumonia, bronchitis) (Sezer et al., 2015). Other SHCs include musculoskeletal problems (osteoporosis; fractures, heterotopic ossification, spasticity, postural changes, contractures), injuries (burns), pain syndromes (nociceptive pain and neuropathic pain), fatigue, heartburn, sexual problems, and depression (Adriaansen et al., 2013, Jensen et al., 2013, Sezer et al., 2015).

Table 2:1: List of the types of Secondary health conditions

Cardiovascular Complications	Orthostatic hypotension (oh); autonomic dysreflexia, thromboembolism; oedema
Skeletal Problems	Contractures, osteoporosis, spinal deformity, heterotopic bone ossification, fractures
Respiratory complications Respiratory	Pneumonia; bronchitis; sleep apnea Atelectasis; pneumonia and respiratory failure
Renal complications	Incontinence; Urinary Tract Infections; urinary retention; kidney stones

Bowel complications	Constipation; Diarrhoea; Incontinence
Spasticity	Hyperreflexia (increased intermittent /sustained involuntary Somatic Reflexes) (Hyperreflexia); clonus, painful muscle spasms; hypertonus
Sleep problems	Insomnia/Sleep difficulties
Sexual problems	Loss of libido; erectile dysfunction; ejaculatory problems
Mental Health Problems	Serious episodes of anxiety; depression
Injuries	Burns; falls
Chronic Pain	Neuropathic pain; nociceptive pain
Pressure Ulcers	

The occurrence of SHCs can vary in the rate of recurrence and in number. The rate of SHCs occurrence can vary from once to being continuous (Piatt et al., 2016, Stillman et al., 2017). Piatt et al. (2016) reported that 66% of the participants experienced SHCs continuously than the 3.9% of the participants who experienced SHCs once in twelve months. In addition, individuals with SCI can experience several SHCs ranging from 1 to 16 SHCs concurrently (Brinkhof et al., 2016; Stillman et al., 2017). For example, Stillman et al., (2017) described the prevalence and cumulative incidence of secondary complications of spinal cord injury (SCI) in the first year after discharge from inpatient rehabilitation, USA. Over the 12 months, twenty-two percent had more than eight SHCs, with an average number of SHCs of 4.7 over a year. Although this study was a secondary analysis of data from a randomized controlled trial, the findings confirm the experience of multiple SHCs over time. Multiple SHCs highlight the need for strategic prevention and management interventions to target multiple SHCs and the associated risk factors.

2.3.2. Risk factors for secondary health conditions

There are non-modifiable and modifiable risk factors that increase susceptibility to developing SHCs (Rimmer et al., 2011). Non-modifiable risk factors include older age, female gender, SCI characteristics (Adriaansen et al., 2013, Rivers et al., 2018). Completeness of injury and higher SCI lesions are associated with SHCs (Adriaansen et al., 2013, Madasa et al., 2020). Modifiable

risk factors include higher body mass index (BMI) (Adriaansen et al., 2013, Rivers et al., 2018), mental health state (January et al., 2014), unemployment (Rivers et al., 2018), low socioeconomic status (Chishtie et al., 2019), substance use (Saunders and Krause, 2010), social support (Guilcher et al., 2013, Müller et al., 2012), access barriers to physical buildings and health promotion services (Maart and Jelsma, 2014, Rimmer et al., 2017). Most of the studies that highlighted the risk factors associated with SHCs were cross-sectional, making it challenging to make a causal inference. A longitudinal mixed study approach is needed to track SHC developments, identify factors influencing the development of SHCs and understand the experiences over time. A better understanding of who is at risk and when SHCs can inform preventive care.

This review will detail the most reported and problematic SHCs in persons with SCI: pain, pressure sores, bowel, and bladder problems (Piatt et al., 2016; Madasa et al., 2020). For each of the SHCs the review will cover the prevalence, causes, risk factors, management and, prevention care.

Pain

Pain is one of the most significant and problematic SHCs experienced by individuals with SCI (Piatt et al., 2016). The prevalence of pain among persons with SCI is high, ranging between 62% to 92% (Müller et al., 2017a, Adriaansen et al., 2013, Madasa et al., 2020), with pain severity ranging from mild to severe (Müller et al., 2017a). People with SCI experience two types of pain syndromes: neuropathic pain and nociceptive pain (musculoskeletal and visceral) (Sezer et al., 2015). However, musculoskeletal pain is the most commonly reported type of pain (Müller et al., 2017b, Adriaansen et al., 2013). The prevalence of musculoskeletal pain ranges from 62% to 87%, affecting mainly the back, shoulder, elbow, wrist, and hand joints (Irwin et al., 2007, Müller et al., 2017b, Sezer et al., 2015). Musculoskeletal pain is caused by overuse of the upper limbs during transfers, pressure relief, and wheelchair propulsion, causing injury to the joint capsule, tendons, ligament, and muscles (Irwin et al., 2007, Sezer et al., 2015). Poor posture and immobility can also lead to muscle imbalance in the upper limb joints, increasing the risk for pain (Irwin et al., 2007, Sezer et al., 2015). In people with tetraplegia, muscle weakness around the shoulder joints can cause subluxation associated with pain in the joint (Irwin et al., 2007). In addition, joint degeneration from repetitive weight-bearing during transfers and pressure relief can cause

musculoskeletal pain (Irwin et al., 2007). Other risk factors for musculoskeletal pain include older age and higher BMI (Adriaansen et al., 2013, Barbetta et al., 2016, Brinkhof et al., 2016). Some risk factors for musculoskeletal pain are modifiable; thus, targeted prevention strategies to are needed.

Although musculoskeletal pain can be troubling, it can be prevented and easily managed compared to neuropathic pain, for which treatment can be elusive (Li et al., 2018). Neuropathic pain is more severe (Li et al., 2018) and results from the damage to the somatosensory nervous system, causing a sharp, stabbing, burning, prickling, and numb sensation (Li et al., 2018, Sezer et al., 2015). It can be spontaneous or triggered by different stimuli, such as temperature and posture changes (Li et al., 2018), and it can be ongoing and chronic (Müller et al., 2017a). The prevalence of neuropathic pain ranges from 42% to 92% (Adriaansen et al., 2013, Müller et al., 2017a), with females and older people having higher neuropathic severity scores (Adriaansen et al., 2013).

The presence of pain affects health, mental well-being, and quality of life (January et al., 2014, Mashola et al., 2019). Neuropathic and musculoskeletal pain is associated with lower quality of life (Adriaansen et al., 2013). Pain restricts participation in home and social life, such as visiting a friend and engaging in leisure activities (Van der Meer et al., 2017), affects work-life, limits occupation choice (Callaway et al., 2015), as well as intimacy (Fuseini et al., 2019). The experience of constant pain in a person with SCI is significant and can affect mental health (Müller et al., 2017b, Jörgensen et al., 2017a), and high pain intensity is associated with depression symptoms (Müller et al., 2017b). Increased pain is associated with SCI duration, thus amplifying the primary disability over time (Richardson et al., 2021). Adequate pain management and prevention is needed to ensure that individuals with SCI can function and participate in life activities (Li et al., 2018).

A multidisciplinary approach is needed when managing pain to minimize the impact of pain on participation restrictions, health and quality of life. Pain management includes pharmaceutical and non-pharmaceutical therapy with varying degrees of relief (Cardenas and Jensen, 2006, Li et al.,

2018). The commonly used pain management treatment is pharmaceutical therapy with anti-depressants, anticonvulsants, and anti-spasticity medication (Sezer et al., 2015). Pharmaceutical therapy challenges are overuse, misuse, and low pain relief (Cardenas and Jensen, 2006, Patel et al., 2017). Other strategies used to manage pain include exercise, physiotherapy, counselling, massage, TENS, mobility, marijuana, keeping busy, and resting (Cardenas and Jensen, 2006, Li et al., 2018). An investigation of pain treatment utilized by people with SCI found that strengthening exercises and marijuana treatment for pain gave more long-lasting relief than medication use (Cardenas and Jensen, 2006). Pain management must be comprehensive to minimize the impact on health and address other SHCs associated with pain, such as contractures, spasms, constipation, Urinary tract infections (UTIs), and pressure sores (Callaway et al., 2015, Müller et al., 2017b).

Pressure ulcer

A pressure ulcer (PU), also referred to as a pressure sore, is a localized injury to the skin and the underlying tissues due to sustained pressure, particularly on bony areas like the ischium, trochanters, sacrum, heel, and the malleolus (Agrawal and Chauhan, 2012, Sezer et al., 2015). Pressure ulcers are troublesome complications that can occur at any time after SCI due to loss of sensation and mobility (Joseph et al. 2016, Wannapakhe et al., 2015). The prevalence of pressure ulcers ranges from 20% to 36%, but even this seemingly low rate is significant considering the negative impact on self-care and participation in life activities (Brienza et al., 2018, Wannapakhe et al., 2015). Risks associated with PU include higher and complete SCI lesions, malnutrition, urinary and bowel incontinence (Agrawal and Chauhan, 2012, Brienza et al., 2018). Poor access to appropriate assistive devices such as pressure relief cushions increases the risk of pressure sores (Øderud, 2014). Therefore a multifactorial approach to PU prevention is required when preventing and managing PU.

Pressure sores are preventable but require life commitment to prevention practices. Prevention practices for pressure sores include daily skin inspection, good nutrition, healthy lifestyles, regular pressure relief and appropriate assistive devices (Sezer et al., 2015, Visser and Visagie, 2019). Prevention of pressure should start during the acute phase and continue throughout the lifespan to prevent the occurrence and impact of PUs. In high-income countries, pressure sores were reported

as the second (Gabbe and Nunn, 2016) and third (DeJong et al., 2013) reason for readmission. In comparison, evidence from a low to middle-income country found that pressure sores were the main reason for several hospital readmissions (Mashola et al., 2019; Oderud, 2014). Managing a pressure sore takes time (Fuseini et al., 2019) and can lead to death if not treated early or correctly (Øderud, 2014). Research to better understand care needs concerning pressure sore prevention care is recommended.

Bladder problems

Bladder problems are the most problematic SHCs people with SCI experience (Divanoglou et al., 2018). The prevalence of bladder problems ranges from 44% to 73% (Adriaansen et al., 2016, Madasa et al., 2020, Van der Meer et al., 2017). The most commonly reported bladder related dysfunction include incontinence (prevalence range 27% to 65%) (Adriaansen et al., 2016, Brinkhof et al., 2016, Park et al., 2017) and UTIs (prevalence range 33% to 59%) (Adriaansen et al., 2013, Rivers et al., 2018, Madasa et al., 2020). Urinary tract infections are among the most frequent reasons for hospital readmission (Gabbe and Nunn, 2016, Mashola et al., 2019) and medication dependence (Patel et al., 2017) and the associated risk factors include higher SCI lesions, prolonged catheterization, unhygienic living environment, and poor sanitation (Øderud, 2014, Sezer et al., 2015).

Bladder problems contribute to poor quality of life (Adriaansen et al., 2016) and low physical and emotional health status (Park et al., 2017). Research shows that people with SCI experience depression and fear of leak accidents in public due to a lack of knowledge of managing bladder problems (Fuseini et al., 2019). Management of bladder problems includes hygienic practice, hydration, medication use, clean intermittent catheterization, and indwelling catheterization (Sezer et al., 2015). However, the management choice for bladder dysfunction depends on the patients' functional ability, health status, access to bladder management training and resources such as clean water and catheters (Øderud, 2014). Regular monitoring and patient support are essential to minimize long-term bladder problems (Sezer et al., 2015).

Bowel problems

Closely linked with bladder problems is bowel problems (Park et al., 2017). Bowel incontinence and constipation are also amongst the top problematic SHCs contributing negatively to the quality of life in persons with SCI (Piatt et al., 2016, Divanoglou et al., 2018). The reported prevalence of bowel problems range between 42% to 66% (Park et al., 2017, Brinkhof et al., 2016, Madasa et al., 2020), and the associated risk factors include gender (female), complete lesion, and the presence of bladder problems (Park et al., 2017). The prevalence of bowel problems does not usually increase over the years, but the impact on overall health and mental health is significant (Park et al., 2017).

Research shows that bowel problems limit function at home and social activities (Van der Meer et al., 2017) and increase disability (Richardson et al., 2021). Fuseini et al. (2019) in Ghana found that people with SCI limited social events involvement due to fear of bowel leaks in public. Management of bowel problems is multifaceted, including a high fibre diet, medication (laxatives, stool softeners, suppository), abdominal massage, digital rectal stimulation, trans-anal irrigation, manual evacuation, and functional electrical stimulation (Sezer et al., 2015). Adequate management of bowel problems is essential to minimize their impact on well-being.

2.4. Prevention care

When managing SHCs in persons with SCI, prevention of these conditions should take priority.

2.4.1. Prevention of diseases/conditions

Prevention of diseases/conditions is central to promoting health (United Nations, 2018, World Health Organization, 1998). Preventing diseases is an ancient concept from health promotion, referring to measures taken to minimize the risk of developing a condition, its progression, and the impact on health (Chang et al., 2009, World Health Organization, 1998). Prevention of diseases can occur at primordial, primary, secondary, tertiary, and quaternary levels (Pandve, 2014a). Primordial disease prevention addresses the structural determinants of health risk factors, and primary prevention addresses the risk factors to prevent the occurrence of a condition or a disease (McColl et al., 2017). Secondary prevention focuses on health maintenance for high-risk groups'

symptomatic groups, detecting and treating the disease or condition early to prevent its progression (McColl et al., 2017). Tertiary prevention seeks to minimize the impact of a condition on health, functioning, and quality of life through rehabilitation (Sherry, 2014). The last level is quaternary prevention, which targets patients with severe conditions to prevent unnecessary tests and interventions that will not benefit the patient (Pandve, 2014b). For a person with SCI, with a high risk for SHCs, prevention focuses mainly at a secondary and tertiary level of prevention.

Prevention strategies for SHCs need to target risk factors to minimize the occurrence and impact of SHCs. Rimmer et al. (2011) developed a conceptual model (Figure 2.2) to provide a common understanding of how SHCs develop, their progression, and the impact on the individual, family, health system and society (Rimmer et al., 2011). The conceptual model includes four interventions to address the modifiable and non-modifiable risk factors for SHCs and prevent the occurrence of SHCs in people with disabilities. The prevention interventions included rehabilitation, health promotion, assistive technology and policy. Evidence on the application of this model in SCI is scarce. Research applying Rimmer's conceptual model is needed to identify appropriate interventions to prevent SHC for people with SCI.

Prevention of any condition needs to be comprehensive, targeting the individual, the community, health providers, organizations, and policy (Cohen and Swift, 1999). For example, the spectrum of prevention (Figure 2.3) is a multilevel framework initially developed to guide injury prevention programs (Cohen and Swift, 1999, Munce et al., 2016). The spectrum of prevention includes different levels that can inform prevention programmes (Cohen and Swift, 1999, Rattray et al., 2002). The different prevention levels include strengthening individual knowledge and skills, promoting community and provider education, fostering coalitions and networks, changing organizational practices, and influencing policy and legislation (Cohen and Swift, 1999). This framework illustrates the importance of a systems approach to prevention care targeting multiple factors influencing health outcomes (Atun, 2012).



Figure 2:2: Spectrum of prevention (Cohen and Swift, 1999)

2.4.2. Systems thinking

Systems thinking is a holistic approach to understanding and solving problems, including health problems (Atun, 2012). A system is a whole structure of different components, processes, behaviours, and patterns to function (MacLachlan and Scherer, 2018). For example, the health care system comprises six interlinked building blocks: health workforce, service delivery, healthcare financing, leadership and governance, medical products and technology, information, and research (World Health Organization, 2009). Processes, structures, and activities must be coordinated within each building block to ensure optimal health outcomes. The health system does not operate in a vacuum. The national and global context influences its function and productivity. Evidence shows that applying systems thinking can strengthen health systems, unpack the complexities of health problems, inform appropriate interventions and improve health outcomes (Atun, 2012, Swanson et al., 2012).

There are many benefits to applying systems thinking in strengthening and transforming the health system. Applying systems thinking in health can help map multiple factors that influence health outcomes, patterns, behaviours, and interlinkages (World Health Organization, 2009). Secondly, systems thinking builds on the bio-ecological approach to health care, ensuring systemic factors

such as poverty and inequity are considered and addressed in health interventions (Tramonti et al., 2020). Systems thinking encourages a shift from linear approaches to multiple-level approaches, given the complexities of health problems (Hamdani et al., 2011, World Health Organization, 2009). For instance, developing a prevention program for SHCs will not be enough to educate people with SCI on SHCs. Other prevention strategies must target the community, organization, providers and influence policy to ensure better health outcomes (Cohen and Swift, 1999, Rattray et al., 2002). Systems thinking encourages partnerships with different sectors and the community, promoting shared vision and continuous learning (Swanson et al., 2012). Lastly, systems thinking encourages constant monitoring and evaluation of interventions to improve outcomes (Hamdani et al., 2011, World Health Organization, 2009). Systems thinking approach has been applied to healthcare transition for youth with disabilities (Hamdani et al., 2011), addressing health system challenges affecting rehabilitation services (Morris et al., 2021), identifying the effects of the COVID- 19 pandemics, and opportunities for people with disabilities (Jesus et al., 2020).

2.4.3. Model of care

There is a need for a holistic model of care to address systemic deficiencies in SCI care and prevent SHCs. Model of care (MoC) is a visual descriptive illustration of the relationship between the health services structured to improve health outcome, address health care system inefficiency, guide the design, implementation, and evaluation of services (Davidson et al., 2006). Scholars researching SCI, acknowledge care gaps, which predispose the development of SHCs people with SCI resulting in poor health outcomes (DeJong and Groah, 2015, DeJong et al., 2011). These researchers advocate strengthening preventive care to reduce SHCs (Lofters et al., 2019, McColl et al., 2017, Guilcher et al., 2013). To decrease readmission to the hospital due to SHCs, DeJong et al. (2013) proposed several ways to strengthen SCI care. Firstly, there should be a shift in SCI care to emphasise proactive, patient-centred, and be prevention-focused. Secondly, SHCs prevention should be strengthened by reorganizing SCI rehabilitation care delivery, moving from linear approaches to SCI care to a systems perspective or approach to care. Lastly, given the chronicity of SCI, SCI care can learn from existing chronic care models (DeJong and Groah, 2015, DeJong et al., 2011).

Spinal cord injury is a chronic condition requiring holistic care to address complex and changing needs across the lifespan. Care models for chronic diseases underscore the importance of patient-centred care and self-management (Hudon et al., 2012, Poitras et al., 2018). Patient-centred care is an empowering approach to care that seeks to partner with the patient to promote health and involve the patient in decision making and planning (Stewart, 2001, Pelzang, 2010). This approach requires a long-term care perspective, seeking to understand the patients' experiences of illness and helping the patient to navigate the health care system (Hudon et al., 2012, Stewart, 2001). It is need-based, prevention-focused, and encourages self-management (Grady and Gough, 2014). An example of a care model incorporating patient-centred care, self-management, and a systems perspective to care is the Expanded Chronic Care Model (ECCM) (Barr et al., 2003).

There are six elements in the ECCM: self-management delivery system design, decision support, information system, building healthy public policy, creating a supportive environment, and strengthening community action (Barr et al., 2003). This expanded chronic care model incorporate population health and health promotion tools and emphasises the importance of environmental support to support the management of chronic conditions (Barr et al., 2003) (Figure 2.4). The model also highlights the importance of partnership between patients, a proactive health care system and an empowered community to improve health outcomes (Barr et al., 2003). The ECCM has previously been used to develop prevention strategies for hypertension in Iran (Eghbali-Babadi et al., 2018), to guide the development of a model for neurological conditions in Canada (Jaglal et al., 2014) and to support HIV pre-exposure prophylaxis (PrEP) in HIV prevention care (ElZarrad et al., 2013). However, the level of evidence is low. Research to assess the effectiveness of the ECCM on preventive care in people with SCI is needed.

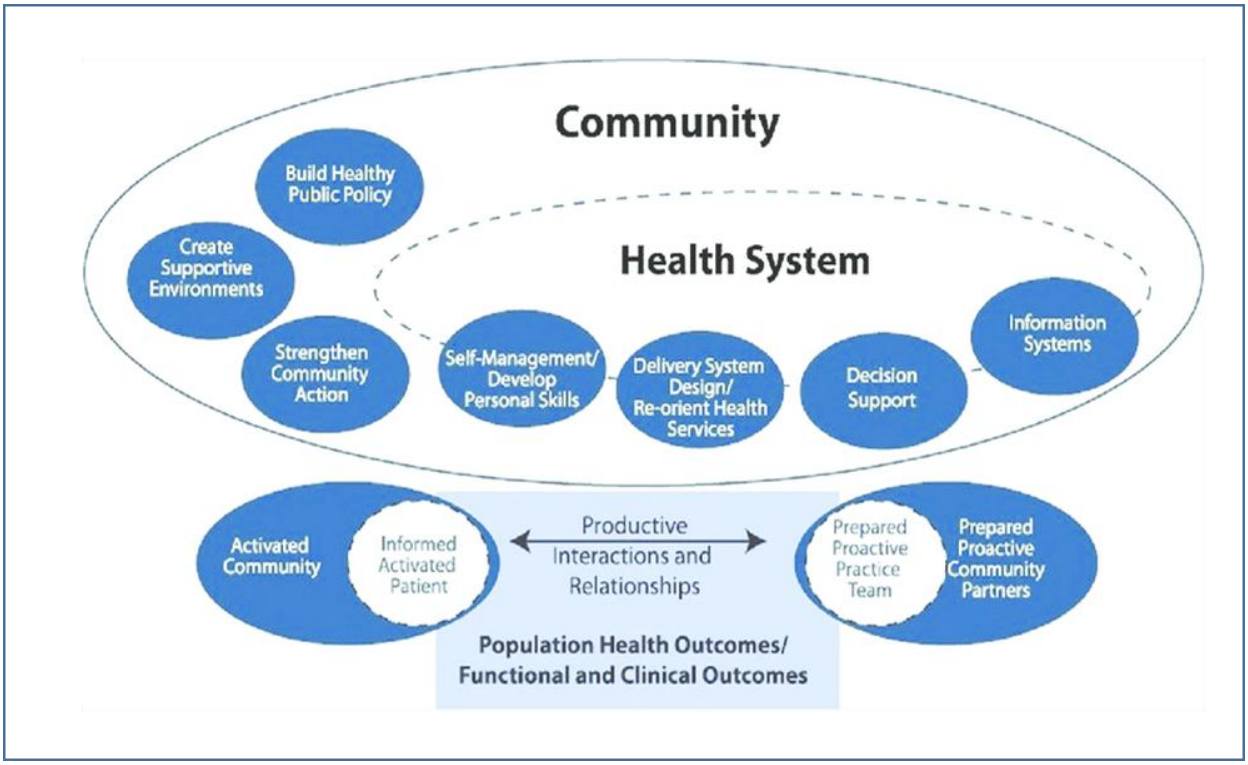


Figure 2:3: Expanded Chronic Care Model (Barr et al., 2003)

Another proposed model that uses a systems approach to improving health outcomes is the system of prevention framework (Sims and Aboelata, 2019). The system of prevention framework is based on systems thinking approach, and it incorporates the spectrum of prevention levels (Figure 2.3). The framework's premise is that systems from different sectors (health, education, mining, etc.) influence health outcomes. Thus they can be re-designed to enhance health. The framework has nine elements that can guide interventions to support SHCs preventive care, namely:

1. Develop a shared vision among all stakeholders
2. Engage in multilevel action to re-design health systems
    a. Strengthen individual knowledge and skills
    b. Promote community education
    c. Educate providers
    d. Foster coalition networks
    e. Change organisational practices

f. Influence policy and legislation

3. Elevate community voices and leadership
4. Facilitate community partnerships and multi-sectoral collaboration
5. Empower the workforce with skills in skills prevention grounded in social justice
6. Make a case for prevention and equity
7. Gather and share data with the community organisations
8. Generate stable sources of funding (Sims and Aboelata, 2019)

A comparison of the ECCM and the System of Prevention framework shows similarities and differences. Both models apply a system thinking approach and encourage multilevel interventions to improve health outcomes. Secondly, both models highlight the importance of empowering patients, communities, and care providers. Thirdly, both models encourage multi-sectoral partnerships to build capacity and form coalitions to effect system-level change. The System of Prevention framework differs from the ECCM in that it focuses on systematizing prevention care across all sectors and not only the health system and community. Secondly, the System of Prevention framework encourages shared vision, co-production of knowledge and funding to support prevention activities. These elements speak to collective action, ownership, and sustainability. Both models guide crucial elements that must be included in care models that seek to enhance health outcomes.

2.5. Spinal cord model of care

Although people with SCI are at high risk for SHCs development, research on prevention care models for SHCs is limited. A recent scoping review identified different SCI models of care delivery (Ho et al., 2021). The SCI models of care focused on transitional rehabilitation, independent living, and specialised home-based care. The features of the SCI model included multidisciplinary care, which included peer mentoring, integration of SCI at a primary level, establishing SCI specialized units to ensure continuity of care, and services to address healthcare access challenges such as telehealth and outreach programmes. Although the scoping review findings highlighted the benefits of the SCI care model in enhancing health outcomes, community integrations and continuity of care, SHCs prevention care was not highlighted.

Much advocacy has been towards strengthening prevention care for SHCs and the need to shift away from reactive SCI care (Dejong et al 2015; Dejong et al., 2011; McColl., 2017). To this end, Dejong et al. (2015) highlighted the need to reorganize SCI care to render "right care at the right time to the right person" and adopt systems approaches to SCI care as interventions to address high rehospitalization rates due to SHCs. However, research to support care practice and policy on prevention care related to SHCs in people with SCI is limited.

Current prevention care practice tends to use linear approaches focusing on individual SHCs and isolated strategies. Isolated strategies such as physical activity, health education, social support, medication, and self-management have been used to prevent SHCs in people with SCI with varying success (Jörgensen et al., 2017a; Guilcher et al., 2012, Munce et al., 2016; Evardone et al., 2018). For example, Lala et al., (2016) developed a model of care for healing pressure ulcers with electrical stimulation therapy for persons with spinal cord injury in Canada. The features of the model of care included collaborative care, establishing SCI specialist care units and capacity building for health professionals. The strength of this study is the use of community-based participatory research that can empower and bring transformative changes. However, comparing the model of care against prevention frameworks, elements such as fostering coalitions and networks, changing organizational practices, and influencing policy and legislation to enhance the health and prevention of SHCs in people with SCI were lacking. There is a need for a model of care that applies systems approaches to guide SCI care practice.

Prevention interventions that ignore contextual factors such as poverty, health system, and social factors are ineffective. A community-based randomised controlled trial based in Bangladesh assessed the effectiveness of an intervention to prevent SHCs and death, two years after discharge in people with spinal cord injury (Hossain et al. 2020). The intervention included home visits, screening for SHCs, advice on SHCs management and referral to local health care facilities when necessary. Post-intervention results showed no significant difference between the control group that received usual care and the intervention group. The reasons for the intervention's failure were the participants' low socioeconomic status, lack of resources, health care access and poor nutritional status, which were not addressed in the intervention (Hossain et al., 2020; Liu et al.

2020). The findings of this study highlight the need for SHCs preventive care models that applies systems approaches,incorportaing multiple interventions and collaborating with other sectors beyond the health care system to promote health.

2.6. Conclusion

This chapter reviewed literature related to SCI's cause, prevalence and incidence, SHCs after SCI, and prevention care in SCI. The evidence presented shows SHCs are prevalent and are impactful on health and participation in life. People with SCI require a holistic, life-long approach to patient care to avoid or minimize the occurrence of SHCs (Njoki et al., 2007, Sienko, 2018). There is a need to apply systems thinking when developing interventions to support the prevention of SHCs and improve health outcomes. There are gaps related to understanding lived experiences of SHCs, prevention of SHCs, contextual factors (personal and environmental) influencing the prevention of SHCs. The model of care for people with long term needs such as SCI must enhance patient-centred care, self-management and encourage multi-sectoral collaboration.

Chapter three provides the outline for the methodology followed to address the study aim.

3. CHAPTER THREE – STUDY PROTOCOL

3.1. Publication details

Chapter three is presented as a published paper. The paper briefly introduces secondary health conditions among people with spinal cord injury and the study methodology. This study used a mixed-method approach with five phases. This chapter was published in *BMC Research Notes*. *BMC Research Notes* is an open-access journal that publishes scientific research methods.

3.2. Journal details

Title of the Publication: Prevention care for secondary health conditions among people living with spinal cord injuries: Research protocol

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3.3. Details of author contribution

The Contributor Roles Taxonomy (CRediT) (Allen et al., 2019b) was used to outline the authors' contribution to the study. The full explanation of the terms is in Appendix G.

Table 3:1: Details of author contribution

	Pilusa	Myezwa	Potterton
Conceptualization	√	√	√
Method	√	√	√
Resources	√		
Manuscript writing draft	√		
Manuscript writing review and editing	√	√	√
Supervision		√	√

3.4. Copyright and permission

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3.5. Published article: Prevention care for secondary health conditions among people living with spinal cord injuries: research protocol

BMC Research Notes

RESEARCH NOTE

Open Access

Prevention care for secondary health conditions among people living with spinal cord injuries: research protocol

Sonti Pilusa*, Hellen Myezwa and Joanne Potterton

Abstract

Objective: People living with spinal cord injuries are at a high risk to experience preventable secondary health conditions in their lifetime, which can lead to rehospitalisation and death. Given the fact that spinal cord injury is a long term disability requiring on-going care, there is need to strengthen prevention of secondary health conditions. This study aims to establish factors influencing prevention care for secondary health conditions among people living with spinal cord injuries in a metropolitan area in order to develop a prevention model of care.

Results: A record review of patients living with spinal cord injuries will be conducted to identify the prevalence of secondary health conditions and associated factors. Semi-structured interviews will be conducted on patients living with spinal cord injuries, their caregivers and therapists to explore the contextual factors (personal and environmental factors) influencing the prevention of secondary health conditions. Thematic analysis will be used to identify the themes. Nominal group technique will be used to develop the prevention model of care for secondary health conditions. This study will be conducted at a tertiary and specialised rehabilitation hospital in South Africa.

Keywords: Injuries, Spinal cord, Spinal cord trauma, Preventative care, Prevention intervention, Secondary complications, Secondary conditions

Introduction

Globally the incidence of spinal cord injury (SCI) has been reported to range between 40 to 80 cases per million, the prevalence being higher for traumatic spinal cord injuries compared with the non-traumatic SCI [1]. In developing countries the incidence of spinal cord injuries ranges from 2.1 to 130.7/million/year, the majority being young males [2]. To date, there is no national prevalence data for spinal cord injuries in South Africa. However, the current available data indicates a high incidence of spinal cord injuries in Cape Town at 75.6 people per million, mainly due to violence (assault and motor vehicle accidents) [3]. The lack of epidemiological data is troubling considering that the main causes of spinal cord injuries (namely violence, HIV and TB) are in the top ten causes of mortality and morbidity in South Africa [4, 5]. Given that there is no cure for spinal cord injury, an understanding of the health status, long term care needs and secondary complications is essential to inform prevention care practice.

People living with spinal cord injuries (PLSCI) develop preventable secondary complications (secondary health conditions) throughout the journey of disability, that worsen the primary disability and can lead to re-hospitalization and death if not managed properly. Secondary health conditions (SHCs) are conditions that develop over time as a result of the primary disability but are not caused by the primary disability, for example, pressure ulcers, urinary tract infection, spasms and pain [6]. High prevalence of these complications among people with spinal cord injuries has been reported [7, 8]. A scoping review on the frequency of secondary health conditions in individuals with spinal cord injury found that the most reported conditions with a high prevalence rate (50% and higher) were pain, bowel and bladder regulation

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problems; muscle spasm; fatigue; heart burn and osteoporosis [7]. A recent study by Mashola et al. [9]. looked at readmission rates and prevalence of secondary health conditions in people with spinal cord injury from 2008 to 2012 in a private spinal hospital based in South Africa. The study found the prevalence of pressure ulcers ranged from 39 to 60% with each readmission and tended to get higher over time. The trend was similar for urinary tract infections although the prevalence was not as high. This study recommended further research on prevention protocols to reduce readmission rates for secondary health conditions. Previous research confirms that people with spinal cord injuries continue to struggle with the challenges posed by preventable secondary health conditions and these challenges are exacerbated post discharge [8].

Persons living with spinal cord injuries need health promotion and prevention services to enhance their wellbeing and quality of life [10, 11]. This means a person living with a spinal cord injury must know how to self-manage, prevent the occurrence SHC and be able to manage SHC if they do occur. On the contrary, evidence indicates that long-term health care in terms of health promotion and prevention services for people with disabilities including spinal cord injuries has not been given enough attention either globally or in South Africa [11–13]. A study by Van Loo et al. [12] described care received, care needs and preventability of secondary conditions according to persons with long-term spinal cord injury (SCI) living at home in the Netherlands. Forty seven percent of the participants received the needed care but 41% still needed extra care. This study indicates that prevention care needs of PLSCI were not fully met. There is a need to understand the experiences of secondary health conditions experienced by people living with spinal cord injuries, how these secondary complications are prevented and factors influencing prevention care for these complications. Thus, the aim of this study, over five phases is to establish factors influencing prevention care for secondary health conditions among people living with spinal cord injuries and to propose a prevention model of care for secondary health conditions.

This manuscript will outline the research proposal used to meet the aim of the study.

Table 1 gives a summary of the methodology for the study across the five phases outlining the study objectives; data needed; study design; location; sources of data; sample size; procedure and data analysis.

Main text

This study is designed as a mixed methods study with five phases. Phase one is a cross-sectional study using a record review to identify the prevalence of secondary health conditions and associated factors (type and level of lesion, duration of the disability, age, risky behaviour) in people living with spinal cord injuries. Phase two is a scoping review of evidence to identify the range of prevention strategies for secondary health conditions (protocol submitted to the JBI database). Phase three and four are qualitative studies that seek to explore participant's experiences of secondary health conditions as well as prevention strategies used by people living with spinal cord injuries and the contextual factors (personal and environmental factors) influencing prevention of secondary health conditions in this population This information will be collected through individual semi-structured interviews. Phase five will involve the development of a prevention model of care for secondary health conditions for people living with spinal cord injuries using the nominal group technique.

Subject selection

In phase one, the hospital records of patients with spinal cord injuries from January 2016 to September 2017 will be reviewed. The hospital records will be from a tertiary hospital and a rehabilitation hospital, based in Gauteng province, South Africa. For phase three and phase four, participants will be recruited at a rehabilitation hospital and will include patients with spinal cord injuries, their caregivers and allied health professionals. For phase five, a nominal group discussion will be conducted with three focus groups i.e. care users (people living with spinal cord injuries and their caregivers), clinical experts in spinal cord injury rehabilitation therapists and lecturers, and rehabilitation hospital managers and provincial rehabilitation services policy makers.

This study has been approved by the Human Research Ethics Committee of the University of the Witwatersrand (M170938), University of Pretoria Research Ethic Committee (36/2018) and registered with the South African National Health Research Database (reference GP201712036). Permission has been granted by the hospitals. Written, informed consent will be obtained from all the participants.

Sample size and inclusion/exclusion criteria

For the first phase, sample size was calculated using data from a previous study that looked at the prevalence of secondary health conditions in people living with spinal cord injuries [14]. The Naing et al. [15] sample size calculator for prevalence studies was used to calculate sample size using a power of 95% and a level of significance of 5%, and a minimum of 323 records will be reviewed. All hospital patient records for people living with spinal cord injuries who were admitted to the hospital during the period January 2016 to September 2017 will be reviewed. Hospital patient records for people living with

Table 1 Summary of the study

	Phase 1	Phase 2	Phase 3	Phase 4	Phase 5
Objectives	To identify the prevalence of secondary health conditions (SHC) and associated factors	To identify the range of prevention strategies for secondary health conditions experienced by people living with spinal cord injuries (PLSCI)	To explore experiences of SHC and strategies used to prevent SHC	To explore contextual factors influencing prevention of SHC among PLSCI	To develop a prevention model of care for SHC
Data needed	SHC and associated factors (types, frequency)	Prevention strategies for SHC	Experiences of SHC and prevention strategies	Personal factors Environmental factors influencing prevention	Components for the model of care
Study design	Record review	Scoping review	Semi-structured interviews	Semi-structured interviews	Nominal group discussion
Location	Tertiary hospital and rehabilitation hospitals		Rehabilitation hospital	Rehabilitation hospital	Rehabilitation hospital
Source of data	Patient records	Relevant literature (published and unpublished) All study designs	People living with spinal cord injuries (PLSCI)	PLSCI, caregivers Health professionals (occupational therapists, physiotherapists, dieticians, speech therapist, social worker, psychologist)	Group 1: Care users—PLSCI and caregivers Group 2: Experts in SCI rehabilitation therapists, lecturers Group 3: Rehabilitation managers and policy makers
Sample size	323 patients records		Minimum 15 people with spinal cord injuries	Minimum 15 people with spinal cord injuries Minimum 15 caregivers Minimum 15 health professionals	5 to 9 participants per group
Inclusion criteria	PLSCI records admitted at a tertiary hospital (Jan 2016–September 2017) PLSCI using OPD clinic at a rehabilitation hospital (Jan 2016–September 2017)	Population: People living with spinal cord injuries female and male, 18 years and above Concept: Prevention strategies for secondary health conditions in terms of rehabilitation, health promotion, assistive technology and policy Context: community, home setting and clinical based studies (hospital and primary health care centres)	PLSCI attending OPD clinic	PLSCI at the OPD clinic Caregivers of PLSCI Health professionals at the rehabilitation hospital	PLSCI and caregivers from phase three Therapists, Lecturers who teach spinal cord injury; Rehabilitation managers; Policy makers
Procedure and instrumentation	Questionnaire	Joanna Briggs Institute Reviewers Manual 2015: Methodology for JBI scoping reviews	Interviews Interview guide	Interviews Interview guide	Nominal group technique
Data analysis	Descriptive statistics Frequencies and percentages Logistic regression analysis	Narrative summary on the number of studies found addressing the study question, study designs, the range of prevention strategies for secondary health conditions	Thematic content analysis	Thematic content analysis	Qualitative data: thematic content analysis Quantitative data: descriptive statistics

spinal cord injuries who attended the outpatient clinic at the hospital during the period January 2016 to September 2017 will also be reviewed.

For phase three and four, a minimum of 15 individual semi-structured interviews will be conducted for people with spinal cord injuries; caregivers and the allied health professional working with patients with spinal cord injuries respectively. Data will be collected till saturation is reached. For phase five, nominal group discussion will be conducted with three groups, each group will have five to nine participants. Group one will comprise of therapists and lecturers; group two will comprise of people living with spinal cord injuries and their caregivers and group three will be the rehabilitation managers and rehabilitation service policy makers.

Study procedures

In phase one, each patient record will be retrieved and data will be extracted using a questionnaire sheet to collect information on the demographic data, type of secondary health conditions, spinal cord injury information (duration since injury, level and cause of injury) and associated risk factors. In phase three the principal investigator will interview the participants with spinal cord injuries to explore experiences of secondary health conditions and strategies used to prevent secondary health conditions and factors influencing prevention care. In phase four the caregivers and the health therapist will be interviewed to explore factors influencing prevention of secondary health conditions among people living with spinal cord injuries. The interviews will be audio-recorded and transcribed verbatim. Data gathered in phases one to four will presented to the participants recruited for phase five and nominal group discussion will be conducted as outlined by Cantrill et al. [16] to identify key components of a prevention model of care for secondary health conditions.

Data analysis

Data from the record review will be analysed using the Statistical Package for the Social Sciences (SPSS) version 22. Significance will be set at p value ≤ 0.05. Regression analysis will be done to assess the associations between the secondary conditions and associated factors (type and level of the lesion; duration of the disability; age; presence of chronic diseases and risky behaviour). Thematic content analysis will be utilised to identify themes from the qualitative data: Data will be coded, similar foci will be categorised and sub-categorised, and thereafter themes will be identified. Coding will be done by the principal investigator and a second coder in two separate sessions and the results will be compared. To ensure trustworthiness of data, an audit trail throughout the research process will be kept in a field journal; detailed description of the data collection, analysis and interpretation will be outlined. Debriefing sessions will take place to discuss the research process, findings and data analysis with the research supervisors [17]. MAXQDA software will be used to analyse and manage the data. Thematic content analysis and descriptive statistics will be used to analyse data from phase five.

Conclusion

Sustainable Development Goal number three; "to ensure healthy lives and promote wellbeing for all" includes people with disabilities [18]. One way of promoting health for people living with spinal cord injuries is through the prevention of secondary complications. The insight gained from this study will contribute to the body of knowledge on secondary complications experienced by people living with spinal cord injuries, shed light on prevention strategies and the factors influencing prevention care. Furthermore the clinicians working with people with spinal cord injuries can use this data for screening purposes and to develop prevention strategies for commonly experienced secondary health conditions. Lastly, policy makers will be able to utilise the findings of this study to inform health promoting policies and to improve the model of care for persons living with spinal cord injuries.

Limitations

The study site will mostly be based in one rehabilitation hospital, thus the findings may not be easily generalised to different contexts. Using purposive sampling may increase responder bias. Nevertheless, this study will give us an understanding of the contextual factors influencing prevention and a prevention model of care informed by the different stakeholders i.e. people with spinal cord injuries, caregivers, rehabilitation therapists and managers, academics and policy makers.

Abbreviations

SCI: spinal cord injury; PLSCI: people living with spinal cord injuries; SHC: secondary health conditions; HIV: Human Immunodeficiency Virus; OPD: outpatient department.

Authors' contributions

SP, HM and JP were involved in the conception and design of the study. SP drafted the manuscript. HM and JP reviewed the manuscript. All authors read and approved the final manuscript.

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Not applicable.

Competing interests

The authors declare that they have no competing interests.

Availability of data and materials
This article is a research proposal. The dataset generated for some of the phases of the study has not been analysed, but will be made available from the corresponding author on reasonable request.

Consent for publication
Not applicable.

Ethics approval and consent to participate
This study has been approved by the Human Research Ethics Committee of the University of the Witwatersrand (M170938), University of Pretoria Research Ethic Committee (36/2018) and registered with the South African National Health Research Database (Reference *GP201712036*). Informed consent will be sought from all the participants.

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4. CHAPTER FOUR: PREVALENCE OF SECONDARY HEALTH CONDITIONS AND ASSOCIATED RISK FACTORS

4.1. Manuscript details

Chapter four is presented as a manuscript structured according to the journal guideline. The paper aims to identify the prevalence of secondary health conditions (SHCs) and associated factors in people with spinal cord injury (SCI). The paper was submitted to the *South African Medical Journal*, and we are working on post-review corrections. In conducting the retrospective study, we aimed to understand better the epidemiology of SHCs in people with SCI and the associated risk factors in the South African context. The findings of the study would help develop tailored prevention strategies.

The manuscript's title is "**Secondary health conditions in people with spinal cord injury, South Africa: Prevalence and associated factors"**.

Journal: *South African Medical Journal*

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4.2. Details of author contribution

The Contributor Roles Taxonomy (CRediT) (Allen et al., 2019b) was used to outline the authors' contribution to the study. The full explanation of the terms is in Appendix G.

Table 4:1: Details of author contribution

	Pilusa	Myezwa	Potterton
Conceptualization	√	√	√
Method	√	√	√
Resources	√		
Manuscript writing draft	√		
Manuscript writing review and editing	√	√	√
Supervision		√	√

4.3. Abstract

Introduction: People with spinal cord injury (SCI) experience preventable secondary health conditions (SHCs), which worsen the disability, lower quality of life, affect health and well-being. There is limited information on the prevalence of secondary health conditions and the associated factors to inform planning and practice in South Africa.

Objective: To identify the prevalence of secondary health conditions and the associated factors in people with spinal cord injury.

Method: We conducted a retrospective review of patients' medical records at a tertiary hospital and rehabilitation centre. Data collected included demographic data, injury profile, secondary health conditions, and associated factors. Data were summarised using descriptive statistics of frequency and percentages. Fischer's exact test was used to determine the association between secondary health conditions and sociodemographic and clinical variables. Mann Whitney U test was used to determine the associated risk factors for secondary health conditions. Multinomial regression was used to determine the predictors of the frequency of SHCs.

Results: Four hundred and twenty-five (425) records were reviewed, 68% of patients were males, and the median age was 45 (35-56) years. The majority (93.7%) of the participants had SHCs, and 78% showed ≥ two SHCs. The results showed that the significant predictors of having ≥3 SHCs are the duration of SCI (p=0.01), site of injury in the upper (p=0.03) and lower thoracic (p=0.01) spine, unemployed (p=0.04), and public hospital income classification (H_0-social grant/ unemployed, H1 earning between 0-R100 000 and Road accident Fund: 0.03, 0.03, and 0.01 respectively).

C**onclusion:** Secondary health conditions are prevalent among patients with spinal cord injury. People with spinal cord injury experience multi-morbidity, which requires multiple management strategies. These findings point to the need for prevention strategies to minimise the occurrence of secondary health conditions.

Keywords: secondary health conditions, secondary complications, spinal cord injury, risk factors, prevalence.

4.4. Introduction

Spinal cord injury (SCI) is a devastating condition, causing severe disability and contributing to the global health burden (GBD 2016 Traumatic Brain Injury and Spinal Cord Injury Collaborators, 2019). There is no national database for SCI in South Africa. However, the Global Burden of Disease Study 2016 estimates the prevalence of traumatic SCI at 206/100000 (GBD 2016 Traumatic Brain Injury and Spinal Cord Injury Collaborators, 2019). This figure could be under-estimated, given that apart from traumatic injuries, several other conditions such as HIV, tuberculosis (TB) and ageing contribute to the burden of SCI. Spinal cord injury has long-term consequences on the individual's health, family, and the health system (Callaway et al., 2015, Fuseini et al., 2019).

Several studies have reported a high prevalence of secondary health conditions (SHCs) in people with SCI (Adriaansen et al., 2013, Adriaansen et al., 2016, Wahman et al., 2019). The spectrum of SHCs includes pain, respiratory problems, oedema, autonomic dysreflexia, pressure sores, spasms, depression, contractures, sexual, bowel, and bladder problems (Adriaansen et al., 2016, Stillman et al., 2017). The prevalence of SHCs increases with the length of time individuals have lived with SCI (Adriaansen et al., 2013). In the early stages of SCI, the prevalence of SHCs ranges from 50-78% (Joseph and Wikmar, 2016, Wahman et al., 2019), increasing to 89- 98.5% four to ten years post- SCI (Adriaansen et al., 2016, Madasa et al., 2020).

Several modifiable and non-modifiable risk factors influence the development of SHCs (Rivers et al., 2018). Non-modifiable risk factors associated with SHCs development include gender, age and SCI profile (type, level, completeness, and duration of injury) (Adriaansen et al., 2013, Brinkhof et al., 2016). Females are more at risk for bladder dysfunction and depression (Brinkhof et al., 2016) and tend to report high pain severity than men (Adriaansen et al., 2013). Males with SCI are more at risk for sexual problems and pressure sores (Brinkhof et al., 2016). Older age is associated with pain, sexual problems, and sleep problems (Brinkhof et al., 2016). People with complete lesions and tetraplegia have a high risk for multiple SHCs (Madasa et al., 2020, Brinkhof et al., 2016, Joseph and Wikmar, 2016, Park et al., 2017). Modifiable risk factors include high BMI (Adriaansen et al., 2013, Rivers et al., 2018), smoking (January et al., 2014), lack of knowledge on SHCs (Visser and Visagie, 2019), unemployment (Rivers et al., 2018), and health care system

inefficiencies (Fuseini et al., 2018, Guilcher et al., 2013). Data on SHCs and associated risk factors in South Africa are still needed to inform patient care and develop targeted context-specific prevention interventions.

Secondary health conditions affect overall health. The presence of SHCs limits self-care, restricts participation in social activities and affects mental well-being (Callaway et al., 2015, Fuseini et al., 2018, Van der Meer et al., 2017, Pilusa et al., 2021b). Over time, SHCs worsen the resulting disability from the spinal cord injury (Richardson et al., 2021). Other consequences of SHCs include high readmission rates (Mashola et al., 2019) and increased mortality rate due to the higher risk of infection from pressure sores and urinary tract infections (Øderud, 2014). Good health among people with disabilities is a fundamental right promoted by Sustainable Developmental Goal no 3 (United Nations, 2006, World Health Organization, 2017a). Understanding the epidemiology of SHCs in SCI and the associated risk factors in South Africa would help develop tailored prevention strategies.

4.5. Methodology

A retrospective study design was used to collect data from medical records of patients with SCI at two tertiary hospitals in Gauteng province (an academic hospital and a rehabilitation hospital). Both hospitals serve 2.92 million people and are referral hospitals for neighbouring provinces that do not have specialised care and rehabilitation hospitals. The rehabilitation hospital admits patients with different physical disabilities, offering medical care, physiotherapy, occupational therapy, social work, speech and hearing therapy. Outpatient care is provided to discharged patients once a month, including medical care, wound care management, repeat medicine and medical consumables.

Only medical records for patients with spinal cord injury at the tertiary hospital admitted from January 2014 and September 2018 were reviewed. Only the medical records of patients with SCI who used the facility between January 2016 and September 2017 and who gave consent during their outpatient department visit were reviewed at the rehabilitation hospital. Medical records of patients with other neurological impairments or pathology such as stroke and amputations were excluded.

The sample size was calculated based on data from a previous study that looked at the prevalence of SHCs in people with SCI (Joseph and Wikmar, 2016). Using a power of 95%, a level of significance of 5%, and 50.3% prevalence for SHCs, a minimum sample size of 385 records was calculated for the sample population (Naing et al., 2006).

4.6. Data collection tool

The researchers developed a questionnaire data collection form based on previous studies on SHCs (Adriaansen et al., 2013). The form had four sections. Section A: included sociodemographic data items (age, marital status, race, income source, and education level). Hospital income categories are used to categorise patients' income status at public health hospitals to determine health care cost subsidy:

H_0 - Social grant, pensioners and unemployed, full subsidy
H1: >R70 000 (single income)/>R100 000 (household income) per annum, partial subsidy
H2: R70 000-R100 000(single income)/ R250 000 to R350 000 (household income) per annum, partial subsidy
H3: > R250 000 (single income)/ R350 000 (household income) per annum, partial subsidy
Road Accident Fund (RAF): Patient who was involved in a pedestrian or motor vehicle accident and are illegible for RAF

Section B included items on the SCI profile (date of injury, type of lesion, cause of injury, level of the injury, ASIA scale score). Section C captured information on risk factors such as smoking, alcohol consumption, metabolic problems and chronic diseases. Section D recorded SHCs. The data collection tool was validated for content validity by rehabilitation therapists. The feedback from the therapists resulted in the addition of risk factors (drugs), chronic conditions (HIV/AIDS); addition of SHCs including deep vein thrombosis, types of bowel problems, grading pressure sores, spasticity, types of injury, postural deformities (scoliosis, kyphosis) and post-traumatic syringomyelia.

4.7. Data analysis

The data was extracted to Microsoft Excel from REDCAP ® and imported into IBM SPSS 25 ® for analysis. The data were summarized using descriptive statistics of frequency and percentages for the categorical variables. Median and interquartile range was used to summarise the continuous variable of age. Fischer's exact test was used to determine the association between secondary health conditions and sociodemographic and clinical variables, and Mann Whitney U was used to evaluate the difference between the age of the participants with or without secondary health conditions. Binary logistic regression was used to determine the predictors of the frequency of secondary health conditions. The level of significance was set at a p-value less than 0.05.

4.8. Ethical considerations

The South African National Health Research Database (reference GP201712036) and the two study sites gave permission before collecting data. The study was approved by the Human Research Ethics Committee of the University of the Witwatersrand (M170938) and the University of Pretoria (36/2018). Informed patient consent was sought from patients with SCI before reviewing the medical records at the rehabilitation hospital. All the medical patient records were given a unique data reference number on the data extraction sheet.

4.9. Results

4.9.1. Socio-demographic characteristics

The sociodemographic characteristics of the participants are presented in Table 4.2. The continuous variable of age and duration since injury ($p<0.05$) were not normally distributed. Therefore were presented as median and interquartile range. The patients' median age was 45 (35-56) years, and most of the patients were males (68%).

Table 4:2: Sociodemographic characteristics of the patients (N=425)

Demographics		**Presence of SHC (N=425)**		
	Total	**Yes (n=398)**	**No (n=27)**	**p-value**
Gender, n (%)				0.67†
Male	289 (68)	272(68.3)	17(63)	
Female	136 (32)	126(31.7)	10(37)	
Age, Median (IQR)	45(35-56)	45(35-57)	41(32-50)	0.31‡
Marital status				0.44†
Single	295(69.4)	273(68.6)	22(81.5)	
Married	126(29.6)	121(30.4)	5(18.5)	
Not stated	4(0.9)	4(1)	-	
Employment				0.02*†
Yes	97(22.9)	85(21.4)	12(44.4)	
No	328(77.1)	313(78.6)	15(55.6)	
Hospital income Classification, n (%)				0.00*†
H_0	118(28.8)	117(29.4)	1(3.7)	
H1	184(44.9)	172(43.2)	12(44.4)	
H2 and H3	45(11)	40(10.1)	5(18.5)	
P(MVA) / Road accident fund(RAF)	63(15.4)	58(14.6)	5(18.5)	
Not stated	15(3.5)	11(2.8)	4(14.8)	
Race, n (%)				0.71†
Black	281 (66.1)	263(66.1)	18(66.7)	
White	125 (29.4)	117(29.4)	8(29.6)	
Mixed	9 (2.1)	9(2.3)	-	
Indian	3 (0.7)	3(0.8)	-	
Not stated	7(1.6)	6(1.5)	1(3.7)	
‡ Mann Whitney U test; †Fischer's exact test; *p-value <0.05				

4.9.2. Spinal cord injury profile and secondary health conditions

Table 4.3 outlines the cause of the patients' spinal cord injury, neurological level, and time since injury. The majority of the patients had traumatic SCI (64.7%), had paraplegia (68.5%), and the median time since injury was 4.2 (2.3 -6.1) years. The range of time since injury was 0.5 -44.17 years.

Table 4:3: Spinal cord injury profile

		Presence of SHC		
	Total	**Yes (n=398)**	**No (n=27)**	**p-value**
Cause of injury				0.54†
Traumatic	275(64.7)	16(59.3)	259(65.1)	
Non-traumatic	150(35.3)	11(40.7)	139(34.9)	
Site of injury				0.00*†
Lower cervical (C5-C8)	69(16.2)	62(15.6)	7(25.9)	
Upper cervical (C2-C4)	59(13.9)	54(13.6)	5(18.5)	
Upper thoracic (T1-T6)	58(13.6)	58(14.6)	-	
Lower thoracic (T7-T12)	114(26.8)	113(28.4)	1(3.7)	
Lumbar (L1-L5)	110(25.9)	101(25.4)	9(33.3)	
Sacral (S1-S5)	6(1.4)	4(1)	2(7.4)	
Not stated	9(2.1)	6(1.5)	3(11.1)	
Type and completeness of injury				0.00*†
No neurological loss	29(6.8)	22(5.5)	7(25.9)	
Paraplegia/incomplete	189(44.5)	173(43.5)	16(59.3)	
Paraplegia/complete	102(24)	102(25.6)	-	
Tetraplegia/incomplete	70(16.5)	67(16.8)	3(11.1)	
Tetraplegia/complete	32(7.5)	31(7.8)	1(3.7)	
Not stated	3(0.7)	3(0.8)	-	
Duration since injury in years, Median (Interquartile range)	4.2(2.3-6.1)	4.3(2.3-6.3)	2.5(1.8-3.8)	0.00*‡
‡ Mann Whitney U test; †Fischer's exact test; *p-value <0.05				

4.9.3. Prevalence of secondary health conditions

Secondary health conditions were present in 93.7% of the patients, and 24.5% had five or more SHCs (Figure 4. 1).

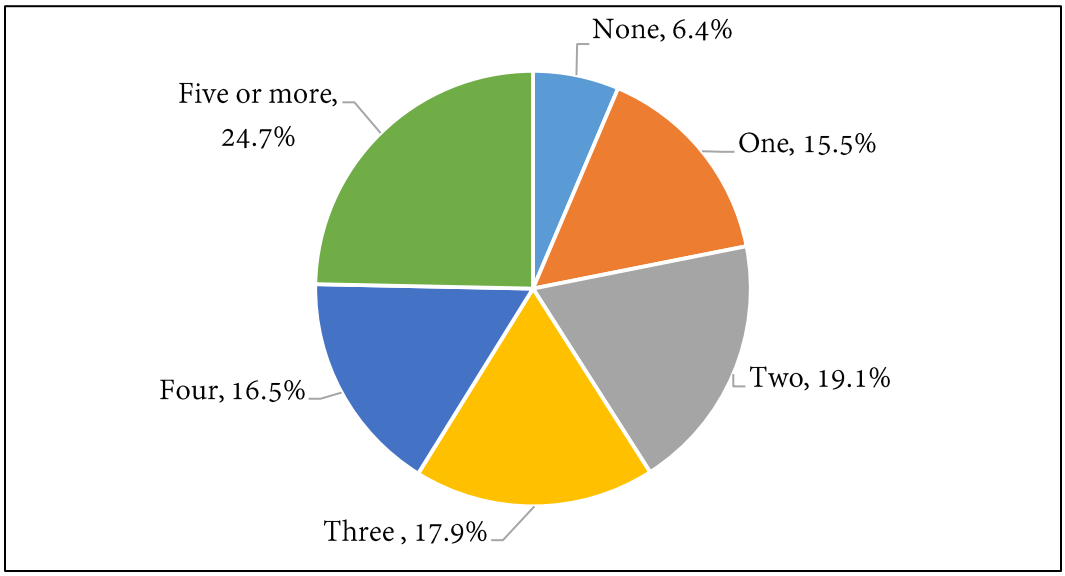


Figure 4:1: Frequency of secondary health conditions (N=425)

4.9.4. Presence of secondary health conditions

The most common SHC identified in this population is the presence of pain (78.1%), bladder problems (64.8%), bowel problems (53.8%) and pressure sores (33.7%) (Figure 4.2).

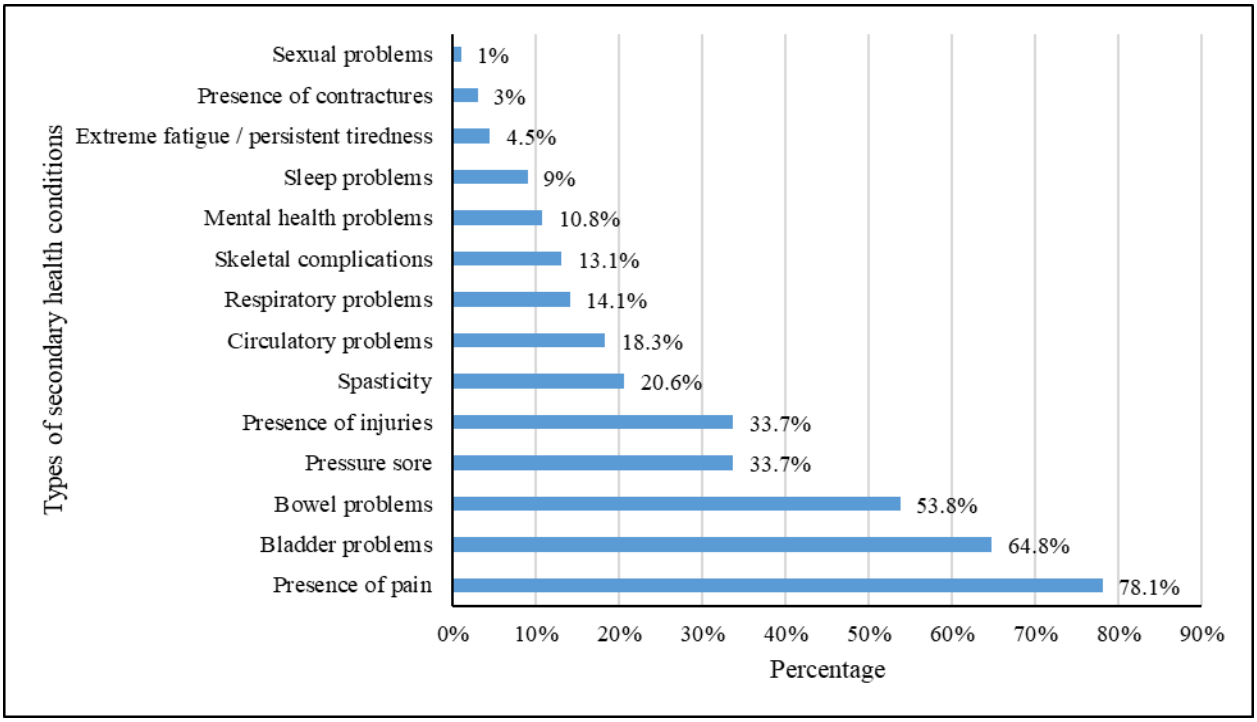


Figure 4:2: Type of secondary health conditions (n=398)

4.9.5. Predictors of secondary health conditions

Univariate binary logistic regression showed that employment status was a significant predictor of the presence of SHCs [B=2.95(1.33-6.53), p=0.01]. Unemployment increased the risk of SHCs by 2.95(1.33-6.53). The result is not statistically significant as the confidence interval crosses 1. Duration of injury is a predictor of secondary health conditions after adjusting for gender and age. As the duration since injury increases by 1, the adjusted odds ratio of presenting with SHC increases by 1.43 95% CI (1.09-1.88), and it is statistically significant (Table 4.4). The median duration of injury was significantly higher in patients with SHCs [4.3(2.3-6.3) years] than in patients with no SHC [2.5(1.8-3.8) years] (Table 4.2). Multivariate stepwise (Forward LR) binary logistic regression, adjusting for gender and age with the following variables - employment status, smoking, duration since the injury, income classification, cause of injury, level of injury and site of injury was performed. Smoking, type of injury and site of injury were excluded as they did not meet the binary logistic regression assumption. Some cells had zero and therefore were not included in the regression model (Mansournia et al., 2018).

Table 4:4: Univariate and multivariate analysis of the predictors of SHCs

	Univariate		**Multivariate**	
	Exp(B) (95% CI)	**p-value**	**Exp(B) (95% CI)**	**p-value**
Income classification				
H_0 - social grant, unemployment	9.75(0.85-111.90)	0.07	5.79(0.44-76.99)	0.18
Road accident fund	0.97(0.18-5.33)	0.97	0.63(0.11-3.78)	0.62
H1: >R70 000 (single income)/>R100 000 (household income) per annum,	1.19(0.25-5.67)	0.82	1.13(0.22-5.78)	0.88
H2 and H3	Reference	Reference	Reference	Reference
Employment status				
No	2.95(1.33-6.53)	0.01	1.67(0.64-4.38)	0.30
Yes	Reference	Reference	Reference	Reference
Duration since injury	1.42(1.13-1.79)	0.00	1.43(1.09-1.88)	0.01

Adjusted for gender and age

4.9.6. Predictors of frequency of secondary health conditions

To determine the predictors of the frequency of SHCs, the frequency was categorised into two categories, low ≤ 3 and high > 3, using the median (3) as the cut-off as described by DeCoster et al. (2011). Participants with no SHCs were excluded from this analysis. Fischer's exact test showed significant association with the frequency of SHCs – employment status (p=0.00), income classification (p=0.00), type of injury (p=0.02), level of injury (p=0.00) and level of completeness (p=0.00). Mann Whitney U showed a significant difference in the duration since injury between low ≤ 3 and high > 3 SHCs. All the variables with a p-value <0.05 were included in the regression model.

Multivariate stepwise (Forward LR) binary logistic regression, adjusting for gender and age with the following variables - employment status, smoking, duration since the injury, income classification, cause of injury, level of injury and site of injury was performed. The excluded variables were – age, gender, level of lesion, smoking and type of injury. The results showed that

level of injury, income classification, duration since injury and employment status were predictors of SHCs > 3 (Table 4. 5). Patients with upper thoracic and lower thoracic injury, on a social grant, road accident fund recipient, earning between R0 toR100 000 per annum or unemployed are more likely to present with >3 SHCs (Table 5).

Site of injury: The adjusted OR of presenting with > 3 SHCs is increased by 3.15 and 3.59 in the participants with upper thoracic [3.15(1.45-6.81)] and lower thoracic [3.59(1.88-6.86)] injuries, respectively, and the result is statistically significant.

Income classification and employment status: The adjusted OR of presenting with > 3 SHCs is increased by 4.08, 5.71 and 3.62 in the social grant [4.08(1.35-12.35)], road accident fund [5.71(1.81-18.09)] and those earning between R0-R100 000 per annum [3.62(1.28-10.24)] respectively and the result is statistically significant. The OR of presenting with > 3 SHCs in the unemployed category [2.49(1.31-4.76)] was increased by 2.49, and the result is statistically significant.

Duration of injury: As the duration since injury increases by 1 year, the odds of presenting with > 3 SHCs increases by 8% [1.08(1.03-1.14)].

Table 4:5: Multivariate logistic regression to determine the predictors of the frequency of SHCs

		p-value	Exp(B)	95% C.I.for EXP(B)	
				Lower	Upper
Step 1a	**Duration since injury in years**	0.00	1.12	1.07	1.17
	Constant	0.00	0.44		
Step 2b	**Site of injury**	0.00			
	Upper cervical	0.23	1.60	0.75	3.42
	Lower cervical	0.31	1.47	0.70	3.10
	Upper thoracic	0.00	3.17	1.52	6.59
	Lower thoracic	0.00	3.49	1.89	6.43
	Lumbar/sacral	Reference	Reference	Reference	Reference
	Duration since injury in years	0.00	1.12	1.07	1.17
	Constant	0.00	0.23		
Step 3c	**Site of injury**	0.00			
	Upper cervical	0.09	1.99	0.91	4.38

	Lower cervical	0.15	1.77	0.82	3.82
	Upper thoracic	0.00	3.75	1.76	7.99
	Lower thoracic	0.00	3.77	2.03	7.02
	Lumbar/sacral	Reference	Reference	Reference	Reference
	Duration years	0.00	1.10	1.05	1.16
	Employment status				
	No	0.00	2.96	1.61	5.46
	Yes	Reference	Reference	Reference	Reference
	Constant	0.00	0.09		
Step 4d					
	Site of injury				
	Upper cervical	0.27	1.58	0.70	3.59
	Lower cervical	0.34	1.49	0.66	3.38
	Upper thoracic	0.00	3.15	1.45	6.81
	Lower thoracic	0.00	3.59	1.88	6.86
	Lumbar / sacral	Reference	Reference	Reference	Reference
	Income classification	0.03			
	H_0: pensioner, social grant, unemployment	0.01	4.08	1.35	12.35
	Road accident fund	0.00	5.71	1.81	18.09
	H1: >R70 000 (single income)/>R100 000 (household income) per annum,	0.02	3.62	1.28	10.24
	H2 and H3	Reference	Reference	Reference	Reference
	Duration since injury in years	0.00	1.10	1.04	1.15
	Employment status				
	No	0.01	2.49	1.31	4.76
	Yes	Reference	Reference	Reference	Reference
	Constant	0.00	0.03		

[a] Variable(s) entered on step 1: Duration since injury in years
[b] Variable(s) entered on step 2: Site of injury.
[c] Variable(s) entered on step 3: Employment status
[d] Variable(s) entered on step 4: Income classification

‘

4.10. Discussion

The study aimed to identify the prevalence of secondary health conditions and associated factors in people with spinal cord injury. As previously reported in other studies (Adriaansen et al., 2013, Adriaansen et al., 2016), the prevalence of SHCs was high (93.7%). The prevalence is higher than that reported by other South Africa-based studies (Joseph and Wikmar, 2016, Madasa et al., 2020). Madasa et al. (2020) reported 89% SHCs prevalence among people four years to post SCI. Joseph and Wikmar (2016) reported 50.3% SHCs prevalence for patients with SCI during the acute

hospitalisation phase. The difference in the findings could be due to the inclusion of patients with a non-traumatic and traumatic lesion in our study, while Madasa et al. (2020) and Joseph and Wikmar (2016) focused only on traumatic SCI. These results confirm the need for preventive care services for people with SCI to minimise the occurrence of SHCs. Continuous surveillance for patients with SCI is needed to track health outcomes, identify needs and inform the development of prevention strategies.

Many patients had multiple SHCs; 24.5% of the patients reported five or more SHCs. The occurrence of many SHCs concurrently is common in people with SCI, with the range of 2 to15 SHCs being reported in other studies (Rivers et al., 2018, Brinkhof et al., 2016, Madasa et al., 2020). The occurrence of multiple SHCs is indicative of the extent and severity of the problem. Having multiple SHCs has been shown to affect the quality of life, functioning (Noonan et al., 2014, Richardson et al., 2021), and life satisfaction (Rivers et al., 2018). Managing more than two SHCs concurrently can lead to polypharmacy (Patel et al., 2017) and high demand for health care (Noonan et al., 2014). These findings must be considered when developing a prevention care model to target multiple SHCs and their associated risk factors.

In order to develop tailored prevention interventions for SHCs, knowledge of the associated factors is essential. The occurrence of many SHCs concurrently has been associated with older age, unemployment, higher BMI (Rivers et al., 2018), complete paraplegia, tetraplegia, and non-traumatic SCI (Brinkhof et al., 2016). However, in our study, we only found injury site, income classification, duration since injury and employment status to be significant predictors for multiple SHCs. Regarding the injury site, upper and lower thoracic participants had significantly higher odds (3.15 and 3.59 respectively) for multiple SHCs. This finding was similar to the findings reported by Brinkhof et al. (2016). Although in Brinkhof's study, complete paraplegia or tetraplegia had a higher chance of multiple SHCs than incomplete paraplegia (Brinkhof et al., 2016). Our findings clarify the high risk for readmission among individuals with SCI lesions in the upper thoracic region (T1-T6) and those with paraplegia (odds ratio 2.6, 2.3 respectively) (Mashola et al., 2019). Individuals with upper and lower thoracic lesions have upper limb strength and should be independent in daily life activities (Sezer et al., 2015). However, considering that people with thoracic SCI lesions use their upper limbs for all activities of daily living, they will be

prone to overuse injuries resulting in pain. Also, upper thoracic lesions may have autonomic dysreflexia and respiratory problems due to paralysis of the respiratory muscles.

The duration of injury was another predictor for multiple SHCs. With each year lived with SCI, there was an 8% increase in the risk of developing SHCs. The presence of SHCs worsens the disability (Richardson et al., 2021), increasing the risk for SHCs (Brinkhof et al., 2016). Other possible reasons for the study findings include "forgetting" to practice prevention care (Visser and Visagie, 2019), mental health (Pilusa et al., 2021a) and systemic environmental barriers (Maart and Jelsma, 2014). These findings could imply the need to include support for people with SCI as they live longer.

Poor socioeconomic status is associated with adverse health outcomes (Von Fintel, 2021, Gordon et al., 2020). Unemployment and social grant income category and patients who earn <R100 000 per annum had significantly higher odds for presenting with more than three SHCs. The impact of unemployment on a person with a disability is devastating because it can lead to loss of life's meaning (Fuseini et al., 2019) and economic vulnerability (Hanass-Hancock and McKenzie, 2017). Living with a disability can be costly due to disability-related costs such as hiring transport, paying a caregiver, and buying medication. Therefore, a social grant might not be enough to cover all the costs (Hanass-Hancock et al., 2017). It was surprising that the patients with Road Accident Fund (RAF) were at risk for multiple SHCs. The Road Accident Fund is an insurance cover for all road users, and people who incur injury or disability can claim for loss of income and medication expenses. The funds ensure access to resources that are needed to self-manage and prevent the occurrence of SHCs. Possible reasons for the relationship between RAF and multiple SHCs could be payment delays or that the funds paid have run out, leaving the individual with no income for long-term disability-related costs. Another perspective could be related to the severity of the injury, that even if there are funds (RAF), the severity of the SCI increases vulnerability to SHCs. Future research is needed to clarify whether the Road Accident Funds improve health outcomes and access to health resources. When developing prevention interventions, economic vulnerability and the impact on disability and health outcomes must be considered (Chishtie et al., 2019, Liu et al., 2020).

The most prevalent SHCs were pain (78.3%), bladder problems (64.6%) and bowel problems (53.4%). Pain, bladder, and bowel problems are the most commonly reported and significant SHCs people with SCI experience (Piatt et al., 2016). Similar to previous studies, pain was the most prevalent SHC (Adriaansen et al., 2016, Madasa et al., 2020). Pain limits self-care (Mothabeng and Mashola, 2019), restricts participation in work-life (Callaway et al., 2015) and is associated with depression (Jörgensen et al., 2017a) and disability (Richardson et al., 2021). Pain is usually managed with medication, but overuse, misuse, dependence, and non-effectiveness must be addressed (Cardenas and Jensen, 2006). In the same breath, bladder and bowel problems are significant health conditions that negatively impact health (Park et al., 2017) and are sources of fear and shame (Pilusa et al., 2021b). They require extra time to manage, thus disrupting daily routines (Van der Meer et al., 2017). Bowel and bladder problems are associated with poor health status (Park et al., 2017), depression (Mashola et al., 2019), and restricted participation in home and social activities (Van der Meer et al., 2017).

4.11. Conclusion

Secondary health conditions are prevalent among people with SCI. A high percentage of patients had multiple SHCs indicating challenges related to preventing SHCs. The predictors of multiple SHCs were SCI duration, thoracic lesion, unemployment and income classification (no income, social grant, road accident fund). These findings underscore the need to strengthen prevention care for people with spinal cord injury. Models of care for people with SCI must address multiple SHCs and the predictors thereof.

4.12. Limitation

Incomplete and illegible medical records posed a challenge. Important information on the severity of the injury and the education level was often missing. It is also possible that SHCs related to mental and sexual health were missed if not asked or deemed important by the healthcare professionals.

4.13. Implications

Practice:

Health professionals can use the findings to inform prevention interventions. For example, patients with SCI should be educated on SHCs throughout the continuum of care.

During clinic visits, screening for SHCs can be conducted to identify risk factors and minimise the occurrence and progress of SHCs.

Patients with associated risk factors for SHCs can be flagged for targeted intervention for follow-up care post-discharge and tailored patient-centred intervention

Research: There is a need for prospective longitudinal studies to track health outcomes related to SCI and identify unmet care needs.

4.14. Summary of chapter

This chapter identifies the prevalence of secondary health conditions and the associated factors in people with spinal cord injury. We found a high prevalence of SHCs, and 78% showed ≥ two SHCs. The results showed that the significant predictors of having multiple SHCs (≥3 SHCs) were duration of SCI, site of injury in the upper and lower thoracic spine and socioeconomic factors. These findings point to the need for prevention strategies to minimize the occurrence of secondary health conditions.

The next chapter will present the experiences of secondary health conditions in people with spinal cord injury.

5. CHAPTER FIVE: EXPERIENCES OF SECONDARY HEALTH CONDITIONS AMONGST PEOPLE WITH SPINAL CORD INJURY IN SOUTH AFRICA: A QUALITATIVE STUDY.

5.1. Publication details

Chapter five is presented as a published paper. This paper emanates from the results of the objective to explore the experiences of secondary health conditions amongst people with spinal cord injury. The key findings of this study were that secondary health conditions limit function, inclusion and affect mental health.

5.2. Journal details

Title of the Publication: Experiences of secondary health conditions amongst people with spinal cord injury in South Africa: A qualitative study.

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5.3. Details of author contribution

The Contributor Roles Taxonomy (CRediT) (Allen et al., 2019b) was used to outline the authors' contribution to the study. The full explanation of the terms is in Appendix G.

Table 5:1: Details of author contribution

	Pilusa	Myezwa	Potterton
Conceptualization	√	√	√
Method	√	√	√
Resources	√		
Manuscript writing draft	√		
Manuscript writing review and editing	√	√	√
Supervision		√	√

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5.5. Published article: Experiences of secondary health conditions amongst people with spinal cord injury in South Africa: A qualitative study

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Experiences of secondary health conditions amongst people with spinal cord injury in South Africa: A qualitative study

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Background: Secondary health conditions (SHCs) such as pain, pressure sores, sexual problems, bowel and bladder problems are prevalent throughout the lifespan of people with spinal cord injury (SCI). Studies have reported that SHCs decrease life expectancy and increase health care costs. Studies on the lived experience of SHCs are, however, limited.

Objectives: To explore the experiences of SHCs amongst people with SCI in a public rehabilitation hospital in South Africa.

Method: Face-to-face semi-structured interviews were conducted with people with SCI from August 2018 to July 2019. All interviews were transcribed verbatim and analysed using a content analysis approach.

Results: Seventeen people with SCI were interviewed. Participants experienced a range of SHCs. The most common experienced SHC was pain (94%). The main theme that emerged from the analysis was 'the impact of secondary health conditions on health and well-being'. The categories linked to the impact were SHCs co-occurrence and how SHCs limit function, restrict participation, affect mental health and disrupt lives.

Conclusion: We found that SHCs were enormously impactful on our participants' lives and health, as illustrated by their stories of fear, embarrassment and shame. Understanding people with SCI experiences of SHCs can enhance communication between people with SCI and health professionals and may help develop prevention strategies.

Clinical implications: To enhance patient-centred care, health professionals are encouraged to actively listen to patients' experiences of illness and the impact on health and wellbeing.

Keywords: secondary health conditions; secondary complications; spinal cord injury; health; wellbeing.

Background

Health is a complex phenomenon that extends beyond dysfunction or impairments. It is a by-product of the interaction between the affected bodily structures and systems, and ability to function and participate in life within a specific context (World Health Organization 2013). Health incorporates a sense of positive emotions about self, the ability to adapt, self-manage and thrive (Huber et al. 2011). Spinal cord injury (SCI) affects physical, mental and social health domains (Fuseini, Aniteye & Alhassan 2019; Jörgensen, Iwarsson & Lexell 2017). Furthermore, across the lifespan, people with SCI are at risk of developing secondary health conditions (SHCs), which lead to poor health (Mittmann, Hitzig & Craven 2014) and quality of life (Mashola & Mothabeng 2019).

Secondary health conditions are health problems, not necessarily caused by the SCI, but which occur because of living with a disability (Rimmer, Chen & Hsieh 2011). The different SHCs that may develop after SCI include pain (neuropathic and musculoskeletal), pressure sores, spasms, postural hypotension, pneumonia, bowel and bladder problems, mental health problems and sexual problems (Brinkhof et al. 2016; Jensen et al. 2013). There is evidence that SHCs are prevalent throughout the lifespan of people with SCI. Some SHCs become more prevalent over time (such as urinary tract infections), whilst others may increase in severity (such as musculoskeletal pain) (Adriaansen et al. 2013, 2016). Certain SHCs remain constant (such as constipation and pressure sores) whilst others may reduce (bowel incontinence and spasticity) over time (Adriaansen et al. 2016). The reported SHCs prevalence in South Africa during the acute hospital phase was estimated at 50% (Joseph & Wikmar 2016), which is markedly lower than that reported in Sweden

(78%) (Wahman et al. 2019). The different estimates could be because of the participants having different SCI profiles. Post rehabilitation estimates of SHCs are higher: 89% in South Africa (Madasa et al. 2020) and 98.5% in the Netherlands (Adriaansen et al. 2016). Given the high prevalence of SHCs post-rehabilitation, it is worth exploring how people with SCI experience SHCs.

In South Africa, studies on SHCs in people with SCI are limited and only three studies have reported on the occurrence of SHCs in the post-rehabilitation phase (Madasa et al. 2020; Mashola & Mothabeng 2019; Mashola, Olorunju & Mothabeng 2019). These studies do not explore the experience of living with SHCs. Madasa et al. (2020) reported the mortality rate and the prevalence of SHCs amongst survivors at 4 years post-injury. Mashola et al. (2019) reported on the high hospital readmission rates of patients with SCI because of SHCs and Mashola and Mothabeng (2019) on the impact of SHCs on quality of life. The latter studies were conducted in a private rehabilitation facility. Thus, there is still a lack of knowledge on the SHCs experienced by people with SCI in public health facilities. Evidence on SHCs experienced by people with SCI in the public health care system is essential because the majority (84%) of South Africans do not have access to health insurance and depend on the already strained public health system (Mayosi & Benatar 2014). There is a need for more, contextually specific, qualitative studies on patients' narratives of their experiences of SHCs. Understanding patients' ill-health experiences can inform the context-based prevention care model of care for people with SCI. Our research question is: *what are the experiences of SHCs, and how do SHCs affect individuals with SCI*? Thus, the objective of our study was to explore the experiences of SHCs amongst people with SCI.

Method

This study is part of a more extensive study that aims to establish factors influencing prevention of SHCs in people with SCI to inform the development of a preventative model of care. We used a phenomenological qualitative approach to give clarity and a more in-depth understanding of the experiences of SHCs (Austin & Sutton 2014; Neubauer, Witkop & Varpio 2019). Relying on the interpretivist paradigm, semi-structured interviews were conducted to explore and gain a deeper understanding of this phenomenon (Thanh, Thi & Thanh 2015).

Our study was based at a 79-bed public tertiary rehabilitation hospital in Gauteng province, South Africa. This hospital also admits patients from other provinces because of the lack of tertiary hospitals in other provinces. The hospital offers inpatient rehabilitation services to patients with stroke, head injuries, SCI and amputation and aims to help patients achieve their highest functional ability through therapy, education programmes, peer support and work-oriented activities. The services available include medical care, pharmacists care, occupational therapy, physiotherapy, speech therapy, dietetics, social work and psychology. Participants who were eligible and consented after the staff approached them were included in our study. A total of 25 people with SCI were approached, 20 of whom were eligible and consented to participate. Two had health-related problems, and one had time constraints thus were not available for the interview. All adult (>18 years) potential participants were considered regardless of gender, time since SCI and injury profile, such as the type of injury and the lesion's completeness. Patients who presented with other neurological conditions (stroke and head injury) were excluded.

Data collection

Semi-structured interviews were conducted using an interview guide developed using the literature related to SHCs and preventative care (Guilcher et al. 2013). The interview was piloted with a researcher experienced in qualitative methods to clarify the questions. Part A of the interview guide included questions on sociodemographic information including age, sex, marital status, injury date, cause and the level of the injury, completeness of injury, occupation and use of an assistive device for mobility. Part B of the interview guide included questions on the experiences of SHCs. The first author obtained written informed consent for the interviews and audio recordings. The interviews were then conducted from August 2018 to July 2019, in the participant's language of choice at the preferred venue and lasted for 45 min on average. Five participants were readmitted for pressure sores, thus were interviewed in the inpatient section of the hospital. When interviews and analysis yielded no new information, data collection was discontinued (Hennink, Kaiser & Marconi 2017).

Data analysis

The interviews that were in the vernacular were translated into English by an independent translator and translation checked before analysis by the first author. Interviews were transcribed verbatim and exported to MAXQDA version 2018.1: a computer-assisted qualitative data analysis software. We used a content analysis approach to analyse the data and understand the participants' experiences. This process entails transforming text into meaningful units, codes, categories and themes (Erlingsson & Brysiewicz 2017). The transcripts were read several times to understand the main ideas expressed by the participants. The authors individually coded a transcript inductively, followed by a discussion on the codes and the categories. A coding framework was developed and used to code the rest of the transcripts deductively. Manual categorisation was conducted by the first author and reviewed by the co-authors. A further abstraction of the data to develop themes related to our study objective was performed by all the authors. The following strategies were employed to ensure data trustworthiness. Code recoding was completed, and final categories were compared with the previous analysis. Debriefing sessions amongst the authors were held throughout the research process to discuss the findings and data analysis. To ensure confirmability of the data, all the interviews were

audio-recorded, field notes were kept and the first author included a reflexive analysis of the interviews.

Our research experience related to disability has informed the analysis of the data. Having worked as therapists in school settings for children with disabilities and non-governmental organisations for people with disabilities, we realise how it is easy to focus on impairments and functional limitations and not look at the whole person to understand the impact of SHCs experienced.

Ethical considerations

Permission to use the study site for data collection was granted by the rehabilitation hospitals. Our study was approved by the Human Research Ethics Committee of the University of the Witwatersrand (M170938) and it was registered on the South African National Health Research Database (GP201712036).

Results

Part A: Demographic profile of the participants

A total of 17 people with SCI were interviewed. The mean age (years) was 44.5 (σ = 13.1) with a range of 27–72 years. The mean time since injury was 9 years (σ = 7.1) and the range was between 1 and 30 years. Table 1 depicts the demographic information collected from Part A of the interview.

TABLE 1: Demographic profile of the participants (*n* = 17).

Description	*n*	%
Gender		
Male	14	82.4
Female	3	17.6
Employment		
Yes	5	29.4
No	12	70.6
Education level		
Tertiary education	4	23.5
Matric	5	29.4
High school	6	35.3
Primary school	2	11.8
Marital status		
Married or staying with a partner	7	41.2
Single	10	58.8
Cause of injury		
Trauma	14	82.4
Non-trauma	3	17.6
Type of spinal cord injury		
Paraplegia	14	82.4
Tetraplegia	3	17.6
Completeness of the injury		
Incomplete	4	23.5
Complete	13	76.5
Level of the injury		
C1–C4	2	11.8
C5–T1	1	5.9
T2–T6	3	17.6
T7–T12	9	52.9
L1–L5	2	11.8
Assistive device		
Wheelchair	14	82.3
Walking aid	2	11.8
None	1	5.9

Part B: Range of secondary health conditions experienced

Table 2 depicts the range of SHCs experienced by the participants.

Participants reported a range of SHCs presented in Table 2. The most common SHC was pain (94%).

Part C: Experience of secondary health conditions

The main theme that emerged from the analysis was the 'impact of SHCs on health and well-being'. There were five categories linked to the main theme: namely, SHCs co-occurrence, limits function, restricts participation, mental health effects and disrupts lives.

Impact of secondary health conditions on health

Secondary health conditions had a negative impact on the different domains of health, body structures and systems, activities and participation in life. Also, the SHCs affected mental well-being and disrupted the usual routine of life.

Secondary health conditions co-occurrence: The co-occurrence of SHCs was noted in osteoporotic bones and

TABLE 2: Range of secondary health conditions experienced (*n* = 17).

Type of secondary health condition	*n*	%
Pain	16	94
Bladder problems		
Incontinence	16	94
Urinary tract infection	4	24
Spastic bladder	2	12
Kidney stones	1	6
Bowel problems		
Incontinence	11	65
Constipation	6	35
Rectal prolapsed	1	6
Bloating	1	6
Psychological problems (depression, worry and stress)	12	71
Pressure sores	10	59
Spasms	9	53
Contractures	3	18
Injuries		
Burns	9	53
Fractures	4	24
Falls	8	47
Sexual issues	7	41
Sleeping disturbances	6	35
Fatigue	4	24
Skeletal problems		
Osteoporosis	2	12
Arthritis	1	6
Myositis ossificans	1	6
Respiratory problems	1	6

fractures, spasms and pain. The presence of one SHC increases vulnerability to other SHCs:

> 'The cramp is on my legs, it goes hand in hand with pain.' (Jane, female, 27 years old)
>
> 'I have osteoporosis – I put my hand under my leg, and as I turned over the femur then I broke my femur.' (Julie, female, 61 years old)
>
> 'I didn't sleep yesterday because of spasms and pains.' (Jared, male, 35 years old)

Limits function: The presence of SHCs limited functioning and mobility. Participants who experienced pressure sores were required to lie in bed for an extended time and thus developed weakness as reported by Jared:

> 'The other pressure sore got worse and even made a hole – you could even see a bone at the back. I was weak and not even able to get out of bed.' (Jared, male, 35 years old)

Similarly, the severity of pain affected Joy's ability to use her assistive devices '… some days the pain is unbearable, I can't hold my crutches.' (Joy, female, 38 years old).

Participants reported how SHCs affected activities of daily living. Julie (female, 61 years old) said her ankle fracture affected bathing 'I broke my right ankle. I had to wear a moon boot for eight weeks. It was such a struggle to bath and shower, it was terrible.' Also, the presence of spasms affected sitting in a wheelchair and made toileting difficult for Joe (male, 38 years old), 'spasms trouble me when I want to go to the toilet. I can't sit, when I try to sit, the one leg goes there.' To prevent further injury because of spasms, one participant reported how he had to rely on medication, 'I live on Lioresal and Baclofen for spasms. I have to otherwise I don't stay in the wheelchair' (Jake, male, 36 years old). Furthermore, Jack highlighted how depression affected self-management and help-seeking behaviour; unfortunately, this made individuals with SCI isolate themselves. 'Some people get too depressed to a point where they stop coming to get their medication, they just stay at home.' (Jack, male, 39 years old).

Restricts participation: Participants reported how SHCs affected their social lives, occupations and relationships. Secondary health conditions restricted the social lives of the participants. Bowel problems made it challenging for some participants to leave their homes. Some participants were afraid that if they went out somewhere, bowel leaks might happen as expressed by Jared and Jane here:

> 'When I have diarrhoea, I don't leave the house, I just sit, and I use the linen saver that they gave us.' (Jared, male, 35 years old)
>
> 'What stresses me the most is, what if I go somewhere and number 2 happens? I can prevent number 1, but number 2!' (Jane, female, 27 years old)

Pain, bladder and bowel problems had a negative impact on work life. Pain affected the participants' mood at work:

> 'The issue of pain when you at work you won't be happy when you have pain … even if people make jokes when the pain comes you won't be happy. It stresses me.' (Jane, female, 27 years old)

Jude had to restrict water consumption when travelling for work-related activities for fear of bladder leakages:

> 'I work in a consulting company. Almost every week I go to Johannesburg ... I don't drink a lot of water because if I drink water, I am going to struggle, I am going to leak.' (Jude, male, 40 years old)

Affects mental health: Secondary health conditions affected the mental health of the participants with regard to their emotional and psychological well-being.

Emotional effects: The participants felt different emotions related to SHCs such as fear, shame, worry and sadness. Many participants mentioned their fear of bowel leakage in public and the embarrassment of not even noticing the leakage when it occurs:

> 'You see, sometimes you can't feel whether you went for number 1 or 2, maybe you hear it from other people, that's where the embarrassment comes from; other people have noticed when you haven't noticed it first.' (Job, male, 44 years old)
>
> 'Number 2 (managing my bowel) troubles my mind ... what if I mess on myself? What if there is a smell? Sometimes when I am sitting, I would think there is a smell when I go to the bathroom to check, there is nothing. I become afraid. What if it happens? It's all in my mind.' (Jane, female, 27 years old)

Participants reported fear related to pressure sore management. Joe highlighted his fear of dying from a pressure sore that was so severe that he asked to be admitted to a hospital so the health professionals could treat the pressure sore appropriately:

> 'I quickly came to the hospital when the pressure sore started because I had a fear that it might kill me, I asked them to admit me because I won't be able to dress the wound from home.' (Joe, male, 38 years old)

Pain was a source of worry stated by Job:

> 'You see what I like about myself, is that I have accepted that I'm injured. I'm no longer worried by the fact that I cannot walk. The only thing that worries me is the pain – not the inability to walk.' (Job, male, 44 years old)

Some participants spoke about feelings of sadness and suicidal ideations because of pain as expressed by Julie and Jake:

> '… Pain is the reason why I was always thinking about suicide, it is that pain.' (Julie, female, 61 years old)
>
> '… So, that's where I've got most of my pain, every day. I don't … drink painkillers for it, not normally. Ehmmm ... maybe once or ... in two months, about. Then…I sit here, and I want to die because then my back is [*fucked*] ... sorry ... it hurts.' (Jake, male, 36 years old)

Male participants expressed stress related to sexual problems. They reported how sexual problems challenged their view of manhood, and there was a sense of hopelessness because they had not found a working solution:

> '… Your wife can leave you because you can no longer have sex with her ... That is the biggest problem about spinal cord injury. Your partner can still leave you ... This can affect you mentally.' (Jasper, male, 44 years old)

'Not getting an erection stresses me and I have no solution.' (Jared, male, 35 years old)

Psychological effects: Experiencing SHCs strengthened some participants' psychological wellbeing. Certain participants found the whole experience of SHCs to be positive in terms of lessons learnt. Valuable lessons learnt included coping strategies, enhancing problem-solving skills**,** learning new ways of 'doing things' and being prepared:

'I fell out of my wheelchair, and I learnt a valuable lesson that day you must always keep your cell phone with you if you are disabled.' (Julie, female, 61 years old)

'[*W*]hen you fall asleep, it feels like somebody is just giving you a pull in your foot. So, you can't sleep, but you learn to cope with it.' (Jex, male, 50 years old)

'I've burnt my feet once, so, what am I going to do differently?, do this, do that. I mean, that is something you've got to figure out yourself. There is no manual in figuring how to do things differently not to burn the feet again.' (Jake, male, 36 years old)

Disrupts lives: Secondary health conditions disrupted the usual routine of life. Participants expressed that they experienced frequent pressure sores, which required prolonged bed rest and hospital readmission disrupting everyday routine such as going to work:

'Once it is open, forget it, it will not heal – pressure sores take forever to heal. Mine has been there for eight years.' (Job, male, 44 years old)

'You find yourself being bedridden for 6, 7 months because of a pressure sore, it takes you back. Lying on the bed is not nice.' (Jane, female, 27 years old)

Discussion

As reported in SCI epidemiological studies, most of the participants were male and had traumatic SCI (Joseph et al. 2015; Sothmann et al. 2015). Unsurprisingly, most participants were unemployed with low education levels, as is often the case for the majority of people with disabilities in South Africa (Hanass-Hancock & McKenzie 2017). Unemployment amongst people with disabilities increases economic vulnerability, which is compounded by out of pocket disability-related costs such as the need for support, accessing health care services and participation in life (Hanass-Hancock & McKenzie 2017; Hanass-Hancock et al. 2017).

The participants experienced a range of SHCs, but the most prevalent SHC was pain (94%). Pain is the most pervasive and significant problem throughout a person's lifespan with SCI (Madasa et al. 2020; Piatt et al. 2016). When patients report pain symptoms their focus is not on the severity and the location of the pain but the different facets of life affected by pain, namely mental health, physiological impairments and personal behaviour (Müller et al. 2017; Yorkston et al. 2010). Pain affects quality of life (Callaway et al. 2015; Mashola & Mothabeng 2019), sleep and mental health (Turk et al. 2016). To cope with pain, an individual can rely on or misuse medication, avoid certain activities that elicit distress, self-isolate and adopt unhealthy ways to seek attention from their families (Keefe & Gil 1986). Therefore, interventions to manage pain need to be holistic, focusing on helping an individual live well in the presence of pain. Self-management strategies can include stress management, coping strategies and exercise, access to pain medication, counselling and alternative treatment such as massage and continual support.

As in previous studies, we found some of the SHCs (spasms and pain) co-occurred (Brinkhof et al. 2016; Park et al. 2017). Brinkhof et al.'s (2016) survey on health conditions in people with SCI found clustering of sexual dysfunction, spasticity, bowel dysfunction, pain, bladder dysfunction and urinary tract infections (Brinkhof et al. 2016). Albeit, the authors gave no reason for the clustering. Equally, depression and anxiety have been reported to increase the risk of SHCs such as urinary tract infections, pain and spasms (January et al. 2014). Park et al. (2017) found 29% of participants with SCI reported experiencing a combination of sexual dysfunction, bowel and bladder incontinence with a high association between these SHCs. The possible reason for the SHCs co-occurrence could be because of the same parasympathetic innervation to the bowel, bladder and reproductive organs. This evidence shows us that some SHCs co-occur meaning SCI care must include regular screening and comprehensive prevention strategies for known SHCs clusters. More research is still needed to understand other SHCs clustering patterns to inform patient assessment and prevention strategies.

Activities of daily living (ADLs) such as bathing, toileting and mobility were limited by pain and spasms. Callaway et al. (2015) found spasms limited self-care activities such as bathing, transfers and bed mobility. The presence of spasms in a person with SCI is linked to decreased daily living activities and the need for assistance from caregivers (McKay, Sweatman & Field-Fote 2018). Participants also expressed how pain affected them at work. Other studies on pain in people with SCI have reported the negative impact of pain on community integration, including returning to work (Callaway et al. 2015; Donnelly & Eng 2005). Callaway et al.'s (2015) study showed how musculoskeletal pain influenced participants with SCI's return to work and work choice, with some requiring regular bed rest to relieve pain. We need to support people with SCI to effectively manage and prevent limiting SHCs such as pain and spasms. Support could be in outreach services and home visits by therapists and community-based workers to monitor well-being and functioning at home. Such interventions can promote independence in daily self-care amongst people with SCI.

Participation in social life was affected by bowel and bladder problems and pain. Participants were afraid to leave their homes because of the fear of bladder and bowel leakage. Bowel and bladder problems are problematic SHCs in people with SCI (Piatt et al. 2016), with a prevalence of 44% bladder dysfunction and 42% bowel dysfunction 4 years post-SCI in South Africa (Madasa et al. 2020). A study conducted in Ghana reported that patients with SCI did not want to participate in social events, such as weddings because of bowel and bladder

incontinence for fear of leakage in public. The fear of leakage could stem from poor management of both bladder and bowel problems because of inadequate access to consumable such as catheters and a lack of adequate education on bowel and bladder problems (Fuseini et al. 2019). Community participation and integration into the labour market are critical outcomes for rehabilitation care contributing to life satisfaction (Carpenter et al. 2007). Thus, SCI care must incorporate social integration and work rehabilitation.

Mental health is an essential component of health, which includes psychological and mental well-being. This is the awareness of self, personal abilities, stress, coping strategies and the ability to work and contribute meaningfully to society (World Health Organization 2004). Secondary health conditions affected the emotional and psychological well-being of our participants. The presence of SHCs, such as pain, created feelings of sadness and suicidal ideations. Other studies have reported a significant association between pain and depression (Jörgensen et al. 2017a; Robinson-Whelen et al. 2014). Muller's et al. (2017) study reported that the leading cause for depression in an individual with pain was feeling restricted in participating in life events because of high pain intensity. Therefore, SHCs prevention strategies for pain must include meaningful participation in life activities such as work, community events, leisure and exercise activities.

Furthermore, male participants expressed feelings of stress and hopelessness regarding sexual problems. Sexual issues are the most significant SHCs amongst men, affecting self-identity, relationships and yet they receive the least treatment (Brinkhof et al. 2016; Callaway et al. 2015). Also with regard to mental health, it was interesting to hear participants reporting that the experience of SHCs taught them valuable lessons such as problem-solving skills, coping strategies and lessons to prepare for future incidents. Some participants' experiences of SHCs developed resilience, a necessary trait for people with chronic conditions, enabling them to adapt and cope with life challenges (Cal et al. 2015; Rohn, Nevedal & Tate 2020). When communicating with people with SCI on challenging experiences of SHCs, it is essential to highlight lessons learnt on problem-solving, coping mechanism because these are positive traits that will help them manage future challenges.

Spinal cord injury is a life-disrupting event affecting personal life and family relationships (Ide-Okochi et al. 2013). Like other studies, we found that SHCs can also disrupt the usual way of living (Fuseini et al. 2019; Nevedal, Kratz & Tate 2016). For example, experiencing pressure sores, lying in one position and being confined to bed for months affects daily routines, separates people with SCI from the outside world and harms their view of self, life and family. As people with SCI are vulnerable to frequent SHCs in their lifespan, we must be more proactive to prevent their occurrence and when they do occur to offer support to patients and the family to manage the disruptions.

In the context of South Africa, our findings provide more evidence to strengthen the use of the biopsychosocial model of care that promotes patient-centred care. The biopsychosocial model of care is holistic and links contextual factors of the patient to care and recognises the patient's role in care. Patient-centred care is an empowering approach to patient care that encourages the patient's active participation in relating problems as they experience them, goal setting and decision-making (Lindberg et al. 2013). We need to recognise that the patients' views on illness and health are shaped by how they experienced them (Kleinman, Eisenberg & Good 1978). Patients want to be listened to and validated by health professionals regarding their health and well-being (Yorkston et al. 2010).

Conclusion

We explored the experience of SHCs amongst people with SCI and found that SHCs were enormously impactful on people with SCI as illustrated by their stories of fear, embarrassment and shame. Secondary health conditions have a profound impact on the health and well-being of people with SCI. It is not only the presence of SHCs that affect people with SCI but the effect they have on mental health, the ability to function, participate in life and how lives are disrupted. Understanding the experience of SHCs can enhance communication between patients with SCI and health professionals and aid in setting appropriate management and prevention goals.

Recommendations

We need more studies on the prevention of SHCs and how to minimise their impact on health and well-being. Health providers should be encouraged to engage and actively listen to patients. We encourage clinicians to use open-ended questions during patient assessments, goal setting and treatment to understand how patients experience illness and its impact on their health.

Limitations

Firstly, given that our study used a qualitative approach, we cannot generalise the findings to other contexts. Secondly, we had very few participants with cervical lesions and female patients with SCI.

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Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

Authors' contributions

S.I.P. conceptualised the study, collected data, analysed data and wrote the manuscript. H.M. and J.P. contributed to the

conceptualisation phase, assisted during data analysis, read several iterations of the article and conducted the final editing.

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Data availability

The data that support the findings of this study are available from the corresponding author, S.I.P., upon reasonable request.

Disclaimer

The views and opinions expressed in this article are those of the authors and do not necessarily reflect the official policy or position of any affiliated agency of the authors.

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5.6. Conclusion

In this chapter, the nuanced experiences of SHCs were explored. In Chapter six, the findings on the experiences related to the prevention and management of SHCs will be discussed.

6. CHAPTER SIX: PREVENTION AND MANAGEMENT OF SECONDARY HEALTH CONDITIONS IN PEOPLE WITH SPINAL CORD INJURY

6.1. Manuscript details

Chapter six is presented as a manuscript. The paper was submitted to the *International Journal of Therapy and Rehabilitation,* and we are working on post-review feedback. The paper explored how people with spinal cord injury prevent and manage secondary health conditions. The key finding was that prevention of secondary health conditions was challenging despite the use of various prevention strategies.

The manuscript's title is 'Exploring prevention and management of secondary health conditions in people with spinal cord injury, South Africa'.

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6.2. Details of author contribution

The Contributor Roles Taxonomy (CRediT) (Allen et al., 2019b) was used to outline the authors' contribution to the study. The full explanation of the terms is in Appendix G.

Table 6:1: Details of author contribution

	Pilusa	Myezwa	Potterton
Conceptualization	√	√	√
Method	√	√	√
Resources	√		
Manuscript writing draft	√		
Manuscript writing review and editing	√	√	√
Supervision		√	√

6.3. Abstract

Background: Preventative care for people with spinal cord injury is neglected, even though secondary health conditions are prevalent among this group. There is limited information on preventative care for secondary health conditions (SHCs) among people with spinal cord injury (SCI). The study aimed to explore how people with spinal cord injury prevent and manage secondary health conditions.

Method: Seventeen individuals with spinal cord injury attending outpatient care at a public rehabilitation hospital were interviewed face to face. All the interviews were transcribed verbatim and analysed using thematic content analysis.

Findings: The participants used different strategies to prevent and manage secondary health conditions such as medication, assistive devices, self-management, resilience coping strategy and therapeutic approaches. The participants found prevention of SHCs "challenging", and some of the strategies were ineffective.

Conclusions: Although many strategies are used to prevent and manage secondary health conditions, the experience is challenging. To minimize the occurrence and the consequence of secondary health conditions among people with spinal cord injury, health professionals must promote and support preventative care for secondary health conditions throughout their lifespan.

Keywords: prevention; spinal cord injury, secondary health conditions, strategies

6.4. Background

The Sustainable Development Goal no. 3, "good health and wellbeing" is central to global development, and it includes people with disabilities (World Health Organization, 2017b, United Nations, 2018). Promoting health in people with chronic conditions such as SCI focuses on self-management, independence in functioning and support to prevent secondary health conditions (SHCs) (McColl et al., 2017). Health-promoting interventions include developing self-management skills, access to health information (Van Loo et al., 2010, Chang et al., 2017), social support (Guilcher et al., 2013), access to adequate health care (Maart and Jelsma, 2014, Paulus-Mokgachane et al., 2019) and participation in physical and leisure activity (Moshola and Mothabeng, 2019). Evidence shows that preventive care for SHCs for people with SCI is an unmet need (Chang et al., 2017, Van Loo et al., 2010, Lofters et al., 2019).

Although there is empirical evidence on the prevalence of SHCs and their impact, research on the experiences of prevention and management of SHCs is limited. Secondary health conditions such as pressure sores, pain, spasms, and urinary tract infections are prevalent throughout the lifespan of individuals with SCI (Adriaansen et al., 2013, Madasa et al., 2020). These secondary complications limit social participation (Piatt et al., 2016), affect employability and work productivity (O'Neill and Dyson-Hudson, 2020) and increase re-hospitalisation (Mashola et al., 2019). Prevention of SHCs includes addressing the risk associated with the occurrence of SHCs to minimize their occurrence and their impact (McColl et al., 2017, Rimmer et al., 2011). Some SHCs are preventable, while others must be managed. For instance, pressure sores and urinary tract infections are preventable, but neuropathic pain needs to be managed. Research on SHCs is needed to understand better the prevention care support needed by people with SCI.

Research shows many factors influencing the prevention of SHCs (Pilusa et al., 2021a, World Health Organization, 2013a, Guilcher et al., 2013). Prevention care success requires the individual to be proactive and take ownership of personal health (Zanini et al., 2020a). People with SCI need to apply health-promoting behaviours daily, manage SHCs when they occur and seek help when needed (Zanini et al., 2020a). Other reported factors include knowledge levels, beliefs on illness (Pilusa et al., 2021a), social support and a medically-oriented health system (Guilcher et al., 2013).

Previous studies on SCI have highlighted that prevention of SHCs is not easy (Chang et al., 2017, Guilcher et al., 2013). Guilchers' study on the journey of care in prevention and management of SHCs in people with SCI reported that prevention of SHCs was an "uphill battle". Other studies reported that people with SCI believed that SHCs are not avoidable and preventable, possibly due to ineffective prevention practices (Chang et al., 2017, Piatt et al., 2016). To date, there is no published study on the experience of preventive care for SHCs in South Africa, despite evidence indicating high readmission rates related to SHCs (Mashola et al., 2019). Understanding the prevention and management of SHCs by people with SCI may help identify areas of improvement and inform prevention interventions. Therefore this study aimed to explore how people with SCI prevent and manage SHCs.

6.5. Methods

Study design: This study forms part of a study aiming to develop a preventive care model for SHCs (Pilusa et al., 2020). In order to explore how people with SCI prevent and manage SHCs an explorative qualitative design was used. According to the interpretive philosophical paradigm, to understand the subjective meaning and nuanced experiences of prevention and management of SHCs, we need to hear narratives of lived experiences from individuals with SCI (Scotland, 2012).

Setting: This study was conducted at a public rehabilitation hospital in South Africa. Patients with SCI attend the outpatient clinic once a month after discharge from the rehabilitation hospital, mainly for doctor consultations and collection of medication and consumables. After discharge from the rehabilitation hospital, there is no guarantee that there will be follow-up care or access to rehabilitation service at a primary health care facility close to home (Sherry, 2014). There are limited rehabilitation hospitals in South Africa, so some patients have to travel long distances using public transport or hired transport to access the rehabilitation hospital. Although there is free primary health care in South Africa, people with disabilities face many barriers when accessing care, such as the lack of medication, health professionals' negative attitude towards people with disabilities, shortage of rehabilitation health professionals, inaccessible buildings and high transport costs (Sherry, 2014, Maart and Jelsma, 2014).

Participants: Patients with SCI who were attending the Out-patient Department (OPD) clinic visit at the rehabilitation hospital were approached by the researcher assisted by the employee at the rehabilitation hospital. In an attempt to gain a broad understanding of how people with SCI prevent and manage SHCs, all people with SCI, irrespective of gender, cause of SCI, level and duration of injury, above the age of 18 were invited to participate in the study.

Data collection: We developed a data collection tool informed by the Guilchers' study on "The journey of care in the prevention and management of secondary health conditions (SHCs) following spinal cord injury (SCI)" (Guilcher et al., 2013). The interview guide had two parts, part A: demographic details and part B, open-ended questions on experiences of SHCs, how SHCs are prevented and managed and factors influencing the prevention of SHCs. The author conducted semi-structured interviews at a venue that was suitable for the participants. Interviews were conducted in the language with which the participants were most familiar. The interviews lasted approximately 60 minutes and were conducted from July 2018 to October 2019. Data collection continued until data saturation was reached. All the interviews were audio-recorded.

Data Analysis: All the interviews were transcribed verbatim for data analysis. The non-English interviews were translated into English. The author read through all the transcripts to ensure accurate transcription and translation. The analysis was conducted using thematic content analysis (Erlingsson and Brysiewicz, 2017). One interview transcript was coded inductively by the author and two co-authors independently, followed by a discussion of the codes and to develop a preliminary coding framework. The subsequent transcripts were analysed deductively, and similar codes were grouped into categories, subcategories and themes. The coding framework was shared, reviewed and debriefed by all coders and underwent continuous reiteration throughout the research process. A manual display of the categories, subcategories and codes developed by the author was shared and reviewed by the co-authors. Regular debriefing sessions were conducted with the authors throughout the research process. MAXQDA 2018.2 was used to manage and analyse data. The quotes were numbered (SCI1, Male and SCI type) to protect anonymity.

Ethical considerations: Permission to use the study site for data collection was granted by the rehabilitation hospital. All the participants formally consented and signed informed consents forms to participate in the study and have the interviews audio-recorded before the interview. This study was approved by the Human Research Ethics Committee of the University of the Witwatersrand (approval number M170938) and registered with the South African National Health Research Database (reference GP201712036).

6.6. Results

6.6.1. Participants demographic profile

Seventeen people with SCI were interviewed. Table I outlines the participants' demographic information. The mean age (years) was 44.5 (SD=13.1) with a range of 27-72 years. The mean time since injury (years) was 9 (SD=7.1), and the range was between 1-30 years.

Table 6:2: Demographic profile of the participants

People With Spinal Cord Injury n (%)		
Gender	Male	14 (82.4)
	Female	3 (17.6)
Employment	Yes	5 (29.4)
	No	12 (70.6)
Education level	Tertiary education	4 (23.5)
	Matric	5 (29.4)
	High school	6 (35.3)
	Primary School	2 (11.8)
Marital status	Married /staying with a partner	7 (41.2)
	Single	10 (58.8)
Cause of injury	Trauma	14 (82.4)
	Non-trauma	3 (17.6)
Type of spinal cord injury	Paraplegia	14 (82.4)
	Quadriplegia	3 (17.6)
Completeness of the injury	Incomplete	4 (23.5)
	Complete	13 (76.5)
	C1-C4	2 (11.8)

Level of the injury	C5-T1	1 (5.9)
	T2-T6	3 (17.6)
	T7-T12	9 (52.9)
	L1-L5	2 (11.8)
Assistive device	Wheelchair	14 (82.3)
	Walking aid	2 (11.8))
	None	1 (5.9)
Presence of at least one SHCs	17 (100)	

Part B Emerged themes

From the analysis, three themes emerged, namely:

1. Prevention of secondary health conditions
2. Management of secondary health conditions
3. Challenging experience

6.6.2. Prevention of secondary health conditions

The participants used self-management and assistive devices to prevent the occurrence of SHCs such as pressure sores and urinary tract infections. For example, some participants used high-quality wheelchair cushions to prevent the occurrence of pressure sores. Self-management practice was used to prevent the occurrence of pressure sores. Table 6.3 illustrates the theme, categories, subcategories and quotes.

Table 6:3: Themes, categories and subcategories: Prevention of secondary health conditions

Category 1:	**Self-management**
Protect skin integrity	*"I am wearing three underpants just to prevent pressure sores, plus I have got some other clothing I cannot wear because I am using the transfer board"* (SCI 10, Complete paraplegia)
Practice safety measures	*"I make sure that I put cold water first before I put hot water. That's how I prevent getting burned" (SCI 2, Complete paraplegia)*

Social support	*I ask my sister sometimes to check my skin on my bums if everything is okay*" (SCI 10, Male Complete paraplegia) *"I have never had pressure sores because when I bath I ask my girlfriend to check my skin"* (SCI 12, Male, Complete paraplegia)
Practice pressure relief	"*I do a lot of pressure reliefs, and I do not like sitting on the couch because they are too comfortable, and you might forget to do pressure reliefs*" (SCI 12, Complete paraplegia)
Hydration	*"I have a suprapubic catheter, and that causes a lot of bladder infections, but I cope with that. I spoke to one urologist, and I drink a lot of water"* (SCI 15, Male Complete paraplegia)
Category 2	**Assistive device**
Using wheelchair cushions, specialised mattress	*For me, not getting pressure sores being in a wheelchair is because of the cushion..I am sitting on one of those air cushions, the Roho cushions"* (SCI 10, Male Complete paraplegia)

Secondary health conditions such as pain, depression were constant health problems, thus needed to be managed. For example, the participants used resilience as a coping strategy, medication, and therapeutic approach to managing pain. Nutrition and hyperbaric therapy were used to facilitate the healing of pressure sores. Table 6.4 illustrates the theme, categories, subcategories and quotes.

Table 6:4: Themes and Subcategories: Management of secondary health conditions

Category 1	**Resilience coping strategy**
Acceptance	*I just deal with pain, sit with it and work through it…., it becomes a second nature thing. It is not that bad anymore"* (SCI 11, Male, Complete paraplegia)
Spirituality	*"for sleeplessness, I just lay, and I pray"* (SCI 15, Male, Complete tetraplegia))
Mindfulness	*"I follow this course of John Kabath on mindfulness. I sit there, and it is for an hour or two something that, I do not concentrate on my pain"* (SCI 16, Female, Complete paraplegia)
Movement	*"Move around. If your body feels sore, move around"* (SCI 17, Male, Complete Paraplegia)

Seek help	*"I am not sure when it (bedsore) developed because the first time I saw it, I immediately came to the rehab hospital, and they said it is bad"* (SCI 5, Male Complete paraplegia)
Category 2	**Therapeutic approaches**
Using TENS machine	*They put TENS machine patches on your shoulders or your muscles, and that also helps a lot for pain"* (SCI 15, Male, Complete tetraplegia)
Massage	*".. massage is also good…., and it relieved the pain"* (SCI 16, Female, Complete paraplegia)
Hyperbaric therapy	*"So I asked if I could go to a hyperbaric unit with this wound to see if it will heal faster than the previous one. It healed within eight weeks"* (SCI 16 Female, Complete paraplegia)
Category 3	**Medication use**
Medication use	*"I choose to drink medication when I am in extreme pain"* (SCI 9, Male, Incomplete paraplegia)
Category 4	**Nutrition**
Healthy diet	"Nutrition is important if you have a pressure sore (SCI 15, Male, Complete paraplegia)

6.6.3. Challenging experience

The participants felt that preventing and managing SHCs was challenging because some strategies "did not work" and prevention practice was difficult. Unfortunately, this made the participants "feel hopeless" about preventing and managing SHCs. The theme, categories and quotes are illustrated in Table 6.5.

Table 6:5: Theme and categories Challenging experience

Theme:	**Challenging experience**
Does not work	*"They say tramadol is the strongest pain killer, but it does nothing to me"* (SCI 6, Female, Incomplete paraplegia) *"The doctor once prescribed some pills for sexual problems, and they did not work, he prescribed more, and they did not work"* (SCI 12, Male, Complete paraplegia)
It is difficult	*"You do learn to live with pain, but it is very hard… it is very hard"* (SCI 16, Female, Complete paraplegia)

Loss of hope	*"This pain is not going to heal – it will heal when I die"* (SCI 3, Male, Complete paraplegia)

6.7. Discussion

People with SCI experience a range of SHCs in their lifespan, which requires prevention care to minimize the risk of occurrence and their impact on health status and quality of life. This study explored how people with SCI cord injury prevent and manage secondary health conditions. Participants used various strategies to manage and prevent SHCs: medication, assistive devices, self-management, therapeutic approaches and resilience coping strategy. Preventing and managing SHCs is challenging.

Self-management is critical to chronic care management (Grady and Gough, 2014). Self-management is a continuous process of taking ownership of personal wellbeing by understanding the illness and its impact, identifying resources to help manage the condition, adopting health-promoting behaviours, and adapting to the illness (Grady and Gough, 2014). Participants practised good personal hygiene, protected skin integrity, and incorporated safety measures to prevent injury in our results. Other strategies used included changing positions and pressure relief practice to prevent the occurrence of pressure sores. Given that there is no cure for SCI, skills and behaviours related to self-management should be developed and supported throughout the journey of care as part of preventive and health maintenance care programme (Munce et al., 2016).

Medication use was a commonly used strategy to manage pain (musculoskeletal and neuropathic), spasms, constipation and urinary tract infection. These findings are similar to previous studies on medication use in people with SCI for pain, spasms, constipation and depression (Cardenas and Jensen, 2006, Patel et al., 2017). There is a high risk of using various medications (prescribed and over the counter medication and supplements) concurrently due to SCI's many impairments (Patel et al., 2017). Given the side effects of medication, medication misuse, dependence, and medication cost, which are not effective, we need to consider non-pharmacological therapy such as massage, TENS, and marijuana (Cardenas and Jensen, 2006, Clark et al., 2017).

Therapeutic approaches, such as massage and TENS, helped manage pain. Studies have confirmed that massage and TENS give more extended pain relief than medication (Diego et al., 2002, Bi et al., 2015). Also, massage therapy has been reported to decrease fatigue, improve sleep and mental health (Diego et al., 2002). Clinicians can use some of these approaches and promote them as alternative pain management strategies

People with chronic illness or disability face a range of challenges in terms of changes in physical and emotional wellbeing and social restrictions that come with living with a disability. Participants in this study used strategies related to resilience such as acceptance, keeping busy, ignoring the pain condition, using spirituality, help-seeking behaviour and social support to prevent and manage SHCs. Resilience is a combination of skills and behaviours such as spirituality, hope and seeking for support, acceptance of the illness and a positive outlook to manage and cope with a stressful situation such as a disability and other conditions related to living with a disability (Stuntzner and Hartley, 2014, Babamohamadi et al., 2011). Previous studies on chronic conditions such as cancer and HIV have reported that resilience reduces fatigue and psychological distress (Tian and Hong, 2014) and plays a role in pain management (Gonzalez et al., 2019). This study provides evidence to support the value of building resilience in people with SCI to help them cope with the disability and the complications that arise due to living with a chronic condition.

Although the participants used various strategies to prevent and manage SHCs, the whole experience was challenging. Our study findings confirm the findings from previous studies that prevention of SHCs is perceived to be challenging, and some SHCs are not preventable or avoidable (Chang et al., 2017, Guilcher et al., 2013). The context where people live and access health can make the experience of disability and prevention care worse. Most of the participants in our study are from under-resourced areas where access to health care and essential resources is limited (Sherry, 2014). In addition, most of the study participants were unemployed and had minimal education making access to healthcare even harder (Gordon et al., 2020). Dealing with the primary disability, SHCs and challenges related to preventing SHCs can lead to hopelessness. Support throughout the lifespan of people with SCI to prevent and manage SHCs is vital. Support can be through community-based rehabilitation where people with SCI can be supported at a

community level by other individuals with similar disabilities. Secondly, support can be from the clinicians when conducting follow-up care and home visits.

6.8. Limitations

We used a qualitative design to understand the experiences of people with SCI. Thus the findings cannot be generalized. Most of the participants were primarily men, paraplegic and traumatic SCI. Although it represents general SCI prevalence (male, traumatic SCI), diversity of SCI profile would have made for a more diverse response from participants. Future research can explore the experiences of females and people with tetraplegia in the prevention and management of SHCs. AIS classification was not recorded in the demographic profile because not all the medical files had information on AIS classification.

6.9. Implications

6.9.1. Practice

Health professionals can explore opportunities for health promotion and education related to the prevention and management of SHCs during clinic visits.

People with SCI experience challenges when preventing and managing SHCs, indicating a need for regular follow-up care and evaluation of prevention strategies.

There is a need to strengthen secondary and tertiary prevention of SHCs. At every patient visit, people with SCI must be screened for SHCs and educated on SHCs.

Given that there is no cure for SCI, skills and behaviours related to self-management management should be developed and supported throughout the journey of care as part of preventive care.

6.9.2. Policy

People with disabilities need access to medication, assistive devices, and maintenance at the primary care level.

6.9.3. Research

We recommend research looking at a model of care that can support the prevention of SHCs.

6.10. Conclusion

In conclusion, the experience of preventing and managing SHCs is challenging despite the various strategies employed to prevent and manage SHCs. There is a need to strengthen prevention care for SHCs throughout the care journey for patients with SCI. With no cure for SCI at hand, we need a holistic prevention model of care to promote a healthy lifestyle, resilience, self-management and continuity of care.

In the next chapter, the paper on personal factors influencing the prevention of SHCs in people with SCI will be presented.

7. CHAPTER SEVEN: PREVENTION STRATEGIES FOR SECONDARY HEALTH CONDITIONS IN PEOPLE WITH SPINAL CORD INJURY: A SCOPING REVIEW

7.1. Manuscript details

Chapter seven is presented as a manuscript structured according to the journal guidelines. The paper aimed to map existing evidence and provide an overview of prevention strategies for secondary health conditions that people with spinal cord injury have reportedly used.

The manuscript's title is 'Prevention strategies for secondary health conditions in people with spinal cord injury: a scoping review'.

This manuscript is under review in JBI Evidence Synthesis. We are working on post review feedback.

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7.2. Details of author contribution

The Contributor Roles Taxonomy (CRediT) (Allen et al., 2019b) was used to outline the authors' contribution to the study. The full explanation of the terms is in Appendix G.

Table 7:1: Details of author contribution

	Pilusa	Myezwa	Potterton	Ajidahun
Conceptualization	√	√	√	
Method	√	√	√	√
Resources	√			
Manuscript writing draft	√			√
Manuscript writing review and editing	√	√	√	√
Supervision		√	√	

7.3. Abstract

Objective: The review's objective was to map existing evidence and provide an overview of prevention strategies for secondary health conditions that people with spinal cord injury have reportedly used.

Introduction: In the lifespan of a person living with spinal cord injury, preventable secondary health conditions are prevalent. However, research on preventive care and the range of prevention strategies used for secondary health conditions are scarce.

Inclusion criteria: Studies on people with spinal cord injury who are over18 years of age and that reported on prevention strategies for secondary health conditions were included. Studies of any design conducted in a clinical setting, home or community-based settings were considered.

Methods: A three-step search strategy was used in this review, for eight databases and four websites, from the inception of the databases to September 2019. All published and unpublished studies in English were considered. After duplicates were removed, titles and abstracts were screened against the inclusion criteria by two independent reviewers. A data extraction sheet that included the study outcome was used.

Results: 400 records were identified. Full-text for 92 articles were assessed, and 35 were included in the final review. The range of prevention strategies included health promotion, rehabilitation, assistive devices, policy and other strategies. Most of the studies reviewed used strategies related to health promotion in exercise and health education.

Conclusion: This study findings show a range of strategies that can be used to prevent secondary health conditions in people with spinal cord injury. Future research can assess the effectiveness of the strategies in preventing secondary health conditions in people with spinal cord injury.

Keywords: Prevention strategies; secondary complications; secondary health conditions; spinal cord injury; health promotion; preventative care

7.4. Introduction

Apart from the debilitating impact of spinal cord injury (SCI), individuals with SCI experience other health complications, such as pain, muscle spasm, pressure sores, bowel and bladder problems (Jörgensen et al., 2017c, Wahman et al., 2019). Collectively, these conditions are called secondary health conditions, secondary conditions or secondary complications. Secondary health conditions (SHCs) can occur throughout the lifespan of an individual with SCI affecting the quality of life (Adriaansen et al., 2016), restricting participation in life (Piatt et al., 2016), increasing hospital readmission and health care costs (Gabbe and Nunn, 2016) and can increase the risk of mortality (Cao et al., 2019). Given the individual and societal outcomes of SHCs, prevention of SHCs is imperative.

Prevention of diseases includes various strategies such as raising awareness, screening, healthy lifestyle, preventing the occurrence of a disease, and promoting and restoring health (Pandve, 2014b, World Health Organisation, 1998). Disease prevention can occur at primary, secondarily, and tertiary (Pandve, 2014b). Related to the prevention of SHCs, primary prevention focuses on minimizing the risks related to SHCs occurrence, whilst secondary prevention looks at limiting the progression of a condition through early detection and treatment (McColl et al., 2017). Tertiary prevention involves managing an existing condition to prevent negative consequences such as death or worsened disability (McColl et al., 2017). Even though some of the SHCs are thought to be preventable, research on preventive care is limited (DeJong and Groah, 2015, Lofters et al., 2019).

Promoting health and wellbeing for all is a global development goal articulated in the Sustainable Development Goal (SDG) number 3 (World Health Organization, 2021). In support of SDG 3 for people with disabilities, Rehabilitation 2030 “call for action” promotes access to rehabilitation across the continuum (World Health Organisation, 2017). Rehabilitation is a process across the continuum of care of a person with a disability that aims to maximize function and participation in critical aspects of life within the individuals’ environment (World Health Organisation, 2017). As such community-based rehabilitation (CBR) was initiated by the World Health Organization (WHO) as a strategy to promote the rights of people with disabilities, enhance social reintegration and improve access to services (Allen et al., 2019a, Mauro et al., 2014). One key focus area for

CBR is health through health promotion, medical care, assistive devices, rehabilitation, and prevention of diseases (World Health Organisation, 2021). However, evidence on CBR based strategies to promote health and prevent SHCs in people with SCI is scarce.

Prevention of SHCs needs to be across a continuum during the hospital phase and continue in the community and home. Previous studies on prevention of SHCs have reported different isolated types of prevention strategies such as physical activity (Jörgensen et al., 2017a), social support (Guilcher et al., 2012), self-management (Munce et al., 2014b, Munce et al., 2016) and health education (Evardone et al., 2018). Rimmer et al. (2011) proposed a conceptual model on the secondary conditions in people with disabilities to identify the risk factors, individual and societal health outcomes, and prevention strategies. The proposed prevention strategies include health promotion, assistive devices, policy and rehabilitation (Rimmer et al., 2011). When assessing the reported prevention strategies against the proposed framework for preventing SHCs the range of prevention strategies utilized has not been well documented. This scoping review maps the evidence and provides an overview of the types of prevention strategies for secondary health conditions that have been reported in the literature. A preliminary search was conducted in the Cochrane Database of Systematic Reviews and the *JBI Database of Systematic Reviews and Implementation Reports*, and no scoping reviews or systematic reviews on this topic were identified.

7.5. Review question

What kind of prevention strategies for secondary health conditions has been implemented or used for people with SCI?

7.6. Inclusion criteria

The inclusion criterion for this scoping review was guided by the population, concepts, and context (PCC) approach.

7.7. Population

The scoping review considered studies on people with SCI. Both non-traumatic and traumatic SCI were included with no limitations on the duration of living with SCI, severity, or lesion level. Studies with female and or male participants who were 18 years and over were included.

7.8. Concept

Papers included reported on prevention strategies for any secondary health condition (pressure sores, urinary tract infection, pain, spasms) at all levels of disease prevention (primary, secondary and tertiary level), including but not limited to: rehabilitation, health promotion, assistive technology and policy. Examples of prevention strategies include physical activity or exercise therapy, self-management intervention, peer mentoring, health education and motivational interviewing.

7.8.1. Definition of concepts

Health promotion is a "process of enabling people to increase control over and improve their health" (World Health Organization, 1986). Health promotion interventions can include exercise interventions, health literacy, self-efficacy skills training, social support, peer support and accessibility of the environment.

Policy can be guidelines that advocate for a person's health care with a disability, as illustrated in the coverage for power-assisted wheelchairs and health insurance coverage (Rimmer et al., 2011, World Health Organization, 2011a)

Rehabilitation is a process across the continuum of care in the lifespan of a person with a disability that aims to maximize functioning and participation in key aspects of life (World Health Organization et al., 2010, Rimmer et al., 2011). Rehabilitation intervention can include patient-orientated therapy, exercises training, family support, counselling, and modification to the environment and self-management strategies.

Assistive devices include equipment used to enhance the functional ability of an individual with a disability and facilitate participation in life events such as power-assisted wheelchairs, prostheses

and specialized computer software (Peters et al., 2017, Rimmer et al., 2011, Moher et al., 2009, Pandve, 2014b).

7.9. Context

The review considered studies on prevention strategies for secondary health conditions in people with SCI conducted in a clinical setting (hospital and primary health care facility), home or community-based setting. The context was not limited to specific geographic locations or racial or gender-based interests.

7.10. Type of sources

This review considered all study designs, including descriptive cross-sectional, experimental, systematic reviews, meta-analysis, and qualitative studies. Opinion letters and conference papers were also considered.

7.11. Methods

This scoping review identified available evidence and relevant literature (published and unpublished) using the JBI methodology (Moher et al., 2009). The published protocol documented the objectives, inclusion criteria and methods for this scoping review Appendix I (Pilusa et al., 2020).

7.11.1. Search strategy

The university research librarian assisted in search strategy development, and a three-step search strategy was used to search the database. The initial search of MEDLINE (PubMed) and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) were conducted, followed by an analysis of the text words in the title and abstract of retrieved papers and of the index terms used to describe the articles. A secondary search using all identified keywords and index terms was undertaken across all included databases. Thirdly, the reference list of all identified reports and articles was searched for additional relevant studies. The search strategy used is outlined in Appendix F. All relevant literature on the prevention strategies for secondary health conditions experienced by people with SCI (published and unpublished) from the inception of the databases to September 2019 in English were considered.

Databases searched included PubMed; PEDro; CINAHL; EMBASE; SCOPUS; Health Source: Nursing/Academic Edition, and SPORTDISCUS. The South African Department of Health website, World Health Organization, Google Scholar and Open Grey were searched for unpublished studies.

7.11.2. Study selection

After duplicates were removed, titles and abstracts were screened against the inclusion criteria by two independent reviewers. Studies that met the inclusion criteria were retrieved and assessed against the inclusion criteria, and the studies that did not meet the inclusion criteria were excluded. A preferred reporting Items for Systematic Reviews and Meta-analysis (PRISMA) flow chart outlined the search process, the number of articles included and excluded with reasons (Moher et al., 2009).

7.11.3. Data extraction

The resulting articles were retrieved, and the following information was extracted: author, year of publication, country of origin, study aim, sample (size, age, and gender) and study outcomes against the inclusion criteria. Data extraction was conducted by the primary reviewer using the data charting table (Table 7.2). A second reviewer confirmed the accuracy of the extraction process based on the inclusion criteria. Charting the results was an iterative process, and the charting table was updated throughout the reviewing process. The study outcome was categorized into health promotion, rehabilitation, assistive devices, policy and other strategies (Table 7.3). Figure 7.2 illustrates the summary of the categories.

7.12. Results

7.12.1. Study inclusion

Three hundred and ninety records were identified, the titles and abstracts of 174 records were screened, and 82 records were excluded as they did not meet the inclusion criteria. Figure 7.1 illustrates the PRISMA flow diagram of the study selection and inclusion process. Full-text of 92 articles were assessed, and 35 were included in the final review (reasons for exclusion outlined in Appendix D). An overview of the study characteristics can be found in Table 7.1.

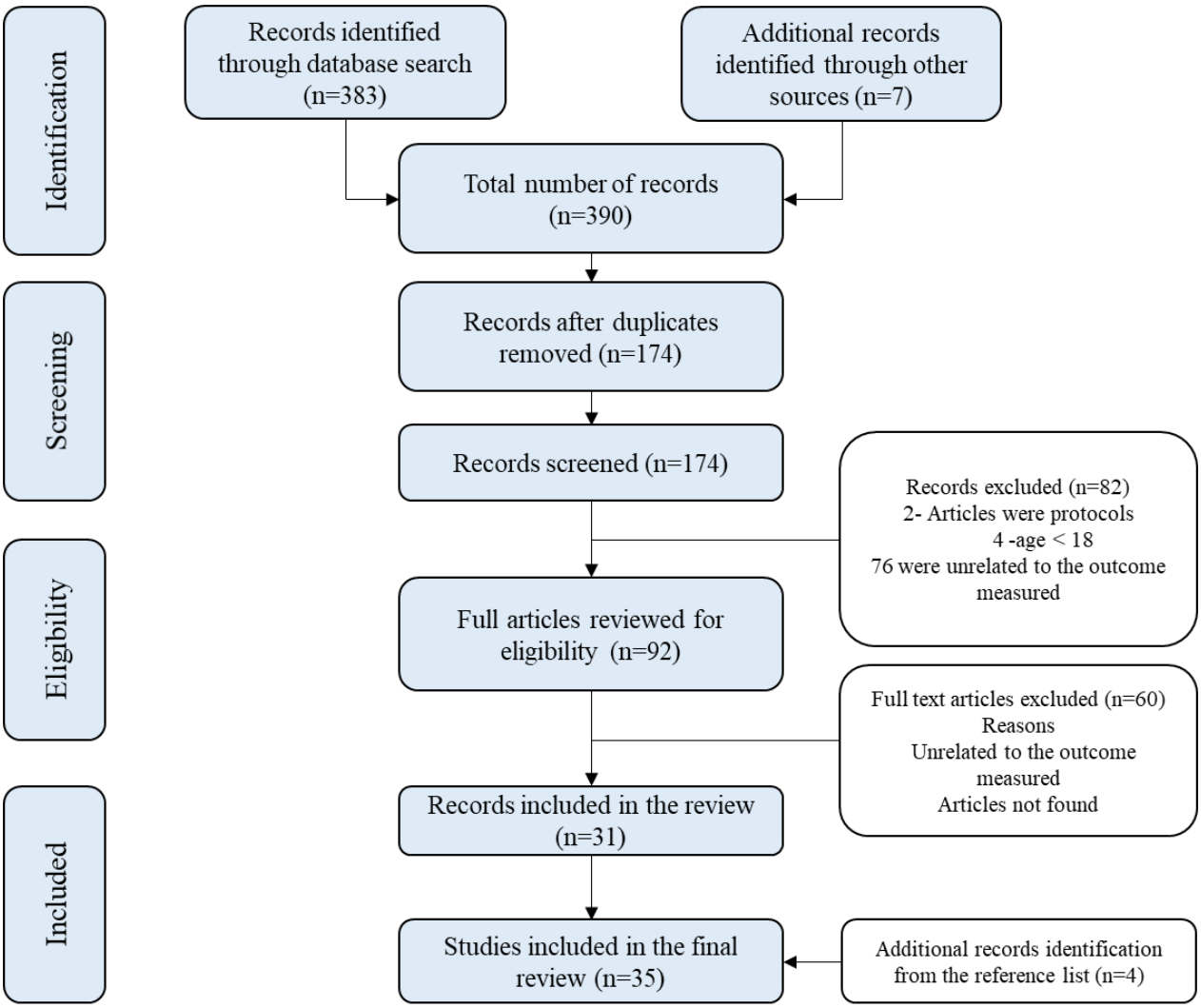


Figure 7:1: PRISMA flow diagram of the study selection and inclusion process (Moher et al., 2009)

Table 7:2: Characteristics of the included studies

Author	Study design	Population (age, sample size and gender)	Settings	Country
Evardone et al. (2018)	Retrospective medical record review	Sample size: 106 Patients Mean age: 52.28±18.73 Gender distribution: 97.2% male	Veterans hospital SCI Center	USA
Daunoraviciene et al. (2018)	Pre and post-intervention	Sample size: 6 Mean age: 58.83 ±14.19 Gender distribution:5 males	Rehabilitation centre	Lithuania
Juszczak et al. (2018)	Cross sectional	Sample size: 45 Mean age: 35±12.65 Gender distribution:82% male	Multiple rehabilitation institutes	USA
Morrison et al. (2018)	Prospective observational cohort with longitudinal follow-up	Sample size: 69 Mean age: 41±15 Gender distribution: 71% male	Rehabilitation centres	USA
Baunsgaard et al. (2018)	prospective, observational, open-label, multi-centre study(intervention)	Sample size: 52 Median age: 35.8 (27.5–52.6) years Gender distribution: 69.2% male	SCI rehabilitation centres	Denmark
Jörgensen et al. (2017a)	Cross-sectional	Sample size: 122 Mean age: 63±9 years Gender distribution: 70% male	Home	Sweden
Akkurt et al. (2017)	Randomized clinical trial	Sample size: 33 Median age: 33 [15-42] years (Intervention); 37 [19-62] (control) Gender distribution (Male): Intervention group 16 (94.1%) control 13 (81.3%)	Rehabilitation hospital	Turkey
Jones and Gassaway (2016)	Experimental and quasi-experimental	Sample size: Study 1: N=158 Study 2: N=208 Age: Not stated Gender distribution: Not stated	Neuro-rehabilitation hospital	USA

Table 7:2: Characteristics of the included studies (Continued)

Meade et al. (2016)	Qualitative approach	Sample size: 44 Mean age: 52.2±10.05 years Gender distribution:70%	Context not specified	USA
Munce et al. (2016)	Qualitative descriptive approach	Sample size: 7 Age range: 39–68 years Gender distribution: 6 males	Community	Canada
Newman et al. (2014)	Community-based participatory research	Sample size: 73 Age: Not stated Gender distribution:71.2%	Community-based	USA
Lau et al. (2013)	Experimental	Sample size: 78 severe neurological patients 21% spinal cord injury Age: Not stated Gender distribution: Not stated	Hospital	China
Strommen (2013)	Literature review	Sample size: Not stated Age: Not stated Gender distribution: Not stated	n/a	USA
Rauch et al. (2013)	Qualitative exploratory design	Sample size: 26 Median age: 44 years (Female), 45(Male) Gender distribution: 50% Male	Community	Switzerland
Houlihan et al. (2011)	Randomized controlled trial.	Sample size: 106 Age: Not stated Gender distribution: Not stated	Homes	USA
Guilcher and Jaglal (2011)	Qualitative approach	Age: Not stated Gender distribution: Not stated Sample size: Not stated	Home	Canada
DeJong et al. (2011)	Opinion report	Sample size: n/a Age: n/a Gender distribution: n/a	n/a	USA
Emamhosseini et al. (2010)	Case study	Sample size: 1 Age: 67 Gender distribution: One male	Urban rehabilitation hospital	USA

Table 7:2: Characteristics of the included studies (Continued)

Curiale et al. (2010b)	Systematic review	Sample size: 28 studies Age: Not stated Gender distribution: Not stated	n/a	Canada
Curiale et al. (2010a)	Systematic review	Sample size: Not stated Age: Not stated Gender distribution: Not stated	n/a	Canada
Van Loo et al. (2010)	Cross-sectional	Sample size: 453 Age: 47.7±13.3 years Gender distribution: 65.1% male	Community	Netherlands
Kehn and Kroll (2009)	Qualitative exploratory design	Sample size: 26 Median age: 52(exercisers), 46(non-exercisers) Gender distribution: 61.5% male	Home	USA
Ljungberg et al. (2009)	Quasi-experimental non-controlled pre-test/post-test.	Sample size: 24 Age: Not stated Gender distribution: Not stated	Inpatient rehabilitation hospital	USA
Tawashy et al. (2009)	Prospective cross-sectional design	Sample size: 49 Mean age: 43.7 Gender distribution: Not stated	Urban community	Taiwan
Bloemen-Vrencken et al. (2007)	Cross-sectional	Sample size: 410 Mean age: 46.9±13.2 years Gender distribution: 66.1% male	Home and community	Netherlands
Manns and May (2007)	Qualitative approach	Sample size: 35 Mean age: 39.0 ±12.1 years Gender distribution: 23 males	Community and the Canadian paraplegic association	Canada
Rowland et al. (2006)	Experimental/control group design	Sample size: 67 Age: 49 males Gender distribution:	Rehabilitation and research institutes	USA
Zemper et al. (2003)	Randomized clinical trial design	Sample size: 43 Mean age: 14 years Gender distribution: 70%	University hospital	USA
Kennedy et al. (2003)	controlled trial	Sample size: 85 Mean age: 34.7 years Gender distribution: 81% male	National spinal injuries centre (inpatient hospital)	United Kingdom

Table 7:2: Characteristics of the included studies (Continued)

Hagglund et al. (2005)	Pre and post-experimental design	Sample size: 60 Mean age: 39±12.85 years Gender distribution: 74% male	Independent living center	USA
Zemper et al. (2003)	Randomized clinical trial design	Sample size: 43 Mean age: 14 years Gender distribution: 70%	University hospital	USA
Kennedy et al. (2003)	controlled trial	Sample size: 85 Mean age: 34.7 years Gender distribution: 81% male	National spinal injuries centre (inpatient hospital)	United Kingdom
Jones et al. (2003)	Multiple baseline analysis across subjects (time-lagged control)	Sample size: 9 Age range: 25–40 years Gender distribution: 7 males	Hospital	USA
Walter et al. (2002)	Record review	Sample size: 99 Age: >50 years Gender distribution: Not stated	Hospital	USA
Phillips et al. (2001)	Intervention study (randomized participants allocation)	Sample size: 111 Age: 35±10.8 (Video), 37±13.1 years (Telephone), 33±11.2 years (standard care) Gender distribution: 75% male (Video), 72% male (Telephone), 82% male (standard care)	Rehabilitation hospital	USA
Gruenthal et al. (1997)	Randomized, double blind, placebo-controlled crossover trial	Sample size: 25 Mean age (range): 42.5 (21-60 years). Gender distribution:22 male	Rehabilitation Center and Veterans Affairs Medical Center Spinal Cord Injury Service	USA
Galloway (1997)	Literature review	Sample size: n/a Age: n/a Gender distribution: n/a	n/a	United Kingdom

All the studies included persons with spinal cord injury, both traumatic and non-traumatic SCI, male and female. In all the studies, the participants were above 18 years of age, time since injury ranged between less than one year to 62 years, and the sample size ranged from 3 to 453 participants. The majority 34 (97.14%) of the studies were based in high-income countries USA (Juszczak et al., 2018, Morrison et al., 2018, Evardone et al., 2018, Jones and Gassaway, 2016, Meade et al., 2016, Newman et al., 2014, Houlihan et al., 2011, Strommen, 2013, DeJong et al., 2011, Emamhosseini et al., 2010, Kehn and Kroll, 2009, Hagglund et al., 2005, Rowland et al., 2006, Zemper et al., 2003, Gruenthal et al., 1997, Jones et al., 2003, Phillips et al., 2001, Walter et al., 2002, Ljungberg et al., 2009), Canada (Munce et al., 2016, Curiale et al., 2010b, Manns and May, 2007, Curiale et al., 2010a, Guilcher and Jaglal, 2011), Netherlands (Bloemen-Vrencken et al., 2007, Van Loo et al., 2010), United Kingdom (Galloway, 1997, Kennedy et al., 2003), Lithuania (Daunoraviciene et al., 2018), Switzerland (Rauch et al., 2013), Denmark (Baunsgaard et al., 2018), Sweden (Jörgensen et al., 2017b), Taiwan (Tawashy et al., 2009) , China (Lau et al., 2013) and only one study from a middle-income country, Turkey (Akkurt et al., 2017). The study designs included two systematic reviews, two literature reviews, seven qualitative approaches, two record reviews, fourteen intervention studies, four cross-sectional studies designs, one opinion report and one case study. The studies were published between 1997 and 2018. A detailed overview of the study details (author, study aim, country, context, participants, study design, data collection method and key findings) of the included studies is presented in Table 7.1.

7.12.2. Review findings

Table 7.2 presents the summary of the review findings. The prevention strategies were categorized into health promotion, rehabilitation, assistive technology, policy and other strategies. Figure 7.3 presents the types of prevention strategies.

Table 7:3: Summary of prevention strategies

	Prevention strategies				
Author	**Health promotion**	**Rehabilitation**	**Assistive device**	**Policy**	**Other**
Evardone et al. (2018)	√				
Daunoraviciene et al. (2018)		√			
Juszczak et al. (2018)		√			
Morrison et al. (2018)		√			
Baunsgaard et al. (2018)		√			
Jörgensen et al. (2017a)	√	√			
Akkurt et al. (2017)	√	√			
Jones and Gassaway (2016)	√	√		√	
Meade et al. (2016)	√	√			
Munce et al. (2016)		√			
Newman et al. (2014)	√	√		√	
Lau et al. (2013)		√			
Strommen (2013)	√	√			√
Rauch et al. (2013)	√	√			
Houlihan et al. (2011)	√			√	
Guilcher and Jaglal (2011)	√			√	
DeJong et al. (2011)	√	√		√	
Emamhosseini et al. (2010)		√	√		
Curiale et al. (2010b)		√			
Curiale et al. (2010a)		√			
Van Loo et al. (2010)	√	√	√	√	√
Kehn and Kroll (2009)	√	√			
Ljungberg et al. (2009)	√	√			
Tawashy et al. (2009)	√	√			
Bloemen-Vrencken et al. (2007)	√	√			√
Manns and May (2007)	√				
Rowland et al. (2006)	√				
Hagglund et al. (2005)	√				
Zemper et al. (2003)	√	√		√	
Kennedy et al. (2003)	√				
Jones et al. (2003)	√	√		√	
Walter et al. (2002)	√	√	√		√
Phillips et al. (2001)	√			√	
Gruenthal et al. (1997)					√
Galloway (1997)	√	√		√	√

Twenty-five studies reported health promotion strategies (Akkurt et al., 2017, Evardone et al., 2018, Galloway, 1997, Phillips et al., 2001, Walter et al., 2002, Jones et al., 2003, Kennedy et al., 2003, Zemper et al., 2003, Hagglund et al., 2005, Manns and May, 2007, Bloemen-Vrencken et al., 2007, Kehn and Kroll, 2009, Ljungberg et al., 2009, Tawashy et al., 2009, Van Loo et al., 2010, DeJong et al., 2011, Guilcher and Jaglal, 2011, Jones and Gassaway, 2016, Meade et al., 2016, Newman et al., 2014, Rauch et al., 2013, Strommen, 2013, Rowland et al., 2006) and twenty-six studies reported on rehabilitation strategies. (Daunoraviciene et al., 2018, Munce et al., 2016, Houlihan et al., 2011, Bloemen-Vrencken et al., 2007, Curiale et al., 2010a, Curiale et al., 2010b, DeJong et al., 2011, Emamhosseini et al., 2010, Kehn and Kroll, 2009, Ljungberg et al., 2009, Tawashy et al., 2009, Van Loo et al., 2010, Juszczak et al., 2018, Zemper et al., 2003, Jones et al., 2003, Walter et al., 2002, Baunsgaard et al., 2018, Galloway, 1997, Jörgensen et al., 2017b, Akkurt et al., 2017, Morrison et al., 2018, Jones and Gassaway, 2016, Lau et al., 2013, Meade et al., 2016, Newman et al., 2014, Strommen, 2013) Only three studies reported on assistive devices (Emamhosseini et al., 2010, Van Loo et al., 2010, Walter et al., 2002), ten on policy (Jones and Gassaway, 2016, Newman et al., 2014, DeJong et al., 2011, Guilcher and Jaglal, 2011, Houlihan et al., 2011, Jones et al., 2003, Zemper et al., 2003, Van Loo et al., 2010, Galloway, 1997, Phillips et al., 2001) and six on other strategies (Strommen, 2013, Van Loo et al., 2010, Bloemen-Vrencken et al., 2007, Walter et al., 2002, Galloway, 1997, Gruenthal et al., 1997).

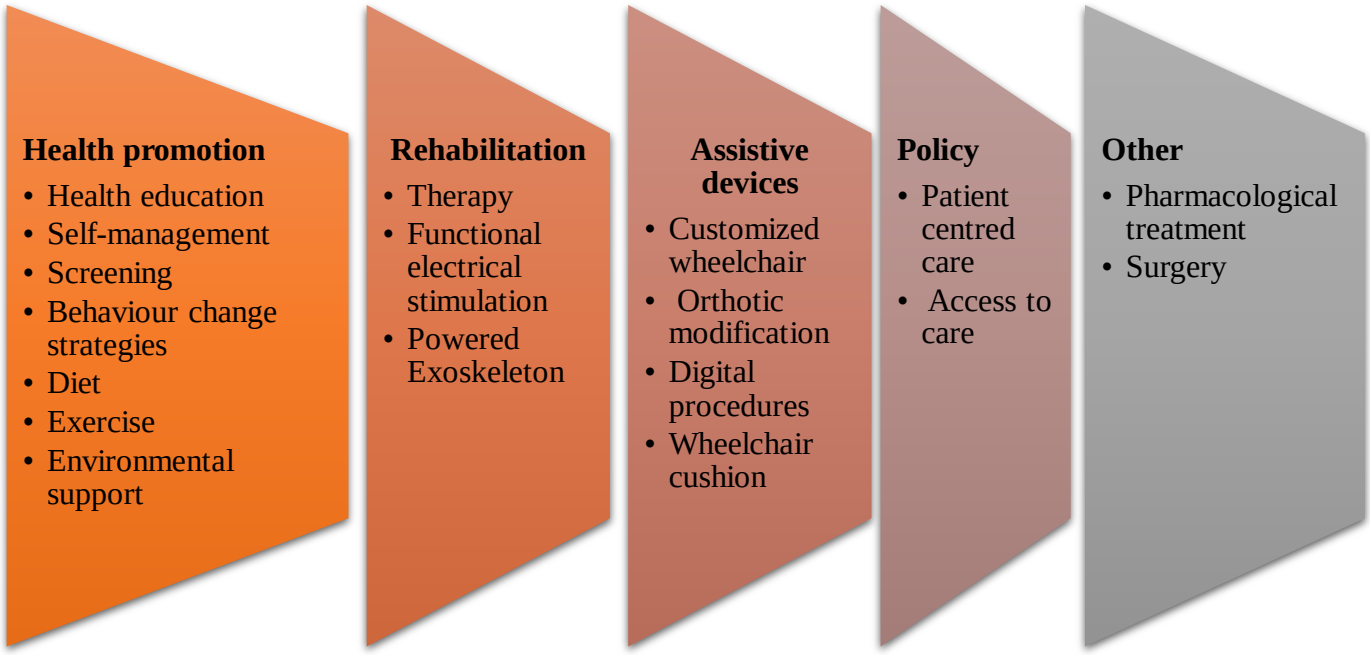


Figure 7:2: Description of the types of prevention strategies

7.12.3. Description of prevention strategies

Prevention strategies related to health promotion included health education, physical activity, screening, behaviour change strategies, diet, exercise, environmental support and policy. Topics covered in the health education included secondary health conditions such as pressure sores, urinary tract infections (UTIs), spasms, and autonomic dysreflexia, deep vein thrombosis, sexual health, pain and psychosocial issues. In addition, education included ways to prevent or manage secondary health conditions through skincare, personal hygiene practice, maintaining healthy lungs, bone health, and preventing further injury and stress management. Bowel and bladder management education included hygiene, types of catheters and proper insertion techniques. Exercise strategies included aerobic exercise, range of motion exercises, participation in activities of daily living and leisure activities. Environmental support included social support and access to the care needed, and screening included SHCs risk assessment and screening for pressure ulcers and depressive symptoms.

Rehabilitation strategies identified from the studies were therapy, self-management and exercises. Therapy included manual therapy using physical or occupational therapy. A powered exoskeleton was used to simulating walking, standing and sitting. At the same time, functional electrical stimulation therapy was used to manage spasticity, osteoporosis and facilitate wound healing. The exercise strategy included a range of motion exercises and leisure-time physical activity. Lastly, self-management activities such as daily monitoring the skin, pressure relief, positioning, daily stretching and involving the caregiver in monitoring skincare were used to prevent SHCs.

Assistive devices such as a wheelchair cushion were used for pressure sore prevention, whilst digital procedures were used for bowel management. One study referred to the orthotic modification to manage osteoarthropathy. Strategies that allude to policy interventions included patient-oriented care and access to care. Patient-oriented care included setting goals with the patient, scheduled visits with a nurse, patient referral to a mental health counsellor and physiotherapist and follow-up care. Access to care included access to primary health services and healthcare professionals.

Pharmaceutical treatment and surgery were classified under the "other" category. Medication was used to manage pain, spasms and bowel problems. Lastly, surgery was recommended for pain management.

7.13. Discussion

A range of prevention strategies for SHCs in people with SCI was identified from 35 articles. These articles mainly were from high-income countries and only one from a middle-income country. There were no studies from low-income countries and none from African countries. Prevention strategies were categorized into health promotion, rehabilitation, assistive device, policy and other prevention strategies. Although it was useful to use Rimmers'conceptual model (2011) to categorize the prevention strategies, some of the concepts, such as exercise, could be categorised into health promotion and rehabilitation. Future research could revise the broad categories in the conceptual model to reveal any relevant nuances for preventing and managing secondary conditions for people with SCI.

Most of the studies reviewed used strategies related to health promotion. Health promotion strategies focused on developing personal skills, health-promoting policies, and a supportive environment. Personal skills were developed through patient and family education on SCI, SHCs, diet, healthy lifestyle, and physical activity was used as a prevention strategy. Educating patients and families empowers them to take ownership of their wellbeing, which is fundamental for disease prevention and self-management (DeJong and Groah, 2015). The studies that alluded to the policy were related to patient-oriented care, access to primary health services and health professionals. Patient-oriented care aims to empower patients to self-manage and involve them in planning and decision-making (Pelzang, 2010).

Regarding safe and health-promoting environments, people with disabilities experience various environmental barriers restricting participation and access to needed health care (Fuseini et al., 2018, Sherry, 2014). Social support, peer support, changes in the environment, access to primary health services and allied health professionals are needed. Future research could look into comprehensive services delivery models such as chronic care models of care and their role in preventing SHCs.

Pharmaceutical treatment was used to prevent and manage pain, spasm, and bowel and bladder problems. Despite evidence of medication misuse, dependence and side effects that increase the risk for SHC development (Cardenas and Jensen, 2006, Clark et al., 2017), for some SHCs, medication is vital. No studies looked at the role of traditional medicine and alternative medicines in the prevention of SHCs. Future research can explore the role of traditional medicine in SHCs prevention.

Reorganizing SCI care has been recommended as a preventative strategy for SHCs (DeJong and Groah, 2015). No studies looked at service delivery models in the prevention of SHCs. Examples of service delivery models that can be explored are the chronic care model and the system of prevention framework (Barr et al., 2003, Sims and Aboelata, 2019). These models highlight the importance of multilevel strategies than linear interventions. Secondly, these models encourage

multi-sectoral partnerships to enhance health outcomes. Future research can explore the role of systems based service delivery models in prevention care for SHCs.

7.14. Conclusion

Previous studies have highlighted the need for more research in preventive care for SHCs among people with SCI (DeJong and Groah, 2015, Mashola et al., 2019). This review gives an overview of the strategies used to prevent SHCs among people with SCI. The range of prevention strategies for SHCs was categorized into health promotion, rehabilitation, policy, medication use and surgery. The overlap between the categories suggests that prevention strategies are not mutually exclusive, but they can work in combination to achieve better health outcomes. Considering the impact of SHCs on quality of life and health care costs, this study provided prevention strategies that could be used to prevent SHCs.

Implications for research: Future research can investigate the effectiveness of the prevention strategies in minimizing the occurrence of SHCs and their impact.

Implications for practice: Prevention strategies such as educational interventions and self-management can be used to inform practice.

7.15. Limitations

Only articles in English were included, and this could have omitted evidence from non-English speaking countries and low-income countries. Secondly, since the purpose of a scoping review is to give an overview of the evidence, information on the effectiveness of the strategies was not reviewed. Since this scoping review included evidence mainly from high-income countries, the results of this scoping review may not reflect low-middle income countries due to the variation in health care systems and access to basic resources.

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Both funders played no role in the design of the study and collection, analysis, and interpretation of data and in writing the manuscript.

7.17. Conflict of interest

The authors declare no conflict of interest. There is no potential conflict of interest or intellectual bias from the funders.

In this chapter, the study findings provide an overview of prevention strategies for secondary health conditions. The following chapter reports the findings on the personal factors influencing the prevention of SHCs.

8. CHAPTER EIGHT: I FORGET TO DO PRESSURE RELIEF ': PERSONAL FACTORS INFLUENCING THE PREVENTION OF SECONDARY HEALTH CONDITIONS IN PEOPLE WITH SPINAL CORD INJURY, SOUTH AFRICA

8.1. Manuscript details

Chapter eight is presented as a published paper. This paper addresses part A of the objective "to explore contextual factors (personal and environmental factors) influencing the prevention of secondary health conditions among people with spinal cord injury. The paper presents the personal factors influencing the prevention of secondary health conditions (SHCs) in people with spinal cord injury (SCI). The personal factors included socioeconomic status; mental well-being (forgetfulness, beliefs, and attitude); lack of knowledge of SHCs and prevention; lifestyle choices and practising prevention care; patient activation (self-management, problem-solving, resilience, self-awareness, help-seeking behaviour) and owning an appropriate assistive device.

Title of the Publication: 'I forget to do pressure relief ': Personal factors influencing the prevention of secondary health conditions in people with spinal cord injury, South Africa

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8.2. Details of author contribution

The Contributor Roles Taxonomy (CRediT) (Allen et al., 2019b) was used to outline the authors' contribution to the study. The full explanation of the terms is in Appendix G.

Table 8:1: Details of author contribution

	Pilusa	Myezwa	Potterton
Conceptualization	√	√	√
Method	√	√	√
Resources	√		
Manuscript writing draft	√		
Manuscript writing review and editing	√	√	√
Supervision		√	√

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8.4. Published article: 'I forget to do pressure relief ': Personal factors influencing the prevention of secondary health conditions in people with spinal cord injury, South Africa

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'I forget to do pressure relief': Personal factors influencing the prevention of secondary health conditions in people with spinal cord injury, South Africa

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Background: Across the lifespan, people with spinal cord injury (SCI) may experience preventable secondary health conditions (SHCs) such as pressures sores, muscle spasms and urinary tract infections (UTIs). Some factors influencing prevention of SHCs include social support, poor access to care and the prevention style of individuals. There is limited research on these factors.

Objective: To explore personal factors influencing the prevention of SHCs in people with SCI.

Method: An explorative qualitative study included participants recruited in an outpatient department at a rehabilitation hospital. Semi-structured interviews were conducted with patients with SCI. Interviews were transcribed verbatim. Data analysis was conducted using content analysis.

Results: Seventeen individuals with SCI were interviewed. From the interview analysis, six personal factors were identified, namely, socio-economic status; mental well-being (forgetfulness, beliefs, attitude); lack of knowledge of SHCs and prevention; lifestyle choices and practising prevention care; patient activation (self-management, problem-solving, resilience, self-awareness, help-seeking behaviour) and owning an appropriate assistive device.

Conclusion: Socio-economic status, mental well-being, knowledge of SHCs and prevention care, behaviour patterns, patient activation and owning an appropriate assistive device can influence prevention of SHCs. To enhance patient-oriented care, a model of care for people with SCI should consider these factors when developing prevention strategies. Future research could look into identifying environmental factors that influence the prevention of SHCs in people with SCI.

Clinical implications: Tailored prevention strategies need to be developed, health professionals must ask patients about individual factors that may be barriers or facilitators to preventing secondary health conditions.

Keywords: secondary health conditions; spinal cord injuries; prevention; factors; ICF.

Introduction

The sustainable development goal number 3 aims to ensure healthy lives and promote well-being for all including people with disabilities (United Nations 2018). Despite health promotion and preventive care for people with disabilities being important, they are often neglected (Lofters et al. 2019). Health promotion and preventative care are a necessity because people with disabilities are at a higher risk for developing preventable secondary complications commonly known as secondary health conditions (SHCs) (Adriaansen et al. 2013).

Secondary health conditions can occur during the lifespan of a person with a spinal cord injury (SCI), and are not caused by the primary injury (SCI) but are related to living with a disability (Rimmer, Chen & Hsieh 2011). They include pressure sores, pain, muscle spasms, bowel and bladder problems. Secondary health conditions can occur during the acute and rehabilitation phases (Wahman et al. 2019), and in the post-discharge phase (Adriaansen et al. 2016), negatively

impacting health outcomes. Given that there is no cure for SCI, care should include the promotion of well-being and prevention of SHCs.

The presence of SHCs in the life of people with SCI can increase levels of disability (Callaway et al. 2015), decrease life expectancy (Oderud 2014) and increase hospital readmission rates (Mashola, Olorunju & Mothabeng 2019). Up to 80% of readmissions amongst people with SCI in one private rehabilitation hospital in South Africa were because of SHCs such as pressure sores and urinary tract infection (UTI) and patients were readmitted up to four times for these preventable SHCs (Mashola et al. 2019). It is still not clear what causes patients with SCI to be re-hospitalised several times for the same SHCs. What could be hindering the prevention of the SHC? Why do some patients manage to prevent SHCs and others do not? To improve health outcomes for people with SCI, we need to understand the factors influencing the prevention of SHCs.

To appreciate the degree of functioning, disability and to develop patient-specific interventions, it is important to understand patients' personal factors. According to the International Classification of Functioning, Disability, and Health (ICF), individual (personal) factors are intrinsic characteristic which are not part of the health condition that can enhance or inhibit health and shape the experience of disability (Grotkamp et al. 2019; World Health Organization 2013). These factors include gender, race, age, presence of other health conditions, lifestyle, habits, coping styles, educational level, profession, past and current experience and psychological assets such as coping style and self-efficacy (Grotkamp et al. 2019; World Health Organization 2013). Considering factors at an individual level in patient assessments and when developing tailored interventions is good practice, promotes patient-centred care and is in line with the Convention on the Rights of Persons with Disabilities, Article 26 on the assessment for rehabilitation based on an individual's strength and weakness (United Nations 2006).

Notwithstanding that preventative care is a collaborative effort amoung health professionals, caregivers and patients, the patient's role and intrinsic influences in preventative care are important (Zanini et al. 2019, 2020).

Patients' activation (Greene & Hibbard 2012); outlook and control over personal care (Munce et al. 2014); knowledge levels of SHCs; attitude to prevention care; belief in personal susceptibility and taking responsibility for personal well-being influence prevention care practice (King, Porter & Vertiz 2008; Zanini et al. 2020). Moreover, belief in one's ability to self-manage has been identified as an essential component of managing a chronic condition (Disler, Gallagher & Davidson 2012; McCorkle et al. 2011).

Other factors that influence the prevention of SHCs that have been mentioned in the literature include participation in neuro-musculoskeletal health behaviours such as range of motion and muscle strengthening exercises (Mashola & Mothabeng 2019), access to assistive devices (Burns & O'Connell 2012; Oderud 2014) and lack of health education on SHCs prevention (Fuseini, Aniteye & Kofi-Helegbe 2018). Intrinsic factors that are seldom linked to the discussion on preventive care, but may explain why some are successful and others not despite doing the right thing, are factors at a molecular level. There is evidence linking the reoccurrence of UTI to malfunctioning of an innate immune activation gene (Godaly, Ambite & Svanborg 2015), meaning that even if an individual practices good bladder management UTI will still occur. Nutritional deficiencies have also been linked to delayed pressure sore healing (Bhagat et al. 2018). Thus, intrinsic factors influencing health, health outcomes and prevention of diseases are many, ranging from genetic predisposition to psychological, mental and physical status.

No study has comprehensively examined personal factors (intrinsic factors) that can influence the prevention of SHCs in people with SCI in South Africa. An understanding of the factors inhibiting or enhancing prevention of SHCs can help clinicians to develop targeted interventions that enhance knowledge, self-management skills, adoption of health-promoting behaviours and foster responsibility for personal well-being. Thus, our study explored and identified personal factors influencing the prevention of SHCs among people with SCI.

Method

An exploratory qualitative study was used to explore the individual factors as described by the ICF (World Health Organization 2013) as the ICF can be used by health professionals to understand factors influencing health outcomes and to inform interventions.

Our study was undertaken at a public tertiary rehabilitation hospital in South Africa, which offers inpatient and outpatient rehabilitation services to patients with stroke, SCI, amputation and head injuries. The rehabilitation hospital is a 79-bed hospital that caters for patients from within and outside the province. The percentage of patients admitted with SCI fluctuates seasonally; after the festive season it is 60% of the admission and drops to 40% during the year.

Purposive sampling was used to recruit potential key informants with SCI attending the outpatient department. Only patients with a SCI diagnosis (traumatic or non-traumatic) and 18 years and above were recruited.

Data collection

Semi-structured interviews were conducted by the first author using an interview guide in the language in which the key informant was familiar. The interview guide had two parts: demographic data and open-ended questions with probing questions on factors related to the prevention of SHCs.

Demographic data included age, gender, educational levels and information on the injury. The participants were asked how they prevented SHCs and what made prevention easier or harder. A pilot study was conducted to test the feasibility of our study and to check for any changes that could be done to improve the clarity of questions and the process.

After informed consent and permission to audio-record the interviews were granted by each participant, interviews were conducted from July 2018 to October 2019. The interviews lasted approximately 60 min and data collection continued until data saturation was reached. The interviews were audio-recorded and debriefing sessions were conducted to discuss the research process, findings and data analysis with the co-authors (H.M. and J.P.).

Data analysis

All the interviews were transcribed verbatim for data analysis. The analysis was conducted using content analysis, a continuous and reflective process of identifying meaning units, coding, grouping similar codes into categories and themes (Erlingsson & Brysiewicz 2017). Depending on the focus of a particular study, abstraction of data can be at a literal level or the manifest content which can then end at the categories level, answering the 'what' question (Graneheim & Lundman 2004). Alternatively, the analysis can go further into the latent content, where themes are identified to answer the 'how' question. The transcripts were read and reread to ensure accuracy of transcription and translation and to get an overall sense of the interviews. Inductive coding was conducted independently on one transcript by the authors and an external expert in qualitative data analysis and public health.

Thereafter separate discussions on the findings were conducted to compare the generated codes. In the discussion, similar codes were grouped together to form subcategories and categories. A preliminary coding framework was developed which was used to code the rest of the transcripts deductively by the first author. The focus of the analysis was on the description of the different factors at play at a personal level influencing the prevention of SHCs, thus the level of analysis ended at the category level. A manual display of the categories and subcategories was presented to the other authors which was followed by a discussion and renaming some of the subcategories and categories. MAXQDA (qualitative data analysis) version 2018.2 was used to manage and analyse data.

To ensure trustworthiness of the data, the following strategies were utilised (Nowell et al. 2017). Credibility was ensured by including only participants who met the inclusion criteria, and who could give a clear narration of the study phenomena. Secondly, regular meetings and debriefing sessions to discuss the research process, data collection, findings and data analysis were conducted with the co-authors. Investigator triangulation was conducted when developing the preliminary coding framework, which was subsequently used to code the rest of the transcripts providing a trail of the coding process (Graneheim & Lundman 2004). To ensure dependability, a detailed description of the data collection, analysis and interpretation was outlined, and a code–recode procedure was used – coding of a segment of data in two separate sessions. Field notes were kept during the data collection phase. For transferability, the context and the demographic data of the participants were explained in detail.

Ethical considerations

Permission to use the study site for data collection was granted by the rehabilitation hospitals. Our study was approved by the Human Research Ethics Committee of the University of the Witwatersrand (M170938) and registered with the South African. National Health Research Database (GP201712036).

Results

Seventeen patients with SCI were interviewed. Table 1 provides an overview of the demographic data of the

TABLE 1: Demographic profile of the participants (n = 17).

Participants with spinal cord injury	*N*	%
Age in years		
Mean (SD)	44.5	13.1
Range	27–72	-
Gender, *n* (%)		
Male	14	82.4
Female	3	17.6
Employed, *n* (%)		
Yes	5	29.4
No	12	70.6
Education level		
Tertiary education	4	23.5
Matric	5	29.4
High school	6	35.3
Primary school	2	11.8
Time since injury		
Mean (SD)	9	7.1
Range (years)	1–30	-
Cause of injury, *n* (%)		
Trauma	14	82.4
Non-trauma	3	17.6
Type of spinal cord injury		
Paraplegia	14	82.4
Quadriplegia	3	17.6
Completeness of the injury		
Incomplete	4	23.5
Complete	13	76.5
Level of the injury		
C1–C4	2	11.8
C5–T1	1	5.9
T2–T6	3	17.6
T7–T12	9	52.9
L1–L5	2	11.8
Assistive device		
Wheelchair	14	82.3
Walking aid	2	11.8
None	1	5.9

SD, standard deviation.

participants. The majority of the participants with SCI were male and had traumatic SCI.

From the interview analysis, six categories were identified, namely, socio-economic status; mental well-being; knowledge on SHCs and prevention; behaviour patterns, patient activation and owning an appropriate assistive device. To protect anonymity, the quotes are numbered (Participant number, gender, age). The results are discussed below and summarised in Tables 2–6.

Socio-economic status of patients with spinal cord injury

Many participants highlighted economic challenges. Participants stated that a lack of adequate finances leads them to not being able to buy healthy food, unable to buy medication or being able to access healthcare services.

High economic status helped patients afford care and assistive devices, thus was perceived as a facilitator for the prevention of SHCs. The subcategories and quotes are illustrated in Table 2.

TABLE 2: Socio-economic status.

Subcategory	Quote
Finances not enough	'I don't work, I buy food with grant money and when the diapers get finished so it becomes hard, so often when I have diarrhoea, I don't leave the house, I just sit and I use the linen saver that they gave us.' (P12, male, 35 years old)
	'The money we get is not enough to buy all these and for travelling purposes – sometimes we even miss our check-up dates because we run out of funds.' (P1, male, 39 years old)
Access to finances	'I feel I am very privileged to have a medical aid that pays Botox for my bladder.' (P16, female, 61 years old)
	'I actually took out the money I saved up to buy myself this cushion, since I moved to the air cushion, I haven't had that problem anymore.' (P11, male, 35 years old)

TABLE 3: Mental well-being.

Subcategory	Quote
Forgetfulness	'I used to forget to do pressure relief.' (P4, male, 32 years old)
Beliefs	'You only get to believe this after you have developed pressure sores – seeing that what you were told is actually true.' (P1, male, 39 years old)
	'I did not listen. I never thought pressure sores will happen to me that easily …. I proved it … it happened and this is the second time it happens.' (P14, male, 34 years old)
Feelings	'What gets on our way sometimes is the shame we have about our conditions … we don't want to show our friends the kinds of things we have to do in such conditions.' (P1, male, 39 years old)
	'[*Reason for not doing pressure reliefs*] remember I told I was abusing drugs that time? I was on drugs and I just didn't care. You see, when you live with an injury, you get angry and sometimes you do just wish to die.' (P3, male, 44 years old)
Attitude	'I learnt the hard way. I got pressure sores, usually, the thing is you underestimate the pressure sore. You think it will heal, no way.' (P15, male, 50 years old)
	'If I want to drink a lot of brandy and coke the whole weekend, I know Monday I'm going to suffer with my bladder. … So, Monday I'll deal with it.' (P17, male, 36 years old)
Past experience	'I also took it very light but I ended up seeing it myself no one can tell me I have experience that this thing is dangerous it can kill you in a month kill you.' (P14, male, 34 years old)
	'The doctor once prescribed some pills for me and they didn't work, he prescribed more and they didn't work so I gave up on trying.' (P12, male, 35 years old)

Mental health status on patients with spinal cord injury

The analysis further showed how mental well-being can influence the prevention of SHCs. The subcategories under mental well-being include forgetfulness, beliefs, feeling and attitudes towards prevention of SHCs and past experience (Table 3).

Knowledge on secondary health conditions and prevention

Some of the participants lacked knowledge on SHCs and how to prevent their occurrence. Quotes for knowledge on SHCs and prevention care are summarised in Table 4.

Behaviour patterns

There were behaviour patterns that facilitate prevention of SHCs such as health promoting lifestyle choices (exercising, quitting smoking and drinking alcohol). On the contrary, some patients even after being educated were not compliant with preventative care practice for SHCs. Some of the participants, although they knew about prevention of SHCs, were not compliant in preventing their occurrence. Subcategories and quotes are illustrated in Table 5.

Patient activation

To prevent and manage SHCs, participants practised self-management, problem-solving, resilience and self-awareness, and help-seeking behaviour. Some participants delayed seeking help early, thus negatively affecting their health outcomes. Subcategories and quotes for activated patients are illustrated in Table 6.

TABLE 4: Knowledge on secondary health conditions and prevention.

Subcategory	Quote
Lack of knowledge on SHC	'I didn't know how a pressure sore looks like when it develops. I didn't understand, I just thought it's a sore and it will be fine.' (P15, male, 50 years old)
	'I really do not understand. You can lift and relief and do all sorts of things, but I don't think it makes any difference it is the same.' (P3, male, 44 years old)
Lack of knowledge on prevention of SHCs	'The cushion I was using was old, since I was discharged with it in 2017; I didn't know that a cushion gets changed every 6 months.' (P15, male, 50 years old)

SHCs, secondary health conditions.

TABLE 5: Behaviour patterns.

Subcategory	Quote
Lifestyle choices	'What helps me with pain management is a stimulating activity, or if I exercise.' (P16, female, 61 years old)
	'For me I think my pressure sores were caused by the drug [*nyaope, "ohock", tik*]. When you take drugs you relax just sit still.' (P3, male, 44 years old)
	'The food we eat at home is not good for us for your condition … They recommend that we eat a lot of fruit and veggies … but we don't eat those foods, we eat pap instead.' (P14, male, 34 years old)
Prevention care practice	'I didn't treat the pressure sore according to how they had told me I started sitting on the wheelchair which I wasn't supposed to.' (P14, male, 34 years old)
	'I do a lot of pressure reliefs.' (P12, male, 35 years old)
	'Even now – when I get healed, I have to continue doing it [*pressure relief*], otherwise the bed sores will come back or I will die.' (P3, male, 44 years old

TABLE 6: Patient activation.

Subcategory	Quote
Self-management	'I get up just after 5 am in the morning, then I take a shower, and do coloplasting every day and after the shower I get into the bed I use methylated spirits for my buttock. I can feel with my hands that my skin is actually feeling good.' (P10, male, 66 years old)
Problem-solving	'I am paralyzed, I have to get in the bath, I've burnt my feet once. So, what am I going to do differently? Change the showerhead, do this, do that. I mean, that's something you've got to figure out yourself.' (P17, male, 36 years old)
Resilience	'I fell out of my wheelchair and I learnt a valuable lesson that day – you must always keep your cell phone with you if you are disabled … I did not have my phone with me. I lay on the floor for over three hours.' (P16, female, 61 years old)
Self-awareness	'Like when I have pain in my left foot, I would sweat on my right side. So then you know you have to check for something that's wrong.' (P15, male, 50 years old)
	'I must be more aware of the body, what the body needs, you know … when I'm feeling tired I don't want to eat … I force myself to eat something.' (P12, male, 35 years old)
Help-seeking behaviour	'I have never had pressure sores because when I bath I ask my girlfriend to check my skin.' (P12, male, 35 years old)
	'Will only mention the bladder leakage to the doctor only when it gets worse.' (P9, male, 40 years old)
Seeking help late	'What could have made it easy for me is upon seeing the bedsore for the first time, I should have went and gotten things to dress it same time.' (P14, male, 34 years old)

Owning an appropriate assistive device

Owning an appropriate assistive device was highlighted as playing an important role in the prevention of SHCs, for example, the use of a wheelchair cushion and special mattress to prevent SHCs. Patients who owned special assistive devices were the ones who could afford to buy one or had received one as a donation:

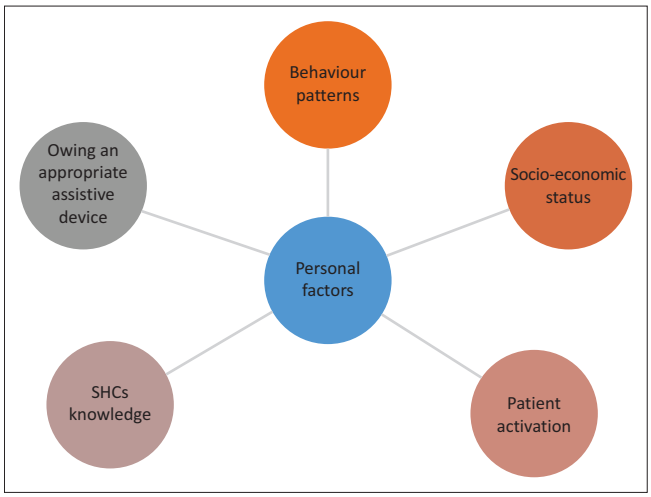
> 'I have that special mattress. If it wasn't for that mattress, I would have had many pressure sores.' (P15, male, 50 years old)

> 'But the major thing I feel also for me not getting pressure sores being in a chair is the cushion I'm sitting on is one of those air cushions, the Roho cushions, 'cos you don't need to do that constant pressure release.' (P11, male, 35 years old)

Discussion

Our study identified personal factors that may influence the prevention of SHCs. The identified personal factors are socio-economic status, mental well-being, knowledge on SHCs and prevention; behaviour patterns, patient activation and owning an appropriate assistive device, as shown in Figure 1.

The socio-economic status of an individual can affect health outcomes and prevention of SHCs. The limitations because of impairments can affect participation in employment resulting in economic vulnerability. The economic vulnerability can also be from the high cost of living with disability-related extra costs for assistive devices, caregiver payment, hiring alternative transport (Hanass-Hancock et al. 2017) and social disability grants being used to cover household needs leaving little for the needs of a person with a disability (Kelly 2019). This may lead to pressure sore development, for example, because of the inability to buy assistive devices (Oderud 2014).



SHCs, secondary health conditions.

FIGURE 1: Personal factors influencing the prevention of secondary health conditions.

Patients with high incomes could afford to buy specialised assistive devices such as wheelchair cushions to aid in preventing SHCs. Those with low income could not even manage to get a healthy diet compromising their nutritional status, thus increasing the risk of the development of SHCs and delaying wound healing for those with an existing pressure sore (Bhagat et al. 2018). There is also a link between lack of finances and mental problems (Zürcher, Tough & Fekete 2019).

Employment is a means of securing an improved economic status, with the evidence indicating that participation in the labour market is generally low for people with disabilities, and the opportunity to gain employment is worsened by low education levels (Hanass-Hancock & McKenzie 2017). In our study, only five participants with SCI were employed, indicating a need for vocational rehabilitation to increase employability. Therefore, as part of vocational rehabilitation, opportunities to learn new skills and to study further should be explored for patients with low education levels. Also, government departments must include people with disabilities in key developmental programmes such as the Expanded Public Works Programme, Sector Education Training Authorities and business training opportunities. Initiatives like this could facilitate the participation of people with SCI in the open market to decrease economic vulnerability.

As SCI is a physical disability, the impact on patients' mental state tends to be ignored. Some participants believed in the occurrence of pressure sores only after they had experienced one. Attitude and beliefs can influence the prevention style adopted whether to be proactive or delegate prevention care (King et al. 2008; Zanini et al. 2020). The study by Zanini et al. (2020) found that patients with SCI, who believed they were at risk of developing pressure sores and that they could do something to prevent them from developing, were more

proactive in preventing their occurrence. According to the health belief model, beliefs play an important role in health behaviour choices (King et al. 2008). Whether or not an individual adopts a specific behaviour will depend on their perception of risk to their health, the severity of the condition, their self-efficacy and the perceived benefit of the change in behaviour. To ensure holistic patient care and adoption of prevention-related behaviour, beliefs, attitudes and feelings towards SCI must be assessed during therapy.

Cognitive and behavioural therapy-based interventions could then be utilised to address patients' beliefs, expectations and the physical components of prevention strategies (Budh, Kowalski & Lundeberg 2006; Ehde, Dillworth & Turner 2014). The use of collaborative care practice is an important strategy, where the inter-professional team, including a psychologist, can plan, implement and evaluate patient care to ensure it is holistic.

Some participants reported a lack of knowledge of SHCs and prevention care. If patients with SCI are not educated on secondary complications that could develop throughout their journey of care they will not be able to prevent their occurrence. Similar findings have been highlighted in a study based in Ghana on experiences of people with SCI (Fuseini et al. 2018) that showed significant need for more information (Van Loo et al. 2010). Lack of knowledge on SHCs is a concern because education on SHCs is fundamental to the prevention of diseases and a key focus area in achieving Sustainable Developmental Goal 3 through strengthening health literacy (World Health Organization 2017). Although knowledge on SHC does not necessarily mean positive behaviour change (Evardone et al. 2018), efforts to educate patients on health and secondary complications throughout their journey are essential. On the contrary, patients can forget what they were taught.

The forgetfulness could be because of their poor mental health state, substance abuse or the fact that it is a new behaviour that needs to be reinforced with external cues. So, it is important for health professionals to look into the principles of learning such as learning styles, applying adult learning principles, readiness to learn, and how information is taught and accessed (Manns & May 2007). The application of these teaching and learning principles has the potential to enhance knowledge levels on SHCs and prevention care.

Despite patients receiving education on SHCs, some participants were not practising prevention care. Compliance with preventive care for pressure sores amongst individuals with SCI depends on the individual's prevention style (Zanini et al. 2020). Some of the characteristics of an individual with a compliant prevention style include extensive knowledge on SHCs, high perception of susceptibility to pressure sores, being proactive to seek support from a health professional when in need, taking responsibility for personal well-being and prioritising prevention of SHCs (Zanini et al. 2020). Individuals who are non-compliant adopt passive prevention measures, have a low perception of susceptibility and delegate responsibility for personal well-being and prevention to caregivers (Zanini et al. 2020). Part of rehabilitation for a person with a chronic condition such as SCI is to encourage patient engagement in personal health through the adoption of health-promoting behaviour.

To ensure prevention of SHCs, models such as the health belief model described above, or the stages of change can be used to encourage the adoption of new behaviour and long-term compliance.

According to the health belief model, compliance or adoption of behaviour such as prevention of SHCs depends on the individual perception of susceptibility, the severity of the health impact and barriers (King et al. 2008). It is important that during inpatient rehabilitation, education that is given on SHCs helps the patients to understand how vulnerable they are to SHCs, the seriousness of the effects of the condition and benefits of recommended preventive care practice, incorporating intrinsic (personal life goals) and extrinsic motivators (caregivers, peers) to help adopt prevention care lifestyle.

Behaviour patterns that include positive health-promoting lifestyle are good for general well-being and prevention of SHCs. Healthy lifestyle behaviours, such as exercising, not smoking or consuming alcohol, enhance prevention of SHCs. This is similar to findings in other studies that protective behaviour such as physical activity prevents or manages SHCs such as pain and depression (Tawashy et al. 2011; Zemper et al. 2003). Unhealthy behaviour such as physical inactivity, smoking and drinking alcohol lead to unhealthy outcomes and are risk factors to other SHCs such as pressure sores (Li, Dipiro & Krause 2017; Saunders & Krause 2010) and non-communicable diseases. Encouraging the adoption of healthy behaviour and increasing personal responsibility towards well-being should be part of the rehabilitation process and the primary focus of care.

Therapists could incorporate the behaviour change models described above when developing interventions or consider the Health Action Process Approach (HAPA). The Health Action Process Approach seeks to take an individual through a process of initiating, implementing and maintenance of change using constructs of setting goals, planning self-efficacy and taking action (Ma et al. 2020). Such interventions have the potential to empower patients and raise awareness of factors that influence behaviour and guide targeted interventions.

The role of a patient with chronic diseases, such as SCI, is key to chronic disease management and better health outcomes.

One of the factors that emerged was patient activation, through self-management, resilience, problem-solving and help-seeking behaviour (Greene & Hibbard 2012). Patient activation is a combination of knowledge, skills, confidence and actions taken to manage health, engage healthcare and improve personal well-being (Hibbard & Greene 2013). Patients with high activation levels tend to engage more in preventive care, adopt healthy lifestyles and have better health outcomes (Greene & Hibbard 2012). To help individuals with SCI, who are vulnerable to SHCs, we need interventions that will increase awareness about their condition, skills and confidence to self-manage, promote personal health and use preventative care services. Such interventions have the potential to empower patients to take an active role in their well-being.

It is important to own appropriate assistive devices as part of preventive care. Assistive devices are essential to facilitate function, participate in life and support self-management (Bloemen et al. 2015; Burns & O'Connell 2012; Oderud 2014). In our context, the main challenge is access to basic assistive devices in terms of availability at a healthcare facility, appropriateness and the cost of purchasing or repairing assistive devices such as wheelchairs (Hanass-Hancock et al. 2017; Sherry 2015). Although universal access to assistive devices is a human right articulated in the Convention on the Rights of Persons with Disabilities, Articles 4, 20 and 26 (United Nations 2006), and is highlighted as a facilitator to achieving the sustainable development goals (Tebbutt et al. 2016), access to good quality assistive devices remains a challenge. Rehabilitation managers and clinicians can advocate for access to essential and appropriate resources as stipulated in the framework and strategy for disability and rehabilitation services in South Africa (Department of Health 2015). But to advocate for these needed resources, data collection on disability and related health outcomes must be strengthened to inform rehabilitation and primary healthcare planning, budgeting and resource allocation for needed aids.

We identified a link between the different reported personal factors. For example, if an individual with SCI does not believe they will develop SHCs they will not comply with prevention care. The relationship between the influencing factors points to the complex nature of health and the intrinsic determinants of health.

For holistic patient-centred care, rehabilitation and prevention care interventions must be tailored based on the understanding of the patients' personal factors.

The impact of genetics and factors at a molecular level that could influence the prevention of SHCs such as UTI were beyond the scope of our study. Future research can explore factors influencing the prevention of SHCs that go beyond the psychosocial and behavioural but that include the influences at an environmental, genetic and a molecular level. In future, researchers could also consider identifying environmental factors that influence the prevention of SHCs in people with SCI. This will expand our understanding of contextual factors in the home, community and organisations that can enhance or hamper the prevention of SHCs.

Limitations

Given that our study used a qualitative methodology, and it was conducted at a single rehabilitation facility, we cannot generalise the findings to the whole SCI population. Our study identified personal factors influencing the prevention of SHCs but did not attempt to rank them based on their level of importance.

Conclusion

To reach the sustainable development goal number 3, patient-oriented care and preventive care for people with a chronic condition such as SCI need to be strengthened throughout the levels of care.

Understanding personal factors and addressing the barriers to the prevention of SHCs can enhance a patient-oriented care approach and inform tailored prevention strategies. To ensure effectiveness in patient care, interventions must incorporate behaviour change models, cognitive behaviour therapy and collaborative patient care practice.

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Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

Authors' contributions

S.P. conceptualised the study, collected and analysed the data, and wrote the final draft. H.M. and J.P. supervised the study, assisted with data analysis and edited the manuscript.

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Data availability

The data that support the findings of this study are available from the corresponding author, S.P., upon reasonable request.

Disclaimer

The views and opinions expressed in this article are those of the authors and do not necessarily reflect the official policy or position of any affiliated agency of the authors.

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8.5. Conclusion

In this chapter, we discussed personal factors influencing the prevention of SHCs. The next chapter will discuss environmental factors influencing the prevention of SHCs.

9. CHAPTER NINE: ENVIRONMENTAL FACTORS INFLUENCING THE PREVENTION OF SECONDARY HEALTH CONDITIONS AMONG PEOPLE WITH SPINAL CORD INJURY

9.1. Manuscript details

Chapter nine is presented as a manuscript structured according to the journal guideline. The paper was submitted to *PLOS ONE* Journal, and we are working on post-review feedback. The paper explored environmental factors influencing the prevention of secondary health conditions among people living with spinal cord injuries.

The manuscript's title is **Environmental factors influencing the prevention of secondary health conditions among people with spinal cord injury, South Africa.**

Journal: *PLOS ONE*

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DHET accredited

Impact factor: 2.74

9.2. Details of author contribution

The Contributor Roles Taxonomy (CRediT) (Allen et al., 2019b) was used to outline the authors' contribution to the study. The full explanation of the terms is in Appendix G.

Table 9:1: Details of author contribution

	Pilusa	Myezwa	Potterton
Conceptualization	√	√	√
Method	√	√	√
Resources	√		
Manuscript writing draft	√		
Manuscript writing review and editing	√	√	√
Supervision		√	√

9.3. Abstract

Background: The environment where people live, work or play can influence health and disability outcomes. People with spinal cord injury develop preventable secondary health conditions that can increase rehospitalisation rates and decrease life quality. Studies on preventative care for secondary health conditions and factors influencing secondary health conditions prevention are scarce in low to middle-income countries.

Aim: To explore environmental factors influencing the prevention of secondary health conditions in people with spinal cord injury.

Setting: The study was based at a public rehabilitation hospital, South Africa.

Methods: Explorative qualitative design was used. Twenty-one therapists, 17 people with spinal cord injury and six caregivers, were interviewed. The interviews were transcribed verbatim. Content analysis was used to analyse data.

Results: The categories that emerged included social support, inefficient health care system, inaccessible built structures and a transport system that is not disability friendly. The healthcare system's inefficiencies were due to a shortage of medical resources (medication, consumables and assistive devices), health workers lacking knowledge on preventing secondary health conditions, and inadequate patient care approach.

Conclusion: Environmental factors influencing the prevention of secondary health conditions are complex and multifactorial. Part of recognising people with disabilities' right to health requires that environmental factors be addressed when developing rehabilitation and prevention programmes.

Keywords: Secondary health conditions, secondary complications, spinal cord injury, prevention, factors, environment

9.4. Introduction

According to the International Classification of Functioning, Disability and Health (ICF), environmental factors are factors outside an individual (extrinsic) where people live, play or work, which can influence health positively or negatively (World Health Organization, 2002). Environmental factors include "products and technology, natural environment and human-made changes to the environment, support and relationships, attitudes, services, systems and policies" (World Health Organization, 2002, p.16). The presence of a disability is not always the main problem for people with disabilities, but it is the presence of systematic environmental factors that shape the experience of disability (Øderud, 2014). There is a need to explore environmental factors that influence health outcomes to inform context-based interventions for people with disabilities in South Africa.

A chronic condition, such as spinal cord injury (SCI), requires long-term care, including rehabilitation, to optimise function, health maintenance and disease prevention. Prevention of diseases is not prioritised among people with SCI even though they are at a high risk of developing complications that are not necessarily caused by the primary disability but can occur because they have a disability (McColl et al., 2017, McColl et al., 2012). These complications are called secondary conditions or secondary health conditions (SHCs) (Jensen et al., 2012). Local studies on SHCs among people with SCI reported a high prevalence of SHCs, ranging from 50% during the acute phase (Joseph and Wikmar, 2016) to 89% four years post-injury (Madasa et al., 2020). The most prevalent SHCs were pressure sores, pulmonary complications, and urinary tract infections during the acute hospital phase (Joseph and Wikmar, 2016). Post-discharge, the most prevalent SHCs were pain, muscle spasms and sleeping problems (Madasa et al., 2020). The presence of SHCs affects the quality of life (Adriaansen et al., 2016), increases hospital readmission (Mashola et al., 2019) and can lead to untimely deaths (Øderud, 2014). Although some SHCs are preventable, evidence shows that preventing SHCs is challenging (Guilcher et al., 2013, Van Loo et al., 2010).

There is a dearth of studies on preventive care for SHCs and factors influencing prevention care for people with SCI in low to middle-income countries. Previous studies based in high-income

countries (Canada and Switzerland) have reported that prevention of SHCs is influenced by personal prevention style, medically oriented model of care, poor transport and built accessibility, social support systems, health professionals' lack of knowledge on SCI and SHCs, and uncoordinated care (Zanini et al., 2020a, Guilcher et al., 2013, Zanini et al., 2020b). Although these studies highlighted relevant factors that influence the prevention of SHCs, the context is not the same as in South Africa. Socioeconomic disparities still exist in South Africa. Many people are unemployed and live in poverty (49%) with limited access to social services (The World Bank, 2018). This situation is even worse for people with disabilities, with most people with disabilities unemployed and 41% living below the poverty line (Graham et al., 2014). Measures to protect vulnerable individuals in South Africa include access to various types of social grants. However, evidence indicates that social grants are not sufficient to meet the needs of an individual with disabilities because of disability-related costs, such as payment for a caregiver, high transport costs and costs related to accessing health services (Hanass-Hancock et al., 2017).

The South African health care system has a government subsidised private and public health sector, but most of the population (84%) depends on the under-resourced public and government-run health care system (Mayosi and Benatar, 2014). The remaining 16% pay for their health insurance giving them access to quality medical resources and readily accessible health care services. The inequitable access to health is one reason why the government has initiated the National Health Insurance (NHI) discourse to bridge the gap and ensure every citizen has access to quality and affordable health care (South Africa National Department of Health, 2015). It is important to note that information about rehabilitation services is limited in the NHI, and the implementation of the NHI has not commenced.

Furthermore, the health care system faces a quadruple disease burden, with most of its resources targeted to managing HIV/AIDS, TB and non-communicable diseases (Mayosi et al., 2012). Care is primarily curative, neglecting long-term impairments and disabilities related to prevalent health problems (Morris et al., 2021). As such, rehabilitation care across the continuum is not prioritised, with a shortage of rehabilitation health professionals, limited research in disability needs, poor implementation of disability management frameworks and poor access to community-based

rehabilitation (Morris et al., 2021, Sherry, 2014). Lack of rehabilitation services that include prevention and health promotion care leaves individuals with disabilities unable to function and participate fully in society. The reported prevalence of disability was estimated to be 7.5% in the 2011 census (Statistics South Africa, 2014), a percentage projected to increase due to the rising ageing population and the impairments related to the quadruple burden of disease (Morris et al., 2021). This increase in the prevalence of disability will increase the demand for health care, rehabilitation and social welfare. With this in mind, context-based studies are necessary to inform the development of appropriate interventions. Thus, this study explored environmental factors that influence the prevention of SHCs among people with SCI.

9.5. Methods

Study design: We used a qualitative design to explore the environmental factors influencing the prevention of SHCs in people with SCI. This study is part of a larger study that aims to establish factors influencing the prevention of SHCs in people with SCI to inform the development of a prevention model of care (Pilusa et al., 2020).

Setting: Participants were recruited from a government-funded rehabilitation hospital in Gauteng, South Africa, and the most populous province. The public rehabilitation hospital caters for people with physical disabilities, including spinal cord injury, from local townships and other provinces due to the lack of rehabilitation hospitals in those provinces. People with SCI may travel up to 100 kilometres to attend their monthly appointments for medication and medical consultation using a hired car because of the lack of wheelchair-accessible public transport.

Recruitment: The first author, assisted by the employee at the rehabilitation hospital, invited patients with SCI who attended the outpatient clinic. Caregivers of people with SCI who consented to the study were invited to participate. The therapists were recruited in the therapy gym.

Study population: Therapists were included if they were employed in the rehabilitation hospital and involved in the care of people with SCI. Caregivers of people with SCI, formal or informal, had to be 18 years or older and willing to participate in the study. Individuals diagnosed with SCI, both non-traumatic and traumatic, were invited to participate in the outpatient medical clinic at the

rehabilitation hospital. Willing participants with SCI 18 years and above were considered regardless of their gender, level and duration of SCI.

Data collection: The researchers developed an interview guide informed by a previous study on SHCs (Guilcher et al., 2013). The interview guide had two parts. Part A covered the participants' sociodemographic data. Part B included questions and probes on the SHCs commonly experienced by people with SCI, prevention and management strategies used, and factors at a personal and environmental level that influenced the prevention of SHCs. Lastly, questions on barriers and facilitators for the prevention of SHCs were asked. The interview guide was piloted on one therapist in the presence of a researcher experienced in qualitative research to clarify the questions. Semi-structured interviews were conducted by the principal researcher at a venue that was suitable for the participants. Interviews for all the therapists and some of the participants with SCI were conducted at the rehabilitation hospital. All the caregivers were interviewed at home. The average length of the interview was 50 min (range 45 min to1h30 min). Interviews were conducted from July 2018 to October 2019 and continued until data saturation was reached when no new information emerged.

Data Analysis: MAXQDA 2018.2 was used to manage and analyse data. All the interviews were audio-recorded and transcribed verbatim for data analysis. The interviews conducted in vernacular were translated to English before the analysis. The quotes are numbered (SC1 1, Therapist 1, Caregiver 1) to protect the participants' anonymity. Data were analysed using content analysis (Erlingsson and Brysiewicz, 2017). The primary investigator read and reread all the transcripts to ensure accurate transcription and get a sense of the content. One interview transcript was coded inductively by the principal investigator and two other researchers independently. After that, we discussed the broad codes, and developed a preliminary coding framework informed by the aim and the ICF environmental concepts. An external researcher experienced in qualitative and public health research coded one transcript, and the categories were compared. We discussed the differences in the concepts used and adapted the coding framework. The deductive analysis was conducted on the subsequent transcripts. Similar codes were grouped into sub-categories and categories. A manual display of the categories, sub-categories and codes was conducted by the principal researcher and reviewed by the other researchers. Regular debriefing sessions were held with the co-authors throughout the research process.

Ethical considerations: Permission to use the study site for data collection was granted by the rehabilitation hospital. All the participants gave written, informed consent and permission to record before the interview. This study was approved by the Human Research Ethics Committee of the University (M170938) and registered with the South African National Health Research Database (reference GP201712036).

9.6. Results

9.6.1. Demographic profile

The sample included forty-four participants (21 therapists, six caregivers and 17 people with SCI). The majority (82%) of the participants with SCI were paraplegic and were unmarried. Four caregivers were female and employed as carers. The therapists interviewed represented diverse professions, and the mean working experience was 8.7 years SD (8.5). Tables 9:2 and 9:3 presents the demographic data of the participants.

Table 9:2: Demographic profile of the participants with SCI

Participants with spinal cord injury (n=17)	
Age in years	
Mean (SD)	44.5 (13.1)
Range	27-72
Gender, n (%)	
Male	14 (82.4)
Female	3 (17.6)
Employed, n (%)	
Yes	5 (29.4)
No	12 (70.6)
Education level, n (%)	
Tertiary education	4 (23.5)
Matric	5 (29.4)
High school	6 (35.3)
Primary School	2 (11.8)
Time since injury	
Mean (SD)	9 (7.1)
Range (years)	1-30
Cause of injury, n (%)	
Trauma	14 (82.4)
Non-trauma	3 (17.6)

Type of spinal cord injury, n (%)	
Paraplegia	14 (82.4)
Quadriplegia	3 (17.6)
Completeness of the injury a	
Incomplete	4 (23.5)
Complete	13 (76.5)
Level of the injury, n (%)	
C1-C4	2 (11.8)
C5-T1	1 (5.9)
T2-T6	3 (17.6)
T7-T12	9 (52.9)
L1-L5	2 (11.8)
Assistive device	
Wheelchair	14 (82.3)
Walking aid	2 (11.8))
None	1 (5.9)
Marital status, n (%)	
Married /staying with a partner	7 (41.2)
Single	10 (58.8)

Table 9:3: Demographic data for the caregivers and the therapists

Caregivers (n=6)	
Age in years	
Mean (SD)	53.9 (12.9)
Range	33-69
Gender, n (%)	
Female	4 (66.7)
Male	2 (33.3)
Employed, n (%)	
Yes	5 (83.3)
No	1 (16.7)
Caregiver role, n (%)	
Formal (i.e. unemployed)	4 (66.7)
Informal (i.e. Family member)	2 (33.3)
Education, n (%)	
No schooling	2 (33.3)
Primary school	2 (33.3)
High school	2 (33.3)
Therapists (n=21)	
Age in years	
Mean (SD)	31.5 (8.3)
Range	22-54
Gender, n (%)	
Female	17 (81)
Male	5 (19)
Professions, n (%)	
Occupational therapy	7 (33.3)
Physiotherapy	6 (28.6)
Social worker	1 (4.8)
Psychologist	1 (4.8)
Speech therapist	2 (9.5)
Dietician	3 (14.3)
Occupational therapist assistant	1 (4.8)
Work experience in years	
Mean (SD)	8.7 (8.5)
Range	1-28

Qualitative data results

Categories evident in the qualitative analysis included the impact of social support, inaccessible built structures and transport systems, and an inefficient health care system.

9.6.2. Social support

Social support from family, caregiver and peers aided the prevention of SHCs. Social support manifested in home adaptation, emotional encouragement, peers sharing experiences, physically assisting with self-care and financial support.

"Patients with a good family support they do very well…, they do not come back with secondary complications" (Therapist 6)

"My support system has collapsed ... That is why I ended up developing bedsores" (SCI 3)

The participants highlighted the importance of the family's knowledge levels on SCI and SHCs in preventing SHCS. If the family member or caregiver lacks knowledge on SHCs, they will not support prevention care.

"When my mother was bathing me…she saw a bedsore and was not aware of what it is" (SCI 5)

"If the caregiver does not know what to do and the patient cannot self-manage... it is trial and error then it's a problem" (Therapist 19)

9.6.3. Inaccessible built structures and transport system

Inaccessible built structures were a barrier to the prevention of SHCs. Built structures in public facilities such as rough terrain, public toilets not suitable for wheelchair users, and uneven sidewalks proved to be barriers.

For example, a therapist said, *"some patients, when they move from here they end up being in the rural, and when in the rural areas you can't even get out of the gate because of the roads, they end up being depressed in the house"* (Therapist 2)

"I came from the hospital on the sidewalk. It is unreal how many times I had to get off the pavement and back on because there is some or other obstacle on the pavement or the cement is uneven" (SCI 16*)*

The participants mentioned how the public transport system was a barrier to the prevention of SHCs. Stigma against and segregation of people with SCI often characterise the public transport system. Participants reported how taxi drivers did not accommodate people using a wheelchair because it takes time to transfer them into the vehicle. Another stressor related to transport was the high cost of hiring an alternative private transport system.

"90% of our patients use public transport like the taxi ….taxi drivers either don't want to stop for them to help them in or when they do go on the taxi they have to pay for two seats because they have a wheelchair" (Therapist 8)

"Sometimes when you have to come for a check-up and getting a taxi is challenging, you have to hire a private car, and this is expensive" (SCI 1)

9.6.4. Inefficient healthcare system

Participants reported how inefficiencies in the health care system hampered the prevention of SHCs. The sub-categories included a shortage of resources and a lack of knowledge on SHCs among health professionals.

Shortage of resources

Participants reported a shortage of medication, consumables for bowel and bladder management and assistive devices. Patients expressed that they run out of medication because they are usually not given enough to last them till the next check-up. *"I ask them for tramadol (pain medication), and they give you one box, and it is meant to last you for three months… sometimes they run out, and you have to wait for that three months*" (SCI 5). The therapist reported that shortage of medication was at times due to budget constraints *"We have shortages of Gabapentin medication because of budget constraints"* (Therapist 16).

Participants with SCI reported that consumables for bowel and bladder management were not always available and were costly if bought privately *"Coloplast I get from the rehabilitation*

hospital. One kit I get every six months they supply to me. Unfortunately, they do not always have it available, and if you have to go and buy it, I think it's about R1,500 for that which is very, very expensive" (SCI 15). Unfortunately, lack of necessary bowel and bladder management consumables increased the risk for infection because individuals with SCI ended up reusing consumables. "*Sometimes we run out of stock you may find that a person is using one catheter for almost six weeks"* (Therapist 3).

Access to assistive devices such as wheelchairs, wheelchair cushion, and specialised aerated mattress helped reduce the risk for pressure sores, as expressed by this participant with SCI:

"…the major thing I also feel for me not getting pressure sores being in a chair is the cushion I'm sitting on. It is one of those air cushions, the Roho cushions, 'cos you don't need to do that constant pressure release…… I took out the money I saved up to buy myself this cushion" (SCI 15)

Some participants highlighted the low quality of the assistive devices issued by the hospital and ended up buying assistive devices privately "*The wheelchair tyres the rehabilitation hospital give you is ten times heavier than the ones I've got now (privately)"* (SCI 17)

Lack of knowledge on SHCs among health professionals

Participants with SCI also expressed how health care workers, including community-based health workers, lacked knowledge on SHCs prevention.

"I was seen by home-based care nurses – they don't know much about bedsore" (SCI 3)

"Even at the local clinic... They are aware that there is something called pressure sores but treating it, no, they don't know how to treat it" (SCI 2)

Where there were hospital standard protocols to prevent pressure sores, health professionals did not comply.

"Then they (nurses) told me I have to turn after every 3 hours but sometimes it happened that 5 hours passed without nurses turning me, so I think that is the cause of the bedsores" (SCI 2)

Inadequate patient care approach

The participants with SCI described how patient care was not holistic, *"Sometimes the wheelchair would give me problems, I will come and explain that I have a problem with the wheelchair they would fix it, but they would not see that the wheelchair cushion needs to be changed*" (SCI 5). Also, care during the in-patient rehabilitation phase was not empowering patients to self-manage post-discharge as described by these therapists:

"We rehab our patient to function in a hospital setting that is one of my biggest problem" (Therapist 2)

"*We mainly focus on secondary complications when it comes closer to the discharge time*" (Therapist 20).

9.7. Discussion

The study aimed to explore environmental factors influencing the prevention of SHCs in people with spinal cord injury by interviewing people with SCI, caregivers and therapists. The environmental factors identified were: the impact of social support, the inaccessibility of built structures and the transport system, and an inefficient health care system.

In agreement with previous studies, good social support from a caregiver and peers enhanced the prevention of SHCs (Munce et al., 2014b, Guilcher et al., 2012). Caregivers are part of a trusted social network helping in the prevention and management of SHCs, offering emotional support, assisting with activities of daily living and linking people with SCI with the health care system (Park et al., 2017, Rivers et al., 2018). Given the critical role caregivers play, the lack of knowledge on SCI and SHCs is worrying because they will not support prevention care. Peer involvement helps in sharing experiences and can be an adjunct to rehabilitation programmes (DeJong and Groah 2015). Given the shortage of health professionals in South Africa, involving the family/caregivers and peers in long-term rehabilitation and preventive care can help yield better health outcomes. Future research in South Africa can explore the role of caregivers and peer support in delivering rehabilitation service delivery.

Despite having the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Article 9 on universal access (United Nations, 2006) and the Sustainable Development Goal 11 on the inclusive and accessible environment (United Nations, 2019), environmental barriers for people with disabilities persist. In this study, inaccessible public transport systems and built structures were barriers to preventive care for SHCs. The main environmental barriers include inaccessible transport and buildings and a negative attitude towards people with disabilities from the community, friends and family (Maart et al., 2007, Maart and Jelsma, 2014). Given the social inequities in South Africa, the inaccessible infrastructure and transport system limits participation in the labour market, access to leisure and health-promoting care services and perpetuates exclusion and poverty. Possible barriers to accessing transport and built structures are poor implementations and enforcement of the UNCRPD convention article 9 (Morris et al., 2021, Venter et al., 2003). For the private mini-bus taxi industry, lack of awareness on universal design and government support to make the vehicles accessible for people with disabilities could be reasons for non-compliance. There is a need to promote universal design as a public good. Strategies that can be explored include awareness campaigns on universal design at all levels of service delivery for both the public and private sectors. Secondly, lobbying relevant departments to implement and enforce building regulations for all new infrastructure development and changing public transport vehicle specifications to be accessible for wheelchair users.

Similar to previous studies, the health system influenced the prevention of SHCs (Guilcher et al., 2013, Zanini et al., 2020b). Shortage of medical resources, health professionals lack of knowledge on prevention of SHCs, and a patient care approach that is not holistic and empowering affected the prevention of SHCs. Comparing the study results with previous studies based in high-income countries, countries with better resources and NHI, participants in this study and the previous ones highlighted how health professionals lacked information on the prevention of SHCs (Guilcher et al., 2013, Zanini et al., 2020b). This finding indicates gaps in the training of health professionals on disability issues, comprehensive chronic care management and general public health promotion. What was also worrying was that patient care protocols that required prevention care practice were not adhered to, proving a low value placed on preventative and rehabilitation care. Then again,

non-compliance to prevention protocols could be due to the shortage of health professionals to ensure adequate patient care.

The SCI care model seems to be more medically oriented. In this study, patient care was not holistic and not empowering persons with SCI to self-manage. Self-management practice is key to owning personal health and maintaining health (Munce et al., 2014b). The possible reasons for not empowering people with SCI could be poor integration of public health in healthcare delivery, not valuing rehabilitation care in the same manner as curative care, and poor understanding of rehabilitation (Morris et al., 2021). According to the WHO, rehabilitation is a continuous process of enabling an individual with a chronic condition and disability to function and participate in society through therapy, health promotion and disease prevention (World Health Organization, 2011a). In light of the burden of chronic diseases facing South Africa, there is a need to prioritise rehabilitation care at all levels of care, including health maintenance and prevention of diseases. Prioritising rehabilitation care can influence planning and resource allocation needed to enhance health for people with disabilities.

The shortage of resources such as medicines, bowel and bladder consumables, and assistive devices affects the prevention of SHCs. Medication shortage is a national problem due to inadequate procurement processes and suppliers (Modisakeng et al., 2020). Also, not prioritising rehabilitation care affects planning and resource allocation for medication and assistive devices needed by people with disabilities (Maart and Jelsma, 2014, Sherry, 2014). Shortage of assistive devices is a common problem in low and middle-income countries (Visagie et al., 2013, Matter and Eide, 2018). Cited reasons for the shortage of assistive devices include lack of budget allocation, inefficient procurement processes, lack of maintenance and repair services and supplier backlogs (Visagie et al., 2013). Lack of essential medical resources drives patients to buy privately, increasing out-of-pocket costs and increasing financial vulnerability.

Access to health for people with disabilities, including SCI, is a human right to be promoted. Since South Africa has ratified the CRPD, issues experienced by people with SCI can be addressed

through UN reporting processes. Firstly, the government can allocate the role of monitoring the convention's implementation to a specific department (e.g. Department of Planning, Monitoring and Evaluation). This department can collaborate with different stakeholders (respective government departments, NGOs for people with disabilities, private sector and training institutions) to monitor implementation and identify implementation problems. A coordinated and integrated approach to implementing the convention can influence planning, resource allocation, and service delivery to promote people with disabilities in all spheres.

This study has some limitations. We only looked at environmental factors for the participants at one rehabilitation hospital. Thus, the findings cannot be generalised to other settings. The sample was purposive, which could imply responder bias. The majority of the participants with SCI were male and had traumatic SCI, consistent with local studies on SCI. Future research should include more females and people with non-traumatic SCI. We had very few participants with a higher level of injury. People with higher-level lesions experience more impairments and functional limitations, increasing SHCs development and hospital readmission risk. Also, people with high lesions could experience more significant barriers returning to the hospital for follow-up, such as inaccessible public transport, high cost to hire private transport, need for caregiver support, and being less likely to be recruited. Future studies are needed to explore specific factors related to people with higher-level lesions.

9.8. Conclusion

Previous studies have highlighted the need to strengthen the prevention of SHCs among people with SCI. One way of strengthening preventative care is to understand the contextual influencing factors. The environmental factors influencing the prevention of SHCs are complex and multiple. There are more factors in the healthcare system that influence the prevention of SHCs as stated by Guilcher et al. (2013). Understanding local problems and context-specific factors regarding resources, accessibility, health professional competence, and patient care is vital given the high burden of diseases and massive inequality and poverty in South Africa. Secondly, these factors highlight the gaps in promoting human rights for people with disabilities.

9.9. Implications

Clinical practice: Understanding the complexity of the factors that act as barriers or facilitators to preventing secondary health conditions is vital when planning rehabilitation care services. When developing rehabilitation and prevention programmes, environmental factors must be considered.

Educational: The results indicated a lack of awareness of SHCs among community-based health professionals. Training and continuing professional development for health professionals can include courses on disability management and the prevention of SHCs.

In this chapter, the environmental factors influencing the prevention of SHCs were explored. The following chapter will present the findings on the services and interventions needed to prevent SHCs in people with SCI.

10. CHAPTER TEN: SERVICES AND INTERVENTIONS NEEDED TO PREVENT SECONDARY HEALTH CONDITIONS THROUGHOUT THE LIFESPAN OF PEOPLE WITH SPINAL CORD INJURY, SOUTH AFRICA

10.1. Manuscript details

Chapter ten is presented as a manuscript. The paper was submitted to the *African Journal of Disability*. The paper explored the services and interventions needed to prevent secondary health conditions throughout the life span of people with spinal cord injury.

The manuscript's title is **Services and interventions needed to prevent secondary health conditions throughout the life span of people with spinal cord injury, South Africa.**

This manuscript is under review in the *African Journal of Disability*

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Journal: *African Journal of Disability*.

DHET accredited

Impact Factor: not stated

10.2. Details of author contribution

The Contributor Roles Taxonomy (CRediT) (Allen et al., 2019b) was used to outline the authors' contribution to the study. The full explanation of the terms is in Appendix G.

Table 10:1: Details of author contribution

	Pilusa	Myezwa	Potterton
Conceptualization	√	√	√
Method	√	√	√
Resources	√		
Manuscript writing draft	√		
Manuscript writing review and editing	√	√	√
Supervision		√	√

10.3. Abstract

Background: Current evidence suggests a need for a care model that supports the prevention of secondary health conditions in people with spinal cord injury. Multiple complex factors influence the prevention of secondary health conditions. A shift in service delivery approach from linear and isolated prevention strategies to holistic and systems-based prevention approaches targeting multiple levels is needed.

Objective: This study aimed to identify the services and interventions needed to prevent secondary health conditions throughout the life span of people with spinal cord injury.

Methodology: We used a descriptive qualitative approach. Data was collected using focus group discussions with professionals in the rehabilitation field. The recorded group discussions were transcribed verbatim, and content analysis was conducted.

Results: Four focus group discussions were conducted. Four themes emerged from the analysis: patient-centred care, access to resources, promotion of health, and skilled healthcare workers.

Conclusions: The suggested services and interventions needed to prevent secondary health conditions target the individuals with SCI, health providers, health systems care approach and other sectors outside the health system. These services and interventions will inform the development of a preventive care model.

Keywords: spinal cord injury, model of care, prevention, secondary health conditions, secondary complications

10.5. Introduction

Holistic care and prevention of secondary health conditions (SHCs) is an unmet need for people with spinal cord injury (SCI). Living with a chronic health condition, such as a spinal cord injury (SCI), increases the risk for SHCs (pain, pressure sores, bladder and bowel problems) (Jensen et al., 2012, Rimmer et al., 2017). Secondary health conditions (SHCs) have a significant impact on the individuals' health (Pilusa et al., 2021a), affect work productivity (Callaway et al., 2015), inclusion (Fuseini et al., 2019), and worsen the primary disability (Richardson et al., 2021). Preventing and managing SHCs is a life-long commitment that requires continued support and interventions to minimise their occurrence.

There is a need for a comprehensive care model that can support prevention care for SHCs and address multiple and complex factors which influence prevention care. Evidence on the prevention of SHCs has looked at isolated interventions, which tend to be linearly oriented, assuming that single interventions (e.g. patient education) in isolation will improve health outcomes (Tramonti et al., 2020, World Health Organization, 2009). Systems thinking approaches to patient care are promoted because they address the whole system, the linkage between the different influencing factors, system behaviours, and encourage multilevel strategies (Atun, 2012, World Health Organization, 2009). Examples of care models that have incorporated systems thinking to improve health outcomes are the expanded chronic care model (Barr et al., 2003) and the system of prevention framework (Sims and Aboelata, 2019). The expanded chronic care model (Figure 10.1) is a framework used to design interventions for managing chronic diseases, incorporating population health promotion principles in the health system organisation and community (Barr et al., 2003). The system of prevention is a framework that guides the development of sustainable prevention approaches to better health outcomes (Sims and Aboelata, 2019). Figure 10.2 presents the elements from both the expanded chronic care model and the system of prevention framework. Both models recognise the socioecological factors that influence health outcomes, the importance of engaging relevant sectors when developing interventions and promoting multilevel strategies to address complex health problems.

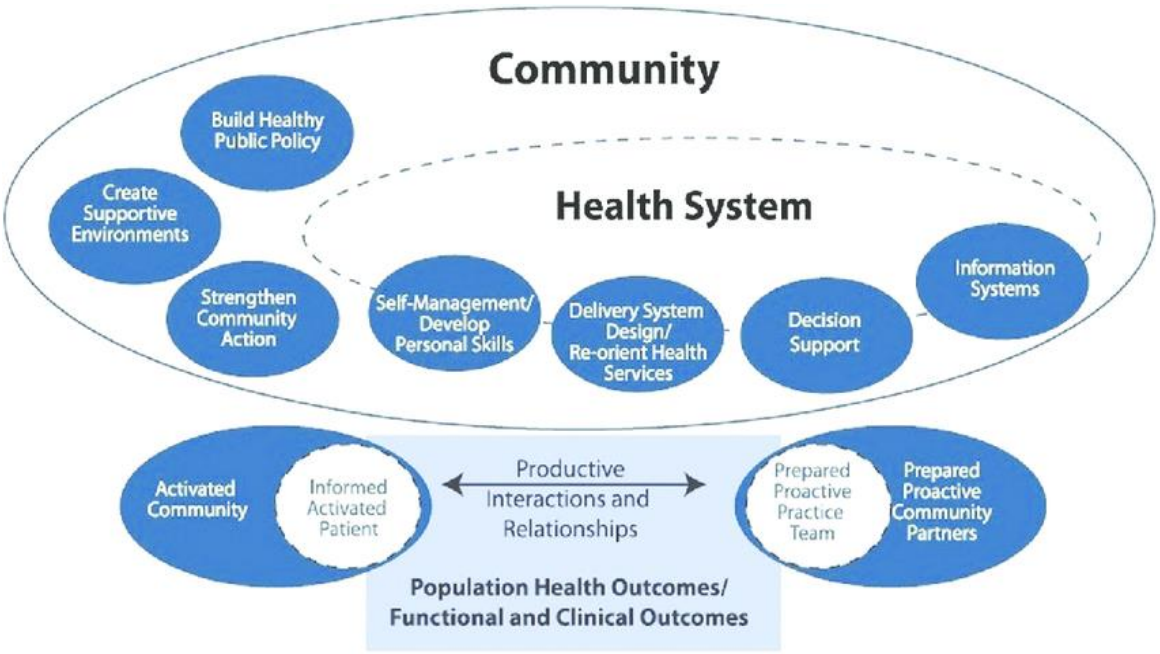


Figure 10:1: Elements of the expanded chronic care model (Barr et al., 2003)

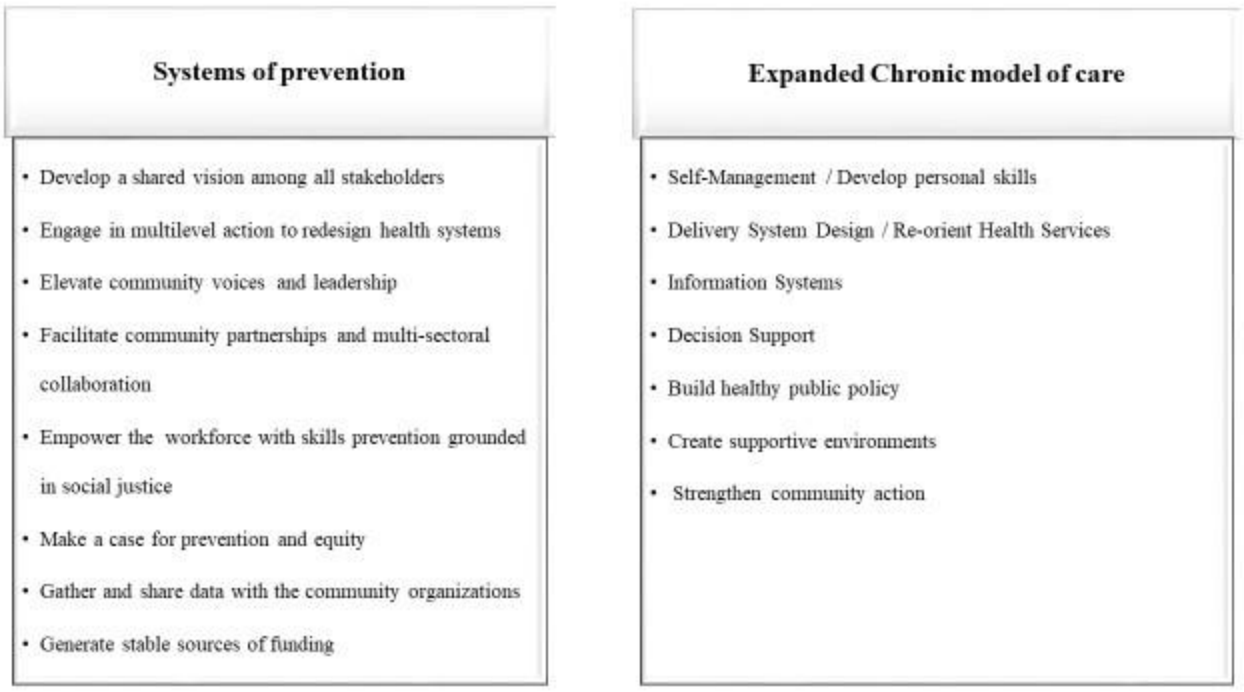


Figure 10:2: Elements of the expanded chronic care model and the system of prevention framework (Barr et al., 2003, Sims and Aboelata, 2019)

Good health among people with disabilities is a fundamental right central to attaining the Sustainable Development Goals (SDG) (United Nations, 2006, World Health Organization, 2017a). To promote health and well-being among people with SCI, we need services and interventions designed to minimise disability and improve access to comprehensive health services. In response to the WHO Rehabilitation 2030 call to action to develop need-based and comprehensive rehabilitation service delivery models (World Health Organization, 2017), this study aimed to identify the services and interventions needed to prevent secondary health conditions across the life span of people with spinal cord injury. The specified services and interventions can inform the development of SHCs prevention care model.

10.6. Methodology

10.6.1. Study design

A descriptive qualitative approach was adopted using focus group discussions. The advantage of using focus group discussion is that discussion and dialogue on ideas specific to the study question can be facilitated.

10.6.2. Context

The public health system in South Africa is overburdened, serving 84% of the population (Mayosi and Benatar, 2014). It is mainly medically oriented, focusing less on rehabilitation care (Morris et al., 2021). An injured person is admitted to a district or tertiary hospital and subsequently referred to the specialised rehabilitation hospital with bed space. There are three public specialised rehabilitation hospitals nationally, which results in certain provinces having to transport patients with SCI to regions with rehabilitation hospitals. After discharge, patients with SCI have to travel to the rehabilitation hospital for medical care, consumables and medication because the primary health facilities sometimes lack specific medicine and competence to manage SCI and SHCs (Maart and Jelsma, 2014, Sherry, 2014). Post-discharge care in the community is minimal due to the lack of health professionals at primary health clinics, lack of transport and lower priority placed on rehabilitation care (Morris et al., 2021, Sherry, 2014).

10.6.3. Participants

A purposive sample included a clinical rehabilitation manager; academic lecturers; rehabilitation directors; rehabilitation medical doctor; health consultant who lives with SCI, and physiotherapists (one runs a non-profit organization for people with disabilities).

10.6.4. Data collection

The group discussions were conducted in July 2020 online using Microsoft Teams by the primary author and a research assistant. The principal researcher conducted a pilot study with three academics specializing in public health, neurology and spinal cord rehabilitation to clarify the research questions. Pilot study data were included in the analysis because there were no changes to the research question. In the focus groups, the aim of the study was explained to the participants. The participants were asked to respond to the question, “Which services and interventions are needed to prevent secondary health conditions throughout the life span of people with SCI?” All

the participants were allowed to ask questions to ensure that everyone understood the research question.

10.6.5. Data analysis

A qualitative design software, MAXQDA version 2018.2, was used to manage and analyse data. All the group discussions were audio-recorded and transcribed verbatim. Content analysis was conducted whereby the text was divided into meaning units, formulating codes, categorizing similar codes, and identifying emerging themes (Erlingsson and Brysiewicz, 2017). The first author read the transcripts to get a general sense of the discussions. The transcripts were coded both inductively and deductively. Codes were grouped into categories and subcategories. A preliminary coding framework was developed and reviewed by all authors. The primary author coded the rest of the transcripts deductively; similar codes were grouped into categories and themes. The other authors reviewed the categories and themes.

10.6.6. Ethical considerations

All the participants gave informed consent and permission to record the discussion. The study was approved by the Human Research Ethics Committee of the University of the Witwatersrand (M170938) and the South African National Health Research Database (reference GP201712036).

10.7. Results

We conducted four focus group discussions with professionals experienced in rehabilitation. Table 10.2 presents the participants' demographic profiles.

Table 10:2: Demographic profile (n=16)

Age (years)	45.25 SD 10.14,min-max 28-61
Gender n (%)	
Male	4 (25)
Female	12 (75)
Level of education	
MSc	7 (43.7)
Bachelor	4 (25)
PhD	4 (25)
Other (MBCHB)	1 (6.3)
Occupation	
Academic lecturers	9 (56)
Clinical rehabilitation manager	1 (6.3)

Rehabilitation directors	2 (12.5)
Rehabilitation medical doctor	1 (6.3)
Health consultant and living with SCI	1 (6.3)
Physiotherapists	2 (12.5)

Four themes emerged from the analysis: patient-centred care, access to resources, promotion of health, and skilled healthcare workers.

10.7.1. Patient-centred care

The participants highlighted the importance of patient-centred care in the prevention of SHCs. Care needs to be holistic and address physical, mental, spiritual, and social aspects of health.

"What is critical is the issue of participating in excursions, in sports, in a whole lot of activities that would improve the mental and the physical as well as the spiritual well-being" (Participant 10)

" …to prevent isolation which leads more into all these secondary complications… try to find ways of re-integrating people with spinal cord injury back into the community and have them play active roles in society" (Participant 13)

Participants also commented on the importance of continuity of care. Patient care needs to be continuous through follow-up care, conducting home visits or seeing patients in the outpatient department to monitor the patients' health and identify risk factors to SHCs.

"Different facilities can incorporate follow-up visits, maybe once in 3 months or once in 6 months. ... To monitor, screen and see how the patient is progressing and if there are any risks and secondary complications that are arising later in the rehab process" (Participant 14)

"Follow-up contact…either the person with SCI is coming to the hospital or a home visit so that we detect the emergence of complications early on and intervene before it's too late. We know how pressure sores can accelerate at a very fast pace, so if we pick that up early on, we can then put in intervention measures" (Participant 16)

Participants emphasised the importance of collaboration between health professionals from many disciplines in SCI care.

"The most important thing in spinal cord injuries is the multi-interdisciplinary approach ...if no doctor is qualified to talk about bowel and bladder management, then the system falls shut because you cannot expect a physio to take that responsibility" (Participant 4)

"*At an institutional level to have a good inpatient care foundation before we can have the patient discharged and going to the community where we have an inter-disciplinary approach with the patient and not have all the health professionals doing isolated prevention interventions" (*Participant 12)

10.7.2. Promotion of health

Promoting health through building personal skills, support systems, and health-promoting policy is vital to SHCs prevention, as highlighted by the participants.

Building personal skill

In terms of building personal skills, the importance of educating the patients and family on SCI, SHCs, early signs of SHCs and healthy living was expressed by this participant:

"*Educate the patient and the family for early warning signs for incontinence, wheelchair maintenance, what pressure sores look like in the beginning phases before it becomes a pressure sore"*(Participant 3)

Besides educating on SHCs, health information could include topics on unhealthy lifestyles.

"*So there is the need to educate about obesity, not eating properly, alcohol or substance abuse to cope with the disability"* (Participant 7).

However, the timing for education is essential:

"*Sometimes you want to teach the patients with SCI about prevention when they have not yet accepted the injury, and you find that they do not remember it five weeks from now"* (Participant 12).

Other skills necessary for enhancing well-being included self-management and coping skills as expressed by this participant:

"Strengthen self-management…so that a person can take care of themselves. Just equipping them with the skills that they need to prevent this complication so that they can do them themselves in case, there is no one around at that time" (Participant 13)

"Empower patients with stress management and coping skills" (Participant 7)

Support system

Many participants reported how a strong support system through family, peers and the health care system helps with SHC prevention. Family helps the individual with SCI with care and creating a supportive and disability-friendly home environment.

"Looking at the immediate family home ... is it conducive for prevention, or does it lead them to have the secondary health conditions? Yes, we might not have the capabilities actually to change that, but once we understand the social standing, we can also include that in the prevention model" (Participant 12).

Participants mentioned how peer support through sharing experiences and health information could help people with SCI prevent SHCs.

" ….have peer supporters or peer counsellors that speak to the patients about pressure sore and how long it usually takes to heal just so that they have feedback from somebody who has experienced it" (Participant 12).

Lastly, the health care system at all levels was identified as a possible source of support when rendering responsive care:

"Also, ensuring that our referral systems within the health sector are effective. If I'm referring a client, I know who this client is going to, and it doesn't end there, and I make sure that the client is aware in terms of who to contact when they get to a certain point in terms of the healthcare system to ensure that we do not have a loss to follow up, which often happens" (Participant 8)

Health-promoting policy

The participants commented on the importance of policies that enable and support the prevention of SHCs.

"… *government policies must enable the reduction of secondary complications"* (Participant 1).

The participants also highlighted the need to have minimum standards for SCI care.

"There is a standard for seating, there is a good thing for wheelchairs that have come out but the rest of therapy, the rest of rehab, especially with spinal there is no standard protocol in this country, and that is a huge deficit in the service" (Participant 4)

10.7.3. Access to resources

Participants discussed how access to basic resources such as water, social grants, assistive devices, and medication facilitated the prevention of SHCs.

Lack of clean water hinders self-management practice for individuals with SCI, as expressed by this participant

"Access to water and electricity. You cannot expect people to do intermittent catheterization if they don't even have water" (Participant 1).

Additionally, participants highlighted the importance of accessible medication and consumables in the prevention and management of SHCs.

"*... Ensuring that supplies that go with the management of spinal cord injury at home are available.. ..Incontinence products, the whole package must be available to manage urine and other products, waste products"* (Participant 16).

"Consistent supply of drugs and continence products is a biggie where in KZN we have battled to have a good supply of Baclofen. ...sometimes it's just been stock out related" (Participant 6).

10.7.4. Skilled healthcare workers

Participants expressed their views on health professional competence in SCI care and the need for continual training to support prevention care.

"I also thought of health care workers who are trained to do regular home visits" (Participant 11)

"Training of health caregivers about the area of prevention" (Participant 13)

10.8. Discussion

This study aimed to identify the services and interventions considered essential to prevent secondary health conditions throughout the life span of people with spinal cord injury. Four themes emerged from the analysis: patient-centred care, access to resources, promotion of health, and skilled healthcare workers. There has been limited research on the prevention of SHCs in people with SCI.

Our findings showed that a patient-centred care approach is crucial to enhance the prevention of SHCs among people with SCI**.** Patient-centred care is a long-term and empowering approach to patient care that is needs-oriented, collaborative, inclusive of family and engages the patient as a critical contributor to personal health (Coulter and Oldham, 2016). Patient-centred approach requires that health professionals be holistic in their approach to care, ensure continuity to care, and work collaboratively (Hudon et al., 2012, Lindberg et al., 2013). Evidence shows that a patient-centred approach improves health outcomes, patient activation levels, and adherence to treatment (Kuipers et al., 2019). However, a positive work environment and professional leadership are essential to facilitate patient-centred care practice (Jardien-Baboo et al., 2016, Poitras et al., 2018). Secondly, continuous health professionals training is needed to ensure competent health promoters who proactively prevent diseases (Jardien-Baboo et al., 2016).

There is a need for continual health professional training to support prevention care. The lack of knowledge on SCI and SHCs care among health professionals disempowers people with SCI and leaves them desperate for care (Fuseini et al., 2018, Guilcher et al., 2013, Zanini et al., 2020b).

Since prevention care relies on the partnership between health professionals and persons with SCI, health professionals need knowledge on SCI, SHCs, biopsychosocial approach to care, preventive care and soft skills such as communication, negotiating, goal setting and interdisciplinary teamwork skills (Tramonti et al., 2020, Zanini et al., 2019). Training health professionals on the topics mentioned above should be part of the undergraduate curriculum and continuous in-service training.

Promoting health maintenance is critical in SCI care to minimise the occurrence of SHCs. The study's participants highlighted the importance of promoting health by building personal skills, support systems, and health-promoting policy. People with SCI can be empowered with SCI and SHCs prevention care information (Chang et al., 2017, Van Loo et al., 2010) and be supported to live healthily. The support system can be from family, friends and health professionals (Lindberg et al., 2013). Involving the family and peers in rehabilitation and prevention care post-discharge can bridge the care needs gap and ensure patient care continuity (Morris et al., 2021). Lastly, health professionals can be part of the support system for people with SCI at all levels of care through follow-up care, regular home visits, outreach services, and telehealth interventions (DeJong and Groah, 2015, Sherry, 2014).

Health-promoting policies are needed to enable and support the prevention of SHC. In the absence of a disability policy, South Africa developed and adopted the Framework and Strategy for Disability and Rehabilitation services 2015-2020 (National Department of Health, 2015). The framework outlines disability management through accessible rehabilitation services, which include disease prevention and health promotion. To date, there is no published outcomes or impact of the Framework and Strategy for Disability and Rehabilitation services 2015-2020. South Africa's challenge is not the absence of health-promoting policies for people with disabilities but the poor policy implementation and the low priority placed on rehabilitation care for people with long-term care needs (Morris et al., 2021, Sherry, 2014). Unless there is a shift from curative care to a biopsychosocial focus to care and prioritising rehabilitation, health promotion, and disease prevention for people with disabilities, health outcomes will not improve.

The last theme that emerged was access to resources that can help prevent and manage SHCs. The participants highlighted the importance of accessible medication and consumables in the

prevention and management of SHCs. Pharmaceutical care is necessary for some SHCs, such as pain, spasm, bladder, and bowel management (Patel et al., 2017). For example, assistive devices are essential for mobility, self-care and to facilitate participation in life activities. The shortage of medical resources needed to prevent SHCs can worsen health outcomes and increase economic vulnerability due to out of pocket expenses for assistive devices and over the counter medication purchases (Hanass-Hancock et al., 2017). To safely manage bladder and bowel problems, clean water is necessary. However, due to unemployment and social inequalities, access to essential services such as safe water and electricity can be unaffordable (Hanass-Hancock and McKenzie, 2017, Statistics South Africa, 2014, The World Bank, 2018). This study points to the importance of inter-sectoral collaboration when planning holistic care for people with SCI, ensuring access to essential services, consumables, and pharmaceutical products.

The study findings were comparable to the expanded chronic care model and system of prevention framework (Figure 10.3) (Barr et al., 2003, Sims and Aboelata, 2019). The missing elements in the study findings were information system, gathering and sharing data with community organisations, community partnership and multi-sectoral partnership. Research on disability needs can help build a case for prevention care intervention and equity. However, research should include people with disabilities and relevant stakeholders in the co-production of knowledge and implementing interventions (Redman et al., 2021). Co-production of knowledge through participatory action research can foster mutual learning, empower the community, and facilitate translation of research into practice. Building partnerships with the community and other sectors is central to sustainable development and recognises the vital role other sectors play in shaping health outcomes. A collective understanding and buy-in from all sectors can inform planning, practices, and processes when redesigning systems to achieve better health outcomes.

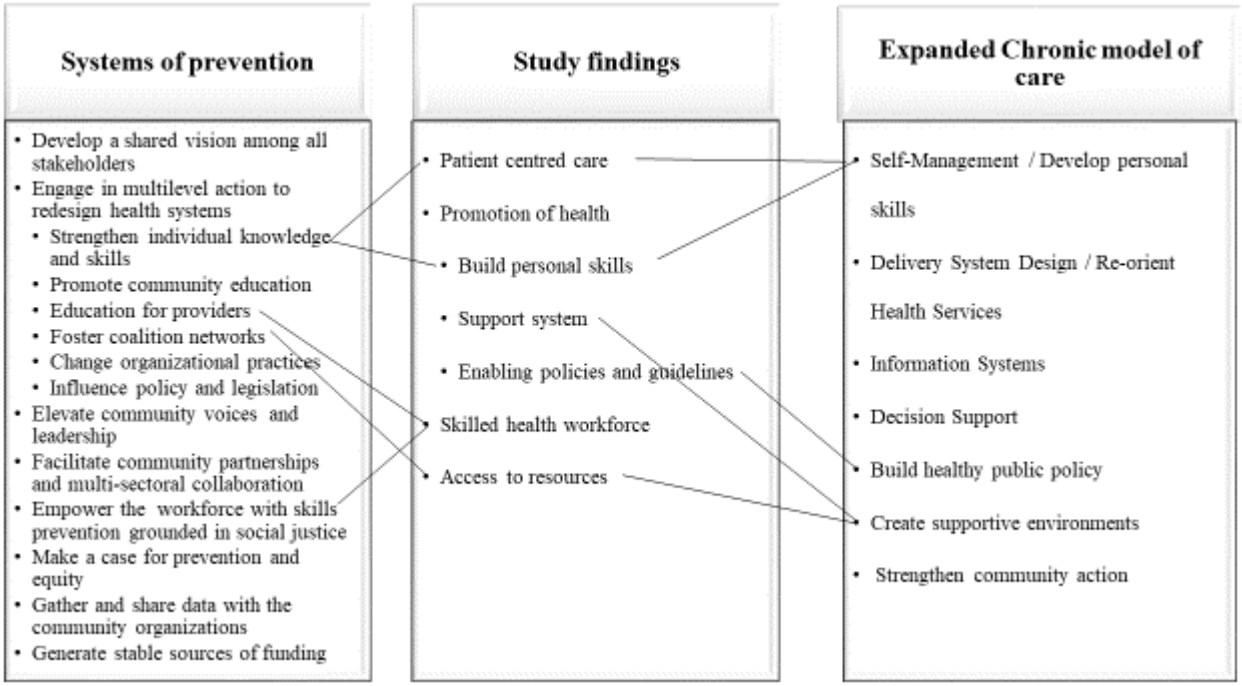


Figure 10:3: Comparison between the emerged themes and the elements from the expanded chronic care model and the system of prevention framework

10.9. Conclusion

To strengthen SHC prevention care among people living with SCI, the prevention model needs to include services and interventions that enhance patient-centred care, ensure access to resources, and promote health by skilled healthcare workers. The interventions and services target different levels and stakeholders, namely, the patients, health professionals, health system care approach and resources from the health system and outside the health system. Systems perspective in service delivery promotes a broader understanding of health problems' complexities and informs intervention design (Atun, 2012, MacLachlan and Scherer, 2018).

10.10. Limitations

This study has some limitations. Due to the COVID-19 pandemic, the country imposed social restrictions; thus, face-to-face group discussion was not possible. The focus group discussions were online, and we had to limit the discussion time due to participants availability based on their

work schedules and the participants' WIFI strength. The therapists based at a rehabilitation hospital were invited to participate. However, none accepted the opportunity to participate in the discussion, possibly due to the health care challenges from the COVID 19 pandemic, affected or infected with COVID-19. Secondly, most of the participants with SCI were unemployed and lived in home situations where online group discussion was going to be difficult. Future research must seek the opinion of people with SCI and therapists.

10.11. Implications

Research: Future implementation research using participatory action research can be used to engage different stakeholders to apply the proposed intervention and evaluate their effectiveness

Practice: health professionals are encouraged to empower people with SCI with knowledge on SHCs, and self-management skills. Patients with SCI can be given pamphlets on SHCS and links to online health resources that can assist them to promote health and prevent SHCs.

Education: Health professionals need continuous in-service training on patient-centred care and the importance of preventive care in disability care.

This chapter presented the findings on the services and interventions needed to prevent SHCs in people with SCI. The following chapter will present the views of health care users and providers on the solutions to improve the prevention of secondary health conditions.

11. CHAPTER ELEVEN: SOLUTIONS TO IMPROVE THE PREVENTION OF SECONDARY HEALTH CONDITIONS AMONG PEOPLE WITH SPINAL CORD INJURY

11.1. Manuscript details

Chapter eleven is presented as a manuscript. The paper has been submitted to the *Spinal Cord Series and Cases.* The paper explores the solutions to improve the prevention of secondary health conditions among people with spinal cord injury. The main theme that emerged was access to adequate health care. The categories linked to the theme were: availability of health services, patient-centred care, strengthen rehabilitation care, access to resources and training health professionals. These findings informed the development of the model of care. The title of the manuscript: "Views of health care users and providers at a rehabilitation hospital: solutions to improve the prevention of secondary health conditions among people with spinal cord injury."

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11.2. Details of author contribution

The Contributor Roles Taxonomy (CRediT) (Allen et al., 2019b) was used to outline the authors' contribution to the study. The full explanation of the terms is in Appendix G.

Table 11:1: Details of author contribution

	Pilusa	Myezwa	Potterton
Conceptualization	√	√	√
Method	√	√	√
Resources	√		
Manuscript writing draft	√		
Manuscript writing review and editing	√	√	√
Supervision		√	√

11.3. Abstract

Study Design: Explorative- qualitative study.

Objective: This study explored solutions to improve the prevention of secondary health conditions in people with spinal cord injury.

Setting: Rehabilitation hospital, South Africa

Methods: Face to face semi-structured interviews were conducted with 21 therapists and 17 people with spinal cord injury at a public rehabilitation hospital. All the interviews were transcribed verbatim. Content analysis was conducted on the transcripts to identify solutions to improve the prevention of secondary health conditions.

Results: The main theme that emerged was access to adequate health care. The categories linked to the main theme were: availability of health services, patient-centred care, strengthen rehabilitation care, access to resources and training health professionals.

Conclusions: Access to adequate health is central to the prevention of secondary health conditions. Care for people with spinal cord injury needs to be empowering and must address rehabilitation care needs across the lifespan. The proposed solutions will inform the development of a care model to support the prevention of secondary health conditions in people with spinal cord injury.

11.4. Introduction

Health disparities still exist for people with chronic conditions such as spinal cord injury. People with spinal cord injury (SCI) have unmet care needs for health information and support to prevent secondary health conditions (SHCs) such as pain, pressure sores, urinary tract infections (Chang et al., 2017, Van Loo et al., 2010). Spinal cord injury care tends to be more reactive instead of proactively preventing SHCs and promoting health (DeJong and Groah, 2015, Guilcher et al., 2013). Studies on SCI show a link between SHCs and increased readmission rates (Mashola et al., 2019), poor health and well-being (Pilusa et al., 2021b). The rising disability prevalence due to the burden of disease in South Africa increases the demand for comprehensive rehabilitation care and population-based public health programmes to minimise SHC occurrence and prevent further disability (Morris et al., 2021, Sherry, 2014).

In order to strengthen SCI care and decrease re-hospitalisation due to SHCs, DeJong and Groah (2015) highlighted the importance of the health care system proactively preventing SHCs, focusing on patient-centred care, and applying systems thinking when developing prevention strategies. Systems thinking is a holistic and collaborative approach to solving problems by analysing the problem's complexities and patterns to inform appropriate interventions (Atun, 2012). Systems thinking encourages a shift from linear and reductionist approaches when solving health problems to multi-level strategies that address underlying influencing health factors (Tramonti et al., 2020). An example of a model that has incorporated multiple strategies to prevent SHCs is the Conceptual Model for Identifying, Preventing and Managing Secondary Conditions in People with Disabilities (Figure 11.1) (Rimmer et al., 2011). The model proposes four prevention strategies for SHCs: assistive devices, rehabilitation, health promotion and policies (Rimmer et al., 2011). Evidence of the application of this model for people with SCI is limited.

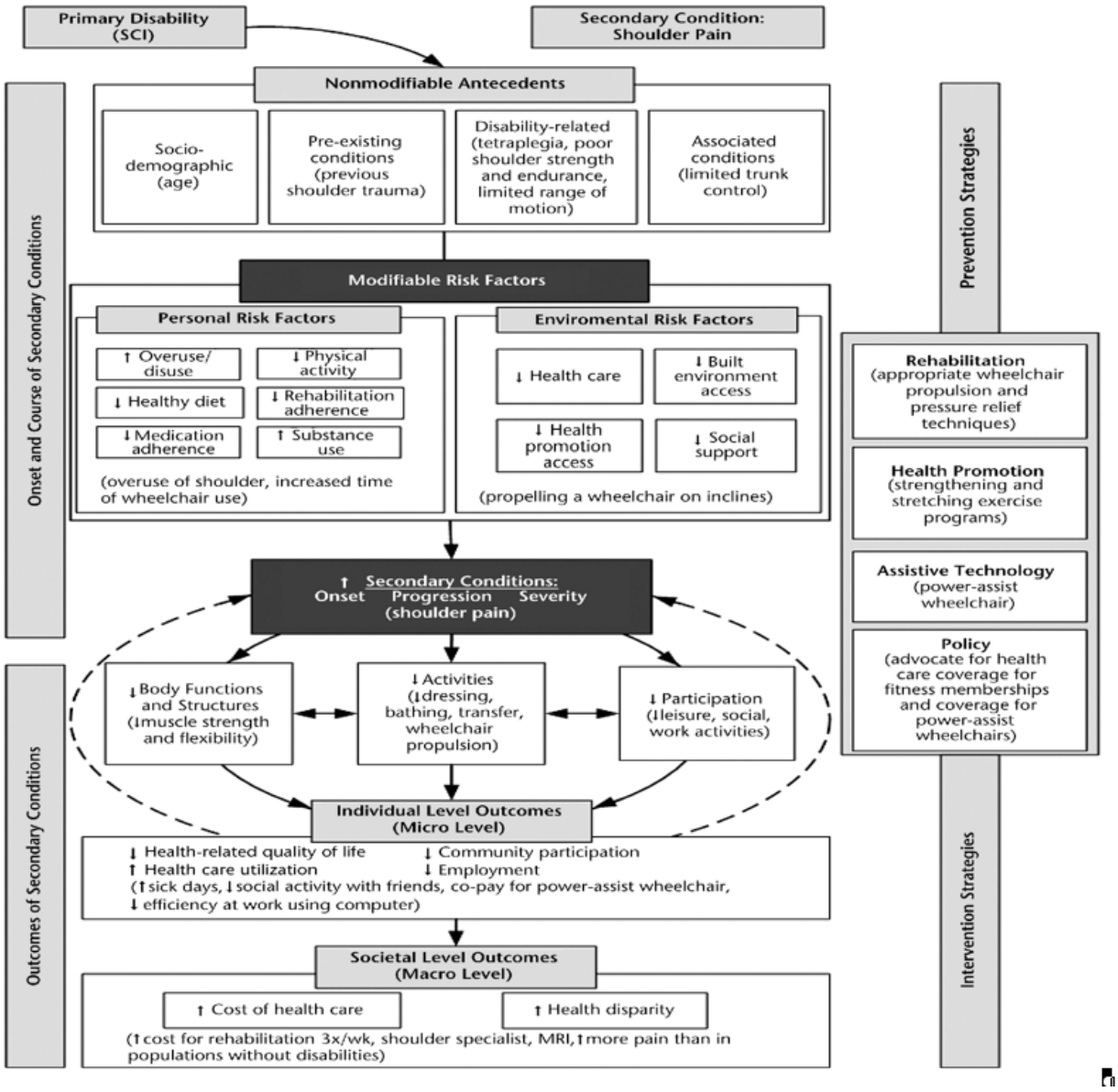


Figure 11:1: Conceptual model for identifying, preventing, and managing secondary conditions in people with disabilities (Rimmer et al., 2011).

Prevention care for SHCs requires a partnership between the patient and health providers (Zanini et al., 2019). The health providers' role in preventing SHCs includes patient-oriented care, empowering individuals with SCI with information on SCI and SHCs, self-management skill, and actively engaging patients in planning and decision-making (Zanini et al., 2019, Lindberg et al., 2013). The patient's role is to take responsibility for their health, self-manage, and seek help when

needed (Zanini et al., 2020a). Building a patient–health care professional partnership has its challenges in understanding each stakeholder's role when setting patient care goals. To enhance inclusive health and develop a responsive prevention care model, we need to listen to both the service users and care providers' views on health and ways to promote well-being. Thus, this study explored solutions to improve the prevention of SHCs in people with SCI.

11.5. Method

Study design: An explorative qualitative approach was used to understand the participants' views on solutions to improve the prevention of SHCs. This study is part of a bigger study on the factors influencing the prevention of SHCs in people with SCI.

Study setting: The study was based at a public rehabilitation hospital in Gauteng, the most populous province in South Africa. The rehabilitation hospital admits patients needing long-term rehabilitation care from tertiary and district hospitals in the province and neighbouring provinces.

Participants: We used purposive sampling to recruit the participants from a public rehabilitation hospital in Gauteng, a populous urban province, South Africa. The participants included individuals with SCI using outpatient medical services and rehabilitation therapists based at the rehabilitation hospital. All the participants had to be 18 years or older to participate in the study. We only included people with SCI and therapists who gave informed consent. People with SCI were included irrespective of sex and SCI injury profile (lesion level, type of injury and duration of the injury).

Data collection: The researchers developed an interview guide and piloted it to ensure the clarity of the questions. The topics covered in the interview guide included common SHCs experienced by people with SCI, prevention strategies for SHCs, factors influencing the prevention of SHCs and solutions to improve the prevention of SHCs. The principal author explained the study to eligible participants, obtained informed consent, and audio recorded the interviews. Face to face interviews were conducted at the hospital in the participant's language of choice. On average, the interviews lasted 45 minutes, and data collection was from August 2018- July 2019.

Data analysis: All the interviews were transcribed verbatim. The principal author read all the transcripts to ensure correct transcription and a sense of narratives. Qualitative data analysis software (MAXQDA version 2018.1) was used to manage and analyse the data following content analysis steps outlined by Erlingsson and Brysiewicz (2017). Using a coding framework developed collectively by the authors, inductive and deductive analysis was conducted, the text was transformed into codes and categories. Debriefing sessions were conducted throughout the research process. The participants' names were not used to ensure anonymity, and the quotes were labelled (SCI, 1, Therapist 1).

Ethical considerations: Data was collected after approval from the Human Research Ethics Committee of the University of the Witwatersrand (M170938), South African National Health Research Database (reference GP201712036) and the study site was granted. Only participants who gave informed consent and permission to record interviews were included in the study. We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during this research.

11.6. Result

The results are presented in two sections, Part A: demographic profile of the participants and Part B: Emerged theme and categories related to the study aim.

11.6.1. Part A: demographic profile of the participants

We interviewed thirty-eight participants (21 therapists; 17 patients with SCI). Table 11.1 and 11.2 provide an overview of the demographic data of the participants. The majority of the participants with SCI were male and had traumatic SCI. The majority of the therapists were occupational therapists and physiotherapists. The demographic data are presented in Table 11:2 and Table 11: 3.

Table 11:2: Demographic profile of the participants with SCI

Participants with spinal cord injury n=17 (%)	
Age in years	
Mean (SD), Range (years)	44.5 (13.1), 27-72
Gender	
Male	14 (82.4)
Female	3 (17.6)
Employed, n (%)	
Yes	5 (29.4)
No	12 (70.6)
Time since injury	
Mean (SD), Range (years)	9 (7.1) , 1-30
Cause of injury	
Trauma	14 (82.4)
Non-traumatic	3 (17.6)
Type of spinal cord injury	
Paraplegia	14 (82.4)
Tetraplegia	3 (17.6)
Completeness of the injury	
Incomplete	4 (23.5)
Complete	13 (76.5)
Level of the injury	
C1-C4	2 (11.8)
C5-T1	1 (5.9)
T2-T6	3 (17.6)
T7-T12	9 (52.9)
L1-L5	2 (11.8)
Assistive device	
Wheelchair	14 (82.3)
Walking aid	2 (11.8))
None	1 (5.9)

Table 11:3: Demographic data for the therapists

Therapists n=21 (%)	
Age (years)	
Mean (SD)	31.5 (8.3)
Range	22-54
Gender, n (%)	
Female	17 (81)
Male	4 (19)
Professions, n (%)	
Occupational therapy	7 (33.3)
Physiotherapy	6 (28.6)
Social worker	1 (4.8)
Psychologist	1 (4.8)
Speech therapist	2 (9.5)
Dietician	3 (14.3)
Occupational therapist assistant	1 (4.8)
Work experience (years)	
Mean (SD)	8.7 (8.5)
Range	1-28

All of the participants with SCI had at least one SHCs, and pain was the most prevalent SHCs.

11.6.2. Part B: Themes and categories related to the study aim.

The main theme that emerged was "Access to adequate health care". The five categories linked to the main theme were:

1. Availability of health care
2. Patient-centred care
3. Strengthen rehabilitation care
4. Access to resources
5. Train health professionals.

Availability of health care

Participants highlighted the need for health care services closer to where they live to render pressure sore management care, weekly check-up and follow-up care.

*"The government can play a role of building a 'pressure sore clinic' in the community where we could go weekly for check-ups" (*SCI 3)

"We need clinics nearby with a rehab facility so that the patients can do check-ups and follow-ups there. One patient comes from Mpumalanga once a month because no clinic helps her there. So, just accessibility, care closer to the patient" (Therapist 15)

"I would prefer if there were physios in the townships as well, where we could go and train during the week just like we do here at the rehabilitation hospital " (SCI 1)

Patient-centred care

Participants with SCI emphasized the importance of patient-centred care, and the sub-categories include listening to patients, health education on SHCs and prevention, and patient support system.

Participants with SCI wanted health professionals to listen to them and involve them in decision-making and care planning.

"What I am fighting for most is that they will listen to me as a patient. It does not matter how much you have studied, listen to me and what I am saying instead of acting like they know" (SCI 6)

"There is only one solution. Listen to people. …we are not the same... But, if only they could listen so that they can know the challenges patients have. How they feel about it. The big thing is, you have to ask the patient….ask the patient about the injury" (SCI7)

"I am not scared to tell them that yes, you studied but not what I am suffering from, this person has never been in my shoes, and the doctor will never know the pain I am in and how I feel. Just listen to me, as I said the neurologists from hospital X, I used to say how about you book me for this test and let's see what you will find and that leads to other tests" (SCI 6)

Most participants mentioned that education for SCI and family on SHCs, SHCs preventative care, self-management and information on assistive devices was necessary to help in preventive care for SHCs.

"The main issue is pressure sores, it bothers people who use wheelchairs, I wish they could teach us more about prevention, and I wish they could explain well how pressure sore develops" (SCI 5)

"People need to be properly taught how to manage secondary conditions ... and when you experience a problem, don't just leave it and think it'll go away, make sure that you take advice, go to speak to someone, and even get a second opinion if needs be" (SCI 11)

"Educate the family and talk to them about the possible risks so they can notice the signs and symptoms in mental health" (Therapist 7)

Participants commented on the importance of a support system for people with SCI, to help them manage their disability, reinforce what they learnt on SHC prevention and share their experiences. The support could be from peers with disabilities and community support groups

"We can have support groups where people with spinal cord injury can go for support, for debriefing and reinforcement of preventative measures" (Therapist 13).

We need (non-government organisations) NGOs to go to during weekends where we can meet and talk. You can have a normal person as a friend, but it is better if it is someone who is going through more or less the same thing as you are. Maybe they can share something they are going through. It would encourage me to be like them instead of stressing of all these other things" (SCI 12)

"What will help, if there are places where persons with SCI can get information from, phone and say, listen, I have this problem, and they can say, okay, we have a network of people, we can get you to contact the people doing this and that…. adapting your house or whatever is needed. Or we can give you a number for a doctor or something that can explain pressure sores." (SCI 15)

Strengthen the rehabilitation care

Participants stressed the importance of strengthening rehabilitation care by ensuring that it is needs-based, supports the transition process, and continuity of care when they are home.

Participants highlighted the importance of ensuring that the patients' needs must inform rehabilitation care and that rehabilitation must start early to enhance ownership of personal health

"They should visit the patients' homes before they discharge them….so they can know that this person's bed is this high, he baths in a bucket… we cannot be trained the same way as someone who uses a bathroom tub" (SCI 12).

"You rehab your patients, you do your toilet transfer where there is something to hold on, but when you get home, it is a different thing, so yes, we are doing our best, but we are not rehabilitating our patients to go function in their settings, that is one of the gaps that I feel that we need to close" (Therapist 2).

The participants discussed that transition from hospital to home setting needs to be managed carefully to ensure patients cope and family could be involved in the process.

"I think the transition between rehab into the community is important because the hospital is a controlled environment. When the patients with spinal cord injury go back home, it is a completely different environment of which they tend not to cope most of them" (Therapist 13).

"We must involve the family as much as possible to ensure that successful transition from rehab to home" (Therapist 11).

Participants stressed the importance of continuity of care through regular patient follow-up care, home visits, and outreach services to ensure patients progressed well and SHCs prevention was supported. Health professionals, community-based workers and peers with disabilities could play a vital role in follow-up care post-discharge.

"A multidisciplinary team must see patients… drive to their homes. .. check on them just to check the environment and also ensure they are fine" (Therapist13)

"At a healthcare level what we need to improve on home visits on a regular base, just to follow up, catch problems before...they are major...." (SCI 10)

Lastly linked to rehabilitation care, participants discussed reintegrating people with SCI back to work and leisure to give them a sense of meaning and helping them prevent SHCs

"Invest money in getting sheltered employment for these people because that is important. If I used to wake up every day and have a life and suddenly no one wants to employ you, that will depress me as well" (Therapist 10)

"Re-integration is not just about going back to your family. It is going back out there, going back to things you used to do, leisure, we get people that if they are not working, they just sit at home …. They should do things that will encourage them to have something to live for, and I think that is very important" (Therapist 10)

"And that is one thing I can say it is very difficult, is to get a proper sports centre where we can go and do sports. .. I am talking about getting involved with sports for people with disabilities" (SCI 17)

Access to resources

Participants identified basic and essential resources for people with SCI to enhance the prevention of SHCs.

Medication and assistive devices

Participants mentioned that people with SCI needed an adequate supply of medication, pressure sore dressings, and consumables for bladder management and nutritional supplements to support the prevention of SHCs.

"Give us enough medication. ….It is painful being unable to sleep because of pain, and you have to wait for 3 months to get more medication" (SCI 5)

"We need adequate drugs, dressings, uhm also if we are giving patients uhm…., catheters …. Using a single-use hydrophilic catheter decreases uhm,…. urinary tract infections, but we don't have those, so if we could give those to patients, it will help to prevent UTI". (Therapist 16)

Participants spoke about the importance of assistive devices and the fact that they must be easily accessible, appropriate, and acceptable.

"having access as well to other types of cushions, or wheelchairs because we only have the standardised ones which are not always best for all patients so that could also help in preventing the pressure sores" (Therapist 1)

"A patient should be able to get the necessary wheelchair that they need at the right time, not waiting ten years to get a new chair " (Therapist 15)

Health professionals

There was also a need for more health professional staff to ensure continuity of care and patient-centred care

"I would start with the adequate staffing because I think the nurses develop bad attitude because they are also fatigued" (Therapist 21)

"Invest in increasing the number of employees in our hospital so that people don't complain over being short-staffed" (Therapist 10)

Other basic resources

Participants suggested a disability-friendly transport system that can transport people with wheelchairs so they can access health services. For example, a participant with SCI said:

"There should be public transport vehicles that load wheelchairs… vehicles with enough space for people and their wheelchairs. Sometimes we wait long for taxis – most of them are not willing to transport us with our wheelchairs... also some people are not able to transfer themselves into the taxis" (SCI1)

"We need to make sure there is easier transport for them so that they can get to the clinics and to work" (Therapist 20)

Participants with SCI mentioned access to safe drinking water and adequate toilet facilities inside the house to make daily living activities easier.

"What could make me happy is that, in the house, I live in, we should have a tap for water inside the house. Things should be easier" (SCI 14)

"If I could get a toilet inside the house, managing my bowel will be easier "(SCI 12)

Train health professionals

Participants noted a gap in the health professionals' knowledge on SCI and SHC prevention. They suggested topics that can be included in the health professional training: disability literacy, SCI care and treating pressure sores.

"Teach health professionals on how to work with people with spinal injuries, especially when they are in the hospital" (SCI15)

*"Teach the NGOs, community-based nurses and home-based carers how to treat pressure sores" (*SCI 1)

"*I think that maybe the nursing staff should be trained on dressing and treating pressure sores because sometimes some of them treat it, but they do not do it the same"* (SCI 2)

"The training for health professional should in such a way that if someone comes with a disability, they know at least what the condition is and how they can help before they transfer to the hospital. But the problem is that I do not think training is that deep, especially when it comes to SCI…" (Therapist 5)

11.7. Discussion

This study explored solutions that can improve SHCs prevention in people with spinal cord injury. From the analysis, the theme that emerged was "access to adequate health care" with five categories: availability of health care, patient-centred care, strengthening rehabilitation care, access to resources and training health professionals presented in Figure 11.2. Access to health care includes one's ability to identify personal healthcare needs, seek and use health services to address health needs entirely (Dassah et al., 2018). The dimensions of healthcare access include acceptability, availability, accommodation, affordability and appropriateness (Dassah et al., 2018). Access to health care services, including rehabilitation care close to where people live, is a human right that people with disabilities have not fully realised (Maart and Jelsma, 2014, United Nations, 2006).

Research shows that access to health care for people with disabilities is limited (Maart and Jelsma, 2014, Vergunst et al., 2017). There is a shortage of rehabilitation services at a primary care level

(Ned et al., 2017), unmet needs for assistive devices, and a lack of home-based care in South Africa (Maart and Jelsma, 2014). However, the unavailability of rehabilitation services could be due to the shortage of rehabilitation therapists (Tiwari et al., 2020). The ratio of rehabilitation therapists was 7.25/100000 population in 2019, which translates to 3.10 physiotherapists, 2.64 occupational therapists and 1.51 speech therapists (Tiwari et al., 2020). Unavailable rehabilitation services in the community force people with disabilities to travel long distances to access healthcare. Nteta et al. (2010) reported that most people based in an urban setting travelled less than 5km to access the primary health facility, either using a taxi or walking to access the health facility. Although this study reported good access to primary health facilities, none of the study participants reported having had a disability. The experiences of people with disabilities are very different. Even if health services are available, getting to the health care facility is not accessible due to lack of disability-friendly transport, high transport costs, architectural and terrain barriers (Maart and Jelsma, 2014, Paulus-Mokgachane et al., 2019, Vergunst et al., 2017). This study's findings point to the need to strengthen access to health care for people with disabilities. Rehabilitation therapists and community-based workers can conduct community-based outreach services and home-based to bridge this gap.

Spinal cord injury is a chronic condition with complex and varying needs due to secondary complications; thus, a patient-centred care approach is needed (Hudon et al., 2012). People with SCI need holistic care and assistance to live well with a chronic condition. However, the health system is medically oriented, ignoring the long-term needs of living with a chronic disease (Ned et al., 2017). People with chronic and multiple conditions are treated in silos with continuous assessments, which do not necessarily lead to better health outcomes (Mangin et al., 2012). Systematic health system challenges such as lack of resources, shortage of human resources, curative focus to care and fragmented care limit patient-centred care experience (Maphumulo and Bhengu, 2019, Sherry, 2014).

Patient-centred care is an enabling approach to care that puts the patient at the centre of care by involving the patient in decision making, planning, recognising the patients' role and the context in personal well-being (Stewart, 2001). Patient-centred care communicates respect and value to the patients by listening to patients experiences of illness and health goals (Hudon et al., 2012). To strengthen patient-centred care, we need to train health professionals to render holistic patient-

centred care across the continuum (Jardien-Baboo et al., 2016). Undergraduate and continuous in-service training can include patient-centred care, biopsychosocial approach to health, the importance of health maintenance and preventative care (Jardien-Baboo et al., 2016). Secondly, organisational changes to support patient-centred care are recommended, such as hiring more health professionals, encouraging collaborative care and patient follow-up care (Hudon et al., 2012, Jardien-Baboo et al., 2016).

This study's participants highlighted the importance of educating people with SCI on SHCs and prevention care to address the unmet need for health information (Van Loo et al., 2010). Health literacy is a vital tool in Sustainable Development Goal no.3 to promote health and behaviour change (World Health Organization, 2017a). Increasing awareness on SCI, self-management and health maintenance is vital for chronic management and patient-centred care (Coulter and Oldham, 2016, Munce et al., 2014a). Factors such as age, beliefs about risks (Chang et al., 2017), educational levels, previous history of SHCs experience, being married and access to online material and technology influence access to health information (Tederko et al., 2017). Thus must be considered when educating people with SCI. An untapped resource for health information in South Africa is peer education and telehealth (DeJong and Groah, 2015). Future research can explore telehealth and peer mentors' role in increasing health awareness for people with SCI.

Social support can help increase access to health services, encourage self-management practice (Munce et al., 2014) and promote the prevention SHCs (Guilcher et al., 2013). Involving the family in care, planning and decision making can strengthen patient-centred care and ensure continuity of care at home (Ned et al., 2017). The second source of support is health professionals when providing continuity of care through home visits, outreach services and regular check-up sessions (Dambi and Jelsma, 2014, Zanini et al., 2019). Unfortunately, health professional's lack of knowledge on SCI and SHCs (Fuseini et al., 2018), shortage of health professionals (Morrison et al., 2018), and lack of transport for home visits (Ned et al., 2017) affect the level of support they can give to patients post-discharge. A new cadre of community-based rehabilitation care workers was introduced to strengthen primary health care and support community-based rehabilitation in South Africa (Rowe and Gamiet, 2019). However, there are challenges in incorporating this group into the broader health care service (Morris et al., 2021). Strengthening partnerships with

rehabilitation care workers can improve skills transfer, continuity of care, and enhance patient support.

The proposed solutions align with the prevention strategies outlined in Rimmer's conceptual model (Rimmer et al., 2011). However, the solutions cover broader aspects of the patient centred care approach in supporting the prevention of SHCs, focusing on the healthcare user, healthcare provider and the healthcare organisation. These findings confirm the importance of systems thinking when strengthening prevention care in people with SCI. Systems-wide multi-level interventions can better respond to the health problems' complexities.

11.8. Conclusions

The proposed solutions to improve the prevention of SHCs revolve around access to adequate health care in terms of health care availability, providing patient-centred care, strengthening rehabilitation care, access to resources and training health professionals. The study findings support the call to integrate rehabilitation at all levels of care and strategic programmes for HIV, TB and non-communicable diseases (Maart and Jelsma, 2014, Sherry, 2014). Integrating rehabilitation at all levels of care will improve access to care, including preventive care, planning and resource allocation for assistive devices, medication and human resources.

11.9. Recommendations

Research

Participatory action research where different stakeholders (people with SCI, caregivers, health care providers)are involved in the process of implementing and evaluating the effectiveness of the suggested solution is recommended.

Future research can explore the role of telehealth and peer mentors in increasing health awareness and improving access to healthcare for people with SCI.

Practice

Health professionals must continually educate patients with SCI on SHCs preventive care and build skills to self-manage. Patient education can be conducted during inpatient and outpatient hospital care. Telehealth can also be used as a platform to educate patients with SCI.

Education

Health professional training must ensure that topics on chronic care and patient-centred care, SCI care needs are covered are included in the curriculum.

11.10. Declarations

Data availability: All data generated or analysed during this study are included in this published article, and its supplementary information file is available from the corresponding author on reasonable request.

Conflict of Interest: The authors declare that they have no competing interests

Author Contributions: This study was part of the SP doctoral degree at the University of the Witwatersrand (South Africa).

SP-conceptualized the study, collected data, analysed data and wrote the manuscript.

HM and JP – supervision during the conceptualisation phase, assisted during data analysis, read several iterations of the paper and conducted the final editing.

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12. CHAPTER TWELVE: INTEGRATIVE DISCUSSION

This chapter includes an integrative synthesis of the PhD study findings titled "Prevention care for secondary health conditions among people with spinal cord injury in the Tshwane Metropolitan area". Data was collected from two public tertiary hospitals in Tshwane Metropolitan. The synthesis will discuss the results in conjunction with available literature as well as outlining the study limitations and strengths.

The study aimed to establish factors influencing the prevention of secondary health conditions (SHCs) among people with spinal cord injury (SCI) in the Tshwane metropolitan area to inform the development of a preventive care model. The study results emanated from eight studies whose results are outlined and depicted as chapters in Figure 12.1.

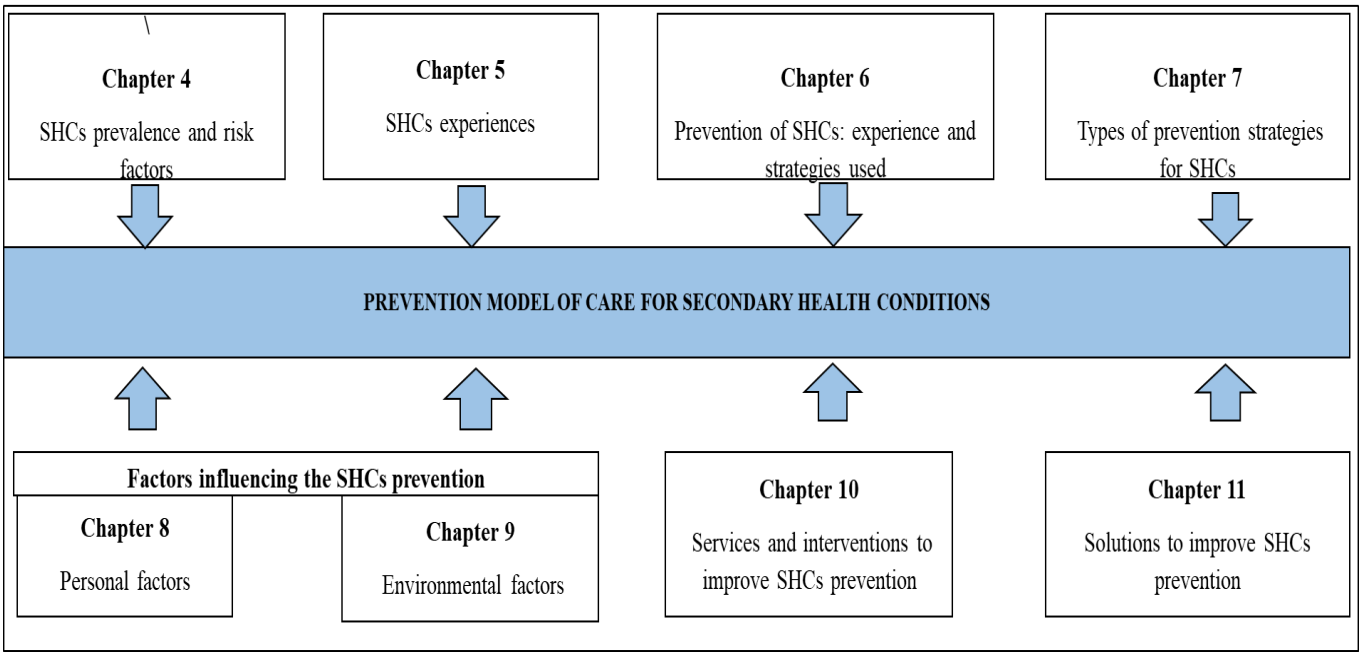


Figure 12:1: Schematic diagram of the studies conducted

To address the study aim, the prevalence of SHCs and the associated risk factors in people with SCI were identified (Chapter Four). In Chapter Five, the nuanced experiences of SHCs, were explored which led to the presentation of how people with SCI prevent SHCs in Chapter Six. In Chapter Seven, the range of prevention strategies were mapped. In Chapters Eight and Nine,

personal and environmental factors influencing the prevention of SHCs in people with SCI were identified. In Chapter Ten, solutions from therapists and people with SCI were explored in order to improve the prevention of SHCs. In Chapter Eleven, the services and interventions needed to prevent SHCs throughout the life span of people with SCI were identified.

SECTION A

This part of the discussion will reflect on the study findings, summarising the main findings followed by an in-depth discussion of the results.

12.1. Summary of results

- The prevalence of SHCs is very high (93.7%) among patients with SCI. The majority of the patients (78%) had two or more SHCs. The significant predictors of multiple SHCs (having more than three SHCs) were: the duration of SCI, the site of injury in the upper and lower thoracic spine, unemployment, receipt of a social grant and compensation from the Road Accident Fund.
- Secondary health conditions have a predominantly negative impact on people with SCI's health and well-being. Secondary health conditions limit function, restrict participation in life situations, disrupt life and affect mental health.
- People with SCI use various strategies to prevent SHCs: medication, assistive devices, healthy lifestyle practice, self-management, resilience coping strategies, and therapeutic approaches. Regardless of the above, the experience of preventing SHCs is challenging, and some of the methods are ineffective, leading to feelings of hopelessness.
- The range of SHCs prevention strategies reported in the literature includes health promotion, rehabilitation, policy, pharmaceutical use and surgery. There is an overlap between prevention strategies, suggesting that they are not mutually exclusive, but they can be combined to achieve better health outcomes.
- Personal factors influencing the prevention of SHCs include socioeconomic status, mental well-being, knowledge about SHCs and their prevention, lifestyle choices, practising prevention care, and owning an appropriate assistive device. Lastly, patient activation in taking ownership of personal care, self-management, problem-solving, resilience and self-awareness, and help-seeking behaviour enhanced the prevention of SHCs.

- Environmental factors influencing the prevention of SHCs include the role of social support, inaccessibility of built structures and the transport system, inefficiency of the healthcare system in terms of a lack of resources, health professionals' lack of knowledge about SHCs and inadequate patient care approach.
- The main theme related to the proposed solutions by therapists and people with SCI to improve the prevention of SHCs was access to adequate health care. The categories related to this care were: the availability of health services, patient-centred care, strengthening rehabilitation care, access to resources and training health professionals.
- The services and interventions to enhance the prevention of SHCs include patient-centred care, access to resources, promotion of health, and skilled healthcare workers.

12.2. Prevalence and predictors of secondary health conditions and predictors

Table 12:1: Prevalence and predictors of SHCs key findings

Key findings
• The prevalence of SHCs among patients with SCI was very high (93.7%). • The majority of the patients (78%) had two or more SHCs. • The significant predictors for multiple SHCs were: duration of SCI, site of injury (upper and lower thoracic spine), unemployment, receipts of social grant and compensation from the Road Accident Fund.

12.2.1. Prevalence of secondary health conditions

The prevalence of SHCs and the associated risk factors were identified (Chapter 4). This study is one of the few local studies to report the prevalence of SHCs in people with SCI (Joseph and Wikmar, 2016, Madasa et al., 2020). From the analysis, the prevalence of SHCs was very high (93.7%) but within the prevalence range reported in other studies on SCI and SHCs (Adriaansen et al., 2016, Madasa et al., 2020, Wannapakhe et al., 2015). One study reported even higher prevalence rates of 98.5% in people who have lived ten years or more with SCI in the Netherlands (Adriaansen et al., 2016). In Thailand, the prevalence rate was 100% in people with SCI six months after discharge from a rehabilitation hospital (Wannapakhe et al., 2015). When the results of this

study were compared with other local studies completed in Cape Town, the SHCs prevalence was higher than that previously reported by Joseph and Wikmar (2016) and Madasa et al. (2020). The difference in the findings was due to the inclusion criteria, SCI duration and study design. Both Cape Town-based studies used a prospective study design but included only TSCI, and data were collected during the acute phase of recovery (Joseph and Wikmar, 2016) and four years post SCI (Madasa et al., 2020). The current study included both TSCI and NTSCI with no limit on SCI duration. The results of this study show that the extent of the SHCs in people with SCI is great, suggesting that people with SCI are struggling to prevent and manage SHCs. Appropriate prevention services and interventions are needed throughout and after the rehabilitation process to minimize the occurrence and progression of SHCs.

12.2.2. Multiple Secondary health conditions

The majority of patients with SCI in this study had multiple SHCs concurrently. The results were not surprising because the focus of care in South Africa tends to be curative, with low priority given to rehabilitation and prevention care, thus increasing the risk for SHCs in those with chronic conditions such as SCI (Morris et al., 2021, Sherry, 2014). The occurrence of multiple SHCs is common in people with SCI, adding to the difficulty of managing SHCs (Brinkhof et al., 2016, Rivers et al., 2018). Experiencing multiple SHCs concurrently can affect one's ability to independently self-manage, limit mobility and affected wellbeing (Rivers et al., 2018). Evidence indicates that experiencing multiple SHCs also limits work prospects (O'Neill and Dyson-Hudson, 2020) and productivity (Cao and Krause, 2021). Experiencing multiple SHCs may require multiple management interventions and increase hospital readmission (Mashola et al., 2019). Holistic care that recognises the whole person and the interaction between the different systems is needed (Guilcher et al., 2013). So when developing prevention guidelines for people with SCI, strategies that address multiple bodily systems and risk factors must be considered (DeJong and Groah, 2015). A good example is promoting physical activity to enhance the prevention of SHCs such as pain and depression and address health-related risk factors (Tawashy et al., 2009, Gaspar et al., 2019, Mashola et al., 2017).

12.2.3. Predictors for multiple SHCs

Spinal cord injury duration was found to be a predictor of multiple SHCs in this study. The results demonstrate that vulnerability to SHCs increases the longer people live with SCI. However, it is expected that the longer a person with a chronic condition lives with a condition, the ability to self-manage will improve. Still, "forgetfulness" (Pilusa et al., 2021a, Visser and Visagie, 2019), state of mental health (Pilusa et al., 2021a) and, in particular, the inaccessible health care system (Vergunst et al., 2017) could have influenced the prevention of SHCs for the cohort in this study.

Poor implementation of policy retard progress to improving health outcomes. The review of the Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020 found many systematic barriers that affected the implementation of the strategy. Some of the barriers were a lack of resources, poor leadership and a shortage of healthcare workers (El Kout et al., 2020). Long-term management for chronic conditions and disability is still not prioritized South African health care system, making continued discussion on living well with a chronic condition and long-term rehabilitation necessary to ensure access to appropriate services (Sherry, 2014).

Patients with a thoracic SCI lesion also had a higher risk for multiple SHCs. These findings are in line with previous research that showed that people with paraplegia particularly high thoracic lesions, had an increased risk for SHCs (Brinkhof et al., 2016, Mothabeng and Mashola, 2019)) and hospital readmission (Mashola et al., 2019). A study by Mashola et al. (2019) reported a high likelihood of readmission for patients with T1-T6 (2.6) lesions and those with paraplegia (2.3) at a private hospital in South Africa (Mashola et al., 2019). Although people with paraplegia have upper limb function and are independent in daily living and transfers, these activities can contribute to musculoskeletal SHCs due to overuse injuries. These findings highlight the importance of empowering individuals with a chronic condition such as SCI to self-manage as part of chronic care management (Poitras et al., 2018). The promotion and support for self-management as part of SCI care can be from trained peer mentors who can share their lived experiences on disability and self-management (DeJong et al., 2013, Joseph et al., 2016). Support can also be from health professionals conducting regular screening, home visits, and outreach services to reinforce health

maintenance and preventative care and identify barriers to practising prevention care (Sherry, 2014).

Other significant predictors for multiple SHCs from our results were unemployment, receipt of a social grant and compensation from the Road Accident Fund. Low socioeconomic status increases vulnerability to poor health outcomes and limits access to health care (Gordon et al., 2020, Maart and Jelsma, 2014, Pilusa et al., 2021a). Evidence indicates that although people with disabilities such as SCI have access to income from social grants in South Africa, the grants are used to support the household (Kelly, 2019), and they are not enough to cover disability-related costs (Hanass-Hancock and McKenzie, 2017, Hanass-Hancock et al., 2017). For instance, people with disabilities may need to hire costly private transport instead of public transport that is not wheelchair accessible (Hanass-Hancock et al., 2017, Maart and Jelsma, 2014). Other costs related to living with a disability include payment of a caregiver and paying for medication, assistive devices and home modification (Hanass-Hancock et al., 2017).

The Road Accident Fund is security insurance that compensates people involved in motor vehicle accidents (MVA) for loss of income, medical bills and support for the deceased dependents (Kempen, 2020). The Road Accident Fund is supposed to facilitate rehabilitation and inclusion for individuals who experience disability due to the MVA (Kaseke, 2010, Kempen, 2020). However, the delays in fund payments, fraud, and the substantial legal cost deducted from the claim often still leave claimants financially vulnerable (Kaseke, 2010).

To address economic vulnerability among people with disabilities, Hanass-Hancock et al. (2017) recommended multi-sectoral collaboration between government departments (health, education, transport, and social development). Fostering collaboration between government departments and other relevant stakeholders such as the Road Accident Fund can help develop a shared vision for promoting health and considering health in policy and planning. The multi-sectoral approach to addressing economic vulnerability highlights the importance of systems thinking perspective when addressing health challenges (Adam, 2014, Sims and Aboelata, 2019). A multi-sectoral partnership can foster learning and encourage efficient use of the limited available resources to enhance health outcomes.

Systems perspective to improving health outcomes emphasizes the importance of a whole-person approach to care, understanding the experiences of diseases and the impact on their life (Hudon et al., 2012). The following section will discuss the experiences of SHCs.

12.3. Experiences of secondary health conditions

Table 12:2: Experiences of secondary health conditions key findings

Key findings
• Secondary health conditions are enormously impactful on health and well-being. • Secondary health conditions limit function, restrict participation, affects mental health, and disrupts lives.

The lived experiences of SHCs in people with SCI were explored (Chapter 5). The narratives on SHCs were not just about the presence of SHCs, but the enormous impact SHCs had on the individuals' health and well-being. The presence of SHCs such as pain negatively affected self-care, mobility and work life. The experience of pressure sores and the restriction of managing a sore caused a significant disruption in the individuals' plans and way of life. The findings of this study agree with previous studies in that SHCs affect every health domain, limit functioning, inclusion, and productivity (Callaway et al., 2015, Fuseini et al., 2019, Van der Meer et al., 2017). Callaway et al. (2015) examined the impact of SHCs on the experiences of people with spinal cord injury in Australia and confirmed that SHCs affected occupation choice and productivity, participation in leisure activities, and affected self-care (Callaway et al.2015). These findings emphasize the importance of holistic care, focusing on the presence of SHCs and prevention thereof and exploring their impact on functioning. Also, to better understand the individuals with SCI, health professionals need to listen to patients experiences of illness, concerns, fears and validate their experiences (Hudon et al., 2012, Yorkston et al., 2010). Listening to patients is essential in building patient-professional partnerships to support prevention care (Zanini et al., 2019). Therefore health professional training needs to include soft skills such as listening, communication, relationship building, respect and a whole-person approach to care (Zanini et al., 2019, Hudon et al., 2012).

The impact of illness on mental health is often neglected. Similar to previous studies, this study found that SHCs affected mental health; the experience of pain was a source of worry, sadness, and suicidal ideation (Li et al., 2018, Fuseini et al., 2019). As previously reported, male participants in our study expressed how sexual problems affected their self-identity and relationships (Callaway et al., 2015, Fuseini et al., 2018). Study participants with bladder and bowel problems were also afraid of experiencing urinary leaks in public, restricting their participation in social events. The impact of bowel and bladder problems on mental health and consequently restricted participation in social activities was reported as common in low-middle income countries (Øderud, 2014, Fuseini et al., 2019). This finding suggests a lack of knowledge and confidence in managing bladder and bowel problems (Visser and Visagie, 2019) and points to other contextual factors influencing poor bladder and bowel management such as access to bowel and bladder training, consumables (catheters), safe drinking water, a hygienic environment and adequate toilet facilities (Øderud, 2014). The impact of SHCs on mental health needs to be explored further, given the increased risk for substance use in people with depressive symptoms (January et al., 2014). The need for collaborative care in SCI to address both physical and mental health needs is thus paramount.

Some of the participants with SCI in this study, however, valued the challenging experiences of SHCs. The surprising finding was hearing narratives of personal growth and strengthened resilience due to experiences of managing SHCs. Resilience is an essential skill in chronic care (Cal et al., 2015, Rohn et al., 2020), as it influences psychological and physical well-being (Tian and Hong, 2014), and it helps the patient engage with personal health (Hibbard and Greene, 2013). Resilience building is essential and can help individuals deal with a chronic condition such as SCI and consequent disruption linked with SHCs. Despite the challenges of SCI and SHCs, individuals with SCI have learnt to cope and derive meaning from life challenges, especially if empowered with skills to develop and nurture resilience. The findings related to experiences of SHCs stress indicate the importance of listening to the patient's narratives and experiences of illness. Understanding how the patient views illness and well-being will help identify beliefs, attitudes toward personal health, health expectations, and health maintenance factors. This understanding

provides knowledge on the barriers to preventive care and well-being which can be targeted and form the entry points for the prevention interventions.

Long-term health maintenance and disease prevention are unmet needs for people with SCI (Chang et al., 2017). The next section will discuss strategies used to prevent SHCs.

12.4. Prevention of secondary health conditions: experience and strategies used

Table 12:3: Prevention experience and strategies used by people with SCI key findings

Key findings
• Strategies used by people with SCI to prevent SHCs were reported as medication, assistive devices, healthy lifestyle practice, self-management, resilience coping strategy, and therapeutic approaches. • The experience of preventing SHCs is challenging, and some of the methods are not effective, leading to feelings of hopelessness. • The range of SHCs prevention strategies reported in literature includes health promotion, rehabilitation, medication use and surgery. The overlap between the categories suggests that prevention strategies are not mutually exclusive, but they can combine to achieve better health outcomes.

12.4.1. Prevention strategies used to prevent SHCs

Strategies used by people with SCI to prevent SHCs varied (Chapter 6). Prevention strategies included pharmaceuticals, assistive devices, a healthy lifestyle, resilience coping strategies, self-management and therapeutic approaches. Of these strategies, medication use was the most reported intervention for managing pain, bladder and bowel problems, and spasms. Medication use raises the concern of polypharmacy and misuse (Patel et al., 2017). Clark et al. (2017) found that sixty-five percent of the participants in their study used medication daily, and 17.6% misused pain medication. The other concern with medication use is side effects that can exacerbate the development of SHCs (Hagen and Rekand, 2015). Gabapentin which is used to treat neuropathic pain, has side effects of drowsiness, fatigue and oedema (Hagen and Rekand, 2015), affecting self-

management and pressure relief practice. Education on safe medication use is imperative, and non-pharmacological therapy to prevent SHCs must be explored (Clark et al., 2017, Guilcher et al., 2020).

The range of prevention strategies evident in the literature was similar to those used by the participants in this study. A scoping review found these strategies included health promotion (exercise, behaviour change strategies), rehabilitation, medication use and surgery (Chapter 7). Some of the categories overlapped, suggesting that prevention strategies can be used in combination to achieve better health outcomes (Rattray et al., 2002). The shift from a linear reductionist approach to multi-strategies should be promoted when addressing health prevention strategies (Atun, 2012). This point can be illustrated by the example of a community-based vocational rehabilitation programme used to facilitate return to work for people with SCI in Singapore (Kee et al., 2020). The community based multifaceted vocational rehabilitation programme focused on physical, psychosocial well-being, work readiness, how to use an assistive device, accessing the physical environment and transport system to facilitate return to work (Kee et al., 2020). The programme combined many strategies with intersectoral collaboration to improve functional independence, return to work and integration.

12.4.2. The experience of preventing SHCs

Despite the range of prevention strategies used in SHCs, our study participants reported that preventing SHCs was challenging. Previous studies reported that people with SCI believe SHCs are unavoidable and difficult to prevent (Chang et al., 2017, Piatt et al., 2016). A Canadian based study reported similar results and reported that preventing SHCs for people with SCI is an *"uphill battle",* shaped by multiple ecological factors (Guilcher et al., 2013). Preventing SHCs is a lifelong commitment that requires daily practice. A situation with such difficulty underscores the importance of supporting prevention care practice and regular evaluation of the prevention strategies to identify care needs and prevention care barriers (Lindberg et al., 2013).

The data in this study revealed that prevention strategies were unsuccessful in managing pain and sexual problems, and the lack of effectiveness left individuals with SCI feeling hopeless. Several

studies from different parts of the world (Brinkhof et al., 2016, Callaway et al., 2015, Li et al., 2018) have also reported difficulties in addressing sexual and pain problems. Brinkhof et al. (2016) reported that 85.5% of the participants with SCI based in Switzerland had not received any treatment for sexual problems. Similarly, Callaway et al. (2015) study on the experiences of SHCs in people with SCI in Australia reported how people with SCI felt hopeless and had given up on finding a working solution for sexual problems. Effective pain management is also challenging due to inadequate pain relief (Cardenas and Jensen, 2006). Li et al. (2018) reported on experiences of neuropathic pain in people with SCI, Taiwan. They found that people with SCI use various strategies ranging from exercise, massage, thermotherapy, distracting activities such as singing, talking to friends and spirituality (Li et al., 2018). However, none were effective in managing pain. Thus, they suggested patient-centred care, which includes understanding the patients' experience of pain and developing need-based interventions (Li et al., 2018). More emphasis should be put on patient-centred care at all levels since this creates an environment to discuss patients' challenges and identify goals and alternative coping strategies (Yorkston et al., 2010, Guilcher et al., 2020).

Many factors such as personal beliefs, attitudes, knowledge, and practice influence the SHCs prevention (Zanini et al., 2020a). The following section of the discussion presents the findings on contextual factors influencing the prevention of SHCs.

12.4.3. Contextual factors influencing the prevention of SHCs

Table 12:4: Contextual factors influencing the prevention of SHCs key findings

Key findings
• Personal factors influencing the prevention of SHCs were: socioeconomic status, mental well-being, lack of knowledge of SHCs and their prevention, lifestyle choices, behaviour pattern, patient activation and owning an appropriate assistive device. • Environmental factors that played a role were: social support, inefficient healthcare system, inaccessible built structures and transport systems.

Contextual factors influencing the prevention of SHCs were explored. The studies presented in Chapters 8 and 9 found personal (Pilusa et al., 2021a) (Chapter 8) and environmental factors (Chapter 9) influencing the successful prevention of SHCs.

12.4.4. Personal factors influencing the prevention of SHCs

The personal factors that influence the prevention of SHCs include socioeconomic status, knowledge of SHCs, compliance to prevention care, mental well-being, patient activation and owning an assistive device (Pilusa et al., 2021a) (Chapter 8). These results demonstrate how factors at an individual level shape prevention practice and health outcomes. Knowledge levels, beliefs about personal susceptibility, attitudes toward personal health can influence prevention care behaviour (Kang et al., 2017, Piatt et al., 2016). A study by Zanini et al. (2020a) identified prevention styles adopted by people with SCI to deal with the risk of developing pressure sores. They found three prevention styles: thoughtful, selective and delegator prevention styles, which were differentiated by personal behaviour, attitude, and SHCs knowledge levels (Zanini et al., 2020a). Individuals with a thoughtful prevention style were knowledgeable on SHCs, proactive and prioritised prevention care and personal health compared to those who delegated prevention care (Zanini et al., 2020a). The individuals with a delegating prevention style were passive, relied on the caregiver for care and had less SHCs knowledge. Understanding factors at an individual level that can influence the prevention of SHCs can inform prevention strategies. The emergence of cognitive behavioural therapy would need to be explored as the trend towards psychologically informed interventions is growing (Mehta et al., 2020). Clinicians can incorporate cognitive behaviour change models such as the health belief model to identify barriers and facilitators to prevention care (King et al., 2008, Ma et al., 2020).

This section confirmed findings that socioeconomic factors are influential to SHCs outcomes. Participants with SCI who were employed or had financial backing could afford to buy specialised assistive devices such as aerated cushions to prevent SHCs such as the occurrence of pressure sores. These findings suggest that people with SCI with low socioeconomic status have greater challenges preventing SHCs, especially since, as indicated above, they are vulnerable to multiple SHCs (confirmed in Chapter 4) (Gordon et al., 2020, Pilusa et al., 2021a). A study based in

Bangladesh highlighted the importance of addressing poverty when developing SHC prevention programmes (Hossain et al., 2020, Liu et al., 2020). Using a randomised controlled community-based intervention for patients with SCI discharged from the hospital, the study assessed morbidity, mortality and SHCs occurrence (Hossain et al., 2020). The intervention included education on SHCs, self-help strategies and follow-up care (home visits supplemented by telephone calls) (Hossain et al., 2020). They found no significant difference between the intervention and the control groups. The cited possible reasons for the intervention's failure were the presence of other mitigating factors such as poverty, poor nutrition and poor access to health care facilities (Hossain et al., 2020, Liu et al., 2020).

Socioeconomic status can be improved by ensuring access to employment, income-generating business opportunities, skills development, and adequate social security. A study based in India evaluated the effects of livelihoods on the well-being of people with disabilities (Mauro et al., 2014). They found that CBR interventions improved access to social security and paid employment (Mauro et al., 2014). High-income countries have adopted a government-funded independent living model that supports people with disabilities to gain independence and integrate into the community (White et al., 2010). Independent living centres are run by people with disabilities where resources, skills training, peer support is offered. They also advocate for the needs of people with disabilities. Low to middle-income countries can learn from this initiative and use the available human capacity and community-based structures to enhance care and improve livelihoods.

Furthermore, these approaches link to environmental factors identified in this study that influence the prevention of SHCs in people with SCI. The following section will discuss environmental factors influencing the prevention of SHCs.

12.4.5. Environmental factors influencing the prevention of SHCs

The environmental factors influencing the prevention of SHCs included social support, inaccessible built structures and transport systems and inefficiencies in the health care system (Chapter 9). As reported in previous studies, social support from family and peers enhance self-management and prevention care (Guilcher et al., 2013, Munce et al., 2014b). Family can play a significant role in helping a person with SCI cope with daily activities and provide emotional support (Guilcher et al., 2013, Munce et al., 2014b). While peer mentors play an essential role in sharing their SCI experience, providing a care information source (Joseph et al., 2016). Given the challenges in accessing rehabilitation services in South Africa (Maart and Jelsma, 2014), working with the patients family and training peer mentors to support people with SCI in the communities can be a viable means to ensure continuity of care and patient support (Joseph et al., 2016, Sherry, 2014). Policymakers need to explore ways of integrating peer mentors in health system service delivery. This initiative can offer employment and community-based support for people with SCI.

Furthermore, inaccessible transport and built structures were found to be common barriers limiting the prevention of SHCs. For instance, lack of disability-friendly housing, living in a shack and sharing a communal toilet made bowel and bladder management stressful. Inaccessible built structures and transport systems are barriers to inclusion in the labour market, leisure activities and health care services (Vergunst et al., 2017, Hammel et al., 2015, Maart and Jelsma, 2014). Policymakers need to promote universal design in the built and transport system as a public good. A multi-sectoral partnership between the relevant stakeholders can ensure safe transport and built structures needed to improve access for people with disabilities. The feasibility of implementing subsidised transport for people with disabilities must be explored, such as the dial a ride initiative in Cape Town (subsidized transport for people with disabilities), which can be adopted in Gauteng province. Other initiatives to improve access to public transport include negotiating with the taxi and Uber industry to have reliable taxis for people with disabilities subsidised by the government (Sherry, 2014). The health care system needs to partner with non-profit organizations for people with disabilities and engage the housing department on the reconstruction and development programme that should be providing disability-friendly houses (Sobantu et al., 2019). The need to

encourage multi-sectoral partnerships to address the social determinants of health that influence health outcomes as described above is once again confirmed.

The health system's primary goal is to optimise health, but we found many health system barriers to SHCs prevention. The health system barriers included a shortage of medical resources, health professionals' lack of knowledge on the prevention of SHCs, and a patient care approach that is not holistic and empowering. Our findings are in line with previous studies on SCI based in high-income (Canada) (Guilcher et al., 2013) and low-income African countries (Ghana and Zimbabwe) (Fuseini et al., 2018, Øderud, 2014). The findings agree that the health system context, the focus of care, processes, practices and health care providers play a pivotal role in influencing disability and health outcomes. Dejong and Groah recommended reorganising SCI service delivery (DeJong and Groah, 2015). Their argument is that for change to occur in SCI and SHCs outcomes, explicitly reducing SCI rehospitalisation, health providers, SCI scholars, and policymakers collectively must do things differently to *"provide the right care at the right time in the right place by the right provider"* (DeJong and Groah, 2015). Therefore patient-centred service delivery models that are responsive to the needs of people with SCI are needed. These service delivery models must be multifaceted, addressing the health system organization, health providers, and users.

Contextual factors influencing the prevention of SHCs are multiple and complex and thus must be understood and catered for when developing service delivery models. The evidence presented above points to the importance of applying systems thinking approach to understand and solve health problems (Atun, 2012). The application of systems thinking has been recommended as a possible solution to strengthen the health system, improve health outcomes and inform policy and research (Adam, 2014, Swanson et al., 2012, World Health Organization, 2009). Systems thinking is a way of thinking or an approach to addressing health problems and developing practical solutions (Adam, 2014). Systems thinking views organisations as a system composed of sub-components, processes, events and behaviours which interact at different levels for a specific purpose (MacLachlan and Scherer, 2018). In our study, the results show that are multiple factors at a personal and environmental level influencing the prevention of care, but more research applying systems thinking tools (concept mapping, social network analysis, system dynamics

modelling) is needed to explore the patterns, interlinkages between the identified influencing factors and to model possible solutions (Swanson et al., 2012).

Applying systems thinking lens when developing models of care to enhance the prevention of SHCs is crucial. For instance, to strengthen the prevention of SHCs in people with SCI, we need strategies that will address the persons with SCI, their families, health providers, health care organization, and other departments that can support health such as education, transport, social development and the Road Accident Fund Agency.

The following sections will discuss the proposed solutions to improve the prevention of SHCs from the various stakeholders.

12.5. The proposed solutions to improve the prevention of SHCs

Table 12:5: Proposed solutions to improve the prevention of SHCs

Key findings
• Multi-faceted strategies were proposed to improve the prevention of SHCs. • Proposed services and interventions included: access to adequate care, patient-centred care, strengthen rehabilitation care services, access to resources, health promotion and skilled health professionals.

12.5.1. Proposed service and interventions to improve the prevention of SHCs

Solutions to improve the prevention of SHCs among people with spinal cord injury from different stakeholders, including the people with spinal cord injury and the health care providers, were explored (Chapter 10 and 11). The proposed solutions include access to adequate care that is continuous and available, implementation of patient-centred care, access to resources, health promotion, skilled healthcare workers and strengthening rehabilitation services (Chapter 10 and 11).

Patient-centred care

From the proposed solutions, the stakeholders agree that to support the prevention of SHCs, SCI care needs to be patient-centred. Patient-centred care is an empowering approach to care that encourages self-management and sees the patient as central to care (Stewart, 2001). Analysis of findings from this study indicates that people with SCI want to be involved in care, listened to, empowered to self-manage, and supported throughout the journey of care (Chapter 9). These findings are similar to elements of patient-centred care in chronic disease management and multi-morbidity (Hudon et al., 2012, Poitras et al., 2018). Patient-centred care elements for chronic disease management include holistic care, listening and validating the patients' illness experience, partnering with the patient, lifelong perspective to care and guiding the patient to navigate the health system (Hudon et al., 2012). To facilitate patient-centred care practice, training of healthcare workers and organisational support is necessary (Poitras et al., 2018, Jardien-Baboo et al., 2016). Health professional training (undergraduate and continuous in-service training) must ensure that topics on chronic care, patient-centred care, specific SCI needs and prevention care are included in the curriculum.

Organizational support to promote patient-centred care includes encouraging health professional collaborative care and multi-sectoral collaboration with patients, communities and other relevant sectors (Swanson et al., 2012, Poitras et al., 2018). Secondly, the health system policymakers need to continuously articulate and emphasize the national 2030 vision "Promote health" to all the stakeholders (South Africa National Planning Commission, 2012). Promoting health should be entrenched in the health professional curricula. Also, regular dialogues with the health professionals and relevant stakeholders is recommended to foster networks and address social determinants of health. To bring about health systems organizational changes and foster patient-centred care, transformational leadership that is supportive and encourages learning at all levels of care is required (Jardien-Baboo et al., 2016, Swanson et al., 2012).

Access to adequate care

Access to health is a neglected right for people with disabilities in South Africa (Maart and Jelsma, 2014, Vergunst et al., 2017). Levesque et al. (2013) define access to health care as an interaction between the users' perception of needs, ability to seek, reach, pay and engage with healthcare services and the health care being available, accomodating, approachable, acceptable, appropriate and affordable. The participants emphasised the importance of access to this type of adequate care in the prevention of SHCs. Care must be need-based, available where persons with SCI live and continuous through follow up care, home visit and outreach services. Current evidence shows poor access to health care in South Africa due to long distances, lack of drugs, and the high cost of transport (Hanass-Hancock et al., 2017, Vergunst et al., 2017, Maart and Jelsma, 2014). Barriers to access are multi-faceted, thus need multi-sectoral partnership to address access barriers. For example, in this study, it was found that the transport system was not disability friendly, and it was costly to hire private transport to access health care. The health system needs to raise awareness of these barriers experienced by people with disabilities and partner with the relevant stakeholders (department of transport, public and private transport systems) to identify solutions to address the barriers. Multi-sectoral partnerships between government departments: health, social development, and public works transport systems, are necessary to improve care access (Sherry, 2014).

Other strategies to improve access to care include prioritizing long-term care and reorganizing service delivery. To improve access to care for people with disabilities, Sherry (2014) recommended prioritising chronic care at the primary health level in her review on disability and rehabilitation in South Africa (Sherry, 2014). Prioritizing chronic care at a primary level can address some of the access barriers (transport cost), foster secondary, tertiary prevention of diseases, and facilitate planning for the health needs of people with long-term conditions such as SCI. A less explored strategy to improve access to health care in South Africa is telehealth (DeJong and Groah, 2015, Morris et al., 2021). Telehealth can facilitate patient and family education on SHCs and preventive care and offer virtual support (Mwaura et al., 2020, Haricharan et al., 2017). However, barriers such as electricity cuts, data costs, connectivity problems must be addressed

(Mwaura et al., 2020). Future research on the effectiveness of telehealth apps and social media to support the prevention of SHCs in people with SCI is needed.

Strengthening rehabilitation care

The prevention of SHC can be enhanced through strengthening rehabilitation services. Participants in this study stressed the importance of strengthening need-based rehabilitation throughout the continuum of care by using interventions to optimise functioning and minimise disability (United Nations, 2006). Improving functioning is key to achieving well-being and health for everyone, including people with disabilities, as articulated in the Sustainable Development Goal (SDG) no.3 (Cieza, 2019, World Health Organization, 2017a). Health maintenance and disease prevention for SHCs at the secondary and tertiary levels should be part of SCI care. However, rehabilitation is not prioritised in South Africa (Ned et al., 2017, Morris et al., 2021), and since there is a shortage of rehabilitation health professionals (Tiwari et al., 2020), access to rehabilitation services and continuity is limited (Maart and Jelsma, 2014, Ned et al., 2017). Considering the increasing demand for rehabilitation due to the ageing population, non-communicable and infectious diseases, efforts to integrate rehabilitation at a primary care level must be strengthened (Cieza, 2019, Sherry, 2014). We need a shift from curative and medically oriented care to holistic care that enables individuals with chronic diseases to live well. Through the undergraduate and in-service training programme, the awareness of holistic chronic care and the value of rehabilitation can be increased.

12.6. Study limitations and strengths

Several study designs were used to address the overall PhD study aim. A retrospective study design was used to identify the prevalence of SHCs and associated risk factors (Chapter 4). The results were based on paper-based patient medical records with illegible handwriting and medical notes based on what the health care professionals prioritised. It is possible that some SHCs (mental and sexual health) were missed if not asked by the health professional or deemed important. Another challenge encountered was a lack of information on the patients educational level and the severity of the SCI (ASIA scale), which are possible risk factors for SHCs. Although impossible to track, it is likely that the patients who accessed the rehabilitation hospital still used the tertiary hospital, thus duplicating patient cases. There is a need to strengthen the health information systems to

ensure that patient information is captured, processed and utilized to better patient care and inform rehabilitation care services (Morris et al., 2020). Despite the stated limitations, this is the first study to identify the prevalence of SHCs and associated factors in people with SCI accessing a public health setting in the most populous province in the country, Gauteng province. The study was comprehensive in that it included patients with TSCI and NTSCI. Future prospective studies are recommended to track the development of SHCs and associated risk factors.

The narratives from the semi-structured interviews and focus group discussions deepened our understanding of SHCs, preventive care and factors influencing the prevention care in people with SCI. Using qualitative design helped answer many questions (why? How?) that the quantitative design could not answer (Darlaston-Jones, 2007, Scotland, 2012). However, there were limitations. We had few participants with SCI who were female. Although there are more males than females with traumatic SCI, at a ratio of 5.25:1 (Sothmann et al., 2015) and no gender difference for NTSCI (Miseer et al., 2019) in South Africa, the experiences of females may have been different, and future research should explore their views on factors influencing the prevention of SHCs.

Considering that cervical lesions are the most common lesions in South Africa, with a prevalence ranging between 29-59% (Miseer et al., 2019, Sothmann et al., 2015, Joseph et al., 2015), the study had few participants with cervical lesions. People with cervical lesions need more caregiver support in activities of daily living such as bathing, dressing, transfers and mobility. It is possible that this group might have experienced many barriers when accessing the OPD clinic Future studies can focus on SHCs prevention needs for this population, and to ensure the inclusion of the "missing groups" future research could be based in the communities to address accessibility challenges. Lastly, the researcher could have purposively recruited participants from different provinces and races to cover different experiences given the uniqueness of each province. Most of the coding process was more deductive, which does not fully align with the interpretive paradigm. As a result, it is possible that other dimensions of the experiences related to SHCs and prevention care were missed.

We had initially planned to conduct nominal group discussions with health users (people with SCI) and providers to identify services and interventions that can inform the prevention care model.

Due to the COVID-19 pandemic restrictions, we could not conduct face-to-face nominal group discussions with health care users and providers from the study setting. Thus, we replaced them with health professionals involved in community-based rehabilitation projects. Despite these limitations, the narratives from the face-to-face interviews gave us solutions to improve the prevention of SHCs.

This study also has limitations related to the terminology used "patient centred care and self - management". In this study, patient-centred care was conceptualized based on chronic care management as an empowering approach to care that focuses on the individual's needs and goals, encouraging partnership and holistic care (Hudon et al 2012). In this definition, person-centred care was implied. Person-centred care sees patients as individuals with unique needs or goals and capable of enhancing personal health, thus they must be engaged respectfully in decision making to achieve better health outcomes (Coulter and Oldham, 2016). Given that person-centred approaches are now emphasised in health care, a discourse on how components of person-centred care such as understanding patients' preferences, giving control and partnership building when managing persons with SCI in our context is necessary.

The study may seem to promote self-management putting the burden of responsibility on the person with SCI. Self-management is an empowering process of taking ownership of personal wellbeing by understanding the illness and its impact, identifying resources to help manage the condition, adopting health-promoting behaviours, and adapting to the illness (Grady and Gough, 2014). Self- responsibility could be overwhelming if not framed within a broader supportive framework from the caregivers and the continual support from the health care providers. In addition, promoting self-management is central to chronic care models where an individual is considered capable of contributing to personal health and well-being.

Adopting transformative approaches such as the participatory action research would have been a more suitable study design to engage people with SCI and contribute to the development and articulation of the prevention care model. The whole process would have allowed a deeper

reflection on the problems related to SHCs prevention, prevention strategies that are working or not working and further development and implementation of the solutions. Participatory action research could have given us a better understanding of the current prevention practice and what works better to ensure the inclusion of the most effective interventions in the model of care.

Despite the study limitation stated above, this is the first study to give the people with SCI, caregivers and service providers a voice related to their experiences on SHCs, prevention care and solutions in South Africa.

12.7. Conclusion

In this chapter, we discussed the study findings against the available evidence in the literature. Secondary health conditions are prevalent among people with SCI, and they affect functioning and wellbeing. People with SCI need support throughout the journey of care to prevent SHCs from occurring and minimise their impact on productivity and inclusion. A patient-centred service delivery model that improves access to adequate healthcare is needed to support prevention care for SHCs. To achieve the national health vision 2030 "promote health" (South Africa National Planning Commission, 2012) and the global Sustainable Development Goal no. 3 "good health and wellbeing"(World Health Organization, 2017a), the focus of care for people with chronic conditions such as SCI needs to change. The focus of care needs to be oriented more toward health maintenance and prevention of diseases to minimize further disability, increased readmission rates, health costs, and worsening health disparities. The health systems cannot change poor health outcomes alone. Multi-sectoral partnerships with the transport systems, social development and housing departments, and community-based organizations are needed to address systemic barriers to improved health outcomes for people with SCI.

In the following chapter, the proposed prevention model of care for SHCs will be presented with an outline of the study implications.

13. CHAPTER THIRTEEN: CONCLUSION

This study aimed to establish factors influencing the prevention of SHCs among people with SCI in the Tshwane metropolitan area to inform the development of a prevention care model for SHCs. Data were collected by retrospective record review, in-depth interviews of patients' caregivers and therapists, and a focus group discussion. In this chapter, the model of care is presented, and the implications of the study are outlined.

13.1. Key findings

The key findings of this study are that:

1) There is a high prevalence of SHCs, and most patients experience multiple SHCs. The predictors of multiple SHCs included SCI duration, thoracic lesion and socioeconomic factors.

2) Exploring how people with SCI experience SHCs revealed that SHCs significantly impact health and well-being. Secondary health conditions limit functioning, affect mental health and disrupt everyday life.

3) Although people with SCI use various strategies to prevent SHCs, prevention remains a challenge.

4) Prevention of SHCs is influenced by personal and environmental factors. The personal factors include socioeconomic status, mental well-being, lack of knowledge on SHCs and prevention, lifestyle choices, behaviour pattern, patient activation and owning appropriate assistive devices. The environmental factors include social support, inefficient healthcare system, inaccessible built structures and transport system.

5) The services and interventions that can improve the prevention of SHCs include patient-centred care, access to adequate health care, promoting health, access to resources, strengthening rehabilitation care and skilled health professionals.

The results from the eight studies (Chapter 4-11) informed the development of the patient-centred prevention care model presented in Figure 13.1.

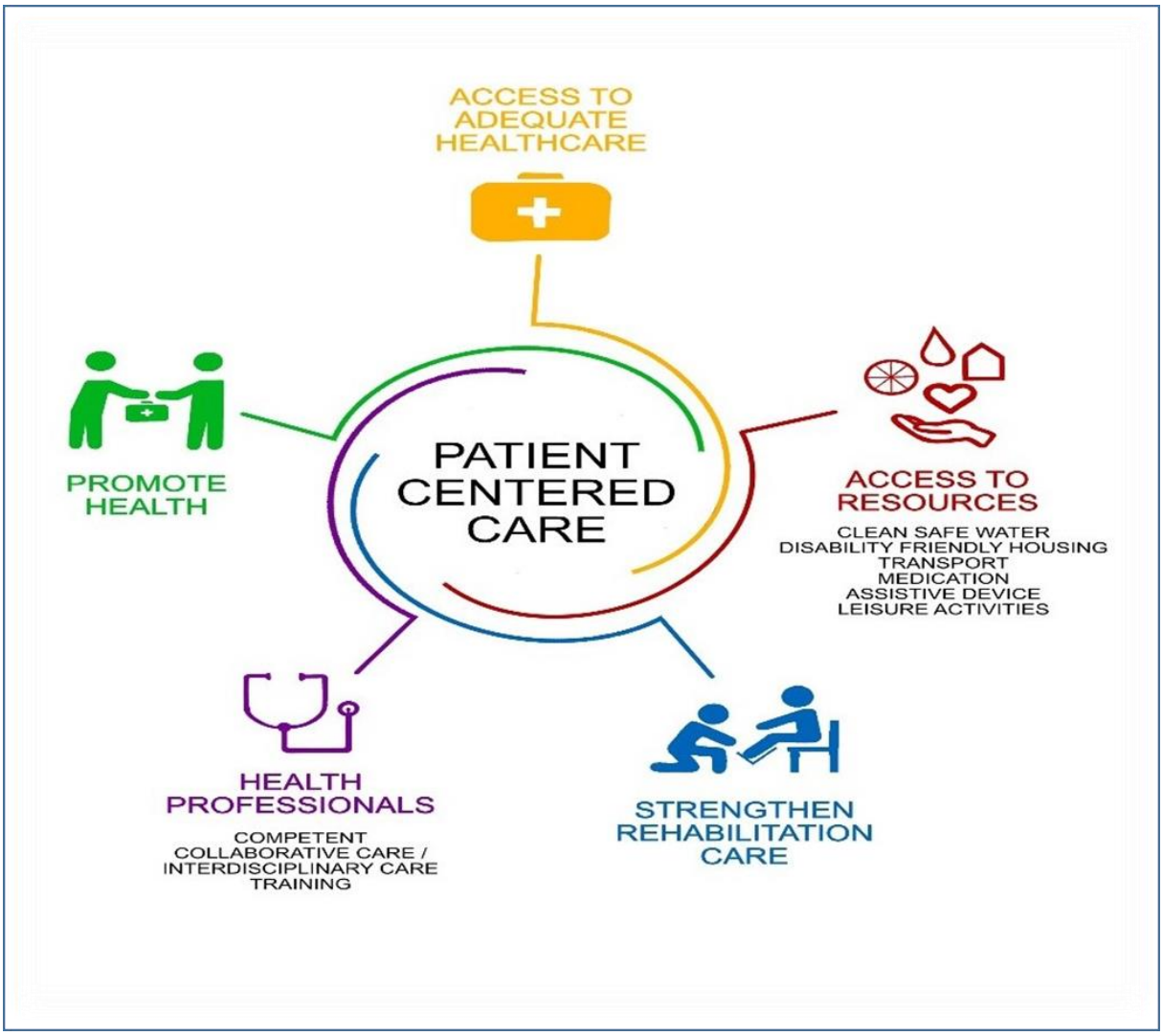


Figure 13:1: Patient-centred prevention care model for secondary health conditions

The elements of the patient-centred prevention care model will be discussed briefly in the following section.

13.1.1. Patient-centred care

The study on SHCs and prevention care experiences revealed how SHCs affect different dimensions of health. Mental health effects included feelings of sadness, fear, worry about their identity and relationships. There was hopelessness because some of the strategies were ineffective. These findings highlight a need for health professionals to practice patient centred care when managing people with SCI. When managing chronic conditions, the patient-centred care approach

stresses the importance of complementing disease objective history with the patient's illness experience (Hudon et al., 2012). To better understand the patients' situation, listening to their illness experience, fears, goals, and expectations is important (Hudon et al., 2012). Patient-centred care promotes a biopsychosocial approach to health (Tramonti et al., 2020) and a whole-person approach when managing a chronic condition (Hudon et al., 2012). Patient-centred care sees the patient as central to care, capable of enhancing personal health and part of the health-promoting team (Pelzang, 2010).

13.1.2. Access to adequate healthcare

Environmental factors influencing the prevention of SHCs included barriers to accessing health care such as inaccessible built structures, a transport system that is not wheelchair friendly and an inefficient health care system. The modified Network Episode Model emphasises the health care system's role, policies and environment in shaping prevention care for SHCs in people with SCI (Guilcher et al., 2013). Our study findings point to the need to improve access to health care to ensure that services are available where people live and are appropriate for people with SCI (Levesque et al., 2013).

13.1.3. Promote health

Data from the study that looked at personal factors influencing the prevention of SHCs, found that the lack of knowledge on SHCs, non-adherence to preventive care, and lifestyle choices influenced the prevention of SHCs. Health literacy, a supportive environment, and governance are key focus areas to achieving Sustainable Developmental Goal no. 3. "Ensure healthy lives and promote well-being for all ages" (World Health Organization, 2017b). Raising awareness on SHCs, healthy lifestyle, and empowering people with SCI to self-manage is vital in chronic care models (Barr et al., 2003) and patient-centred care approaches (Poitras et al., 2018).

13.1.4. Strengthening of rehabilitation

In the study on the prevalence of SHCs, we found a very high SHCs prevalence and the predictors for experiencing multiple SHCs were SCI duration, thoracic lesions and socioeconomic factors. This finding points to the need for rehabilitation throughout the lifespan. Rehabilitation includes optimising functioning, minimising disability, and promoting integration into society (World Health Organization, 2011a). Access to rehabilitation services in the community is needed to support the transition from hospital to home and offer life-long rehabilitation maintenance care to help people with SCI live well with chronic conditions. A key aspect of rehabilitation is to facilitate community reintegration and return to work. Interventions can include creating partnerships with community-based organizations to offer skills training, peer support, advocacy for systemic changes to facilitate independent living, access to needed resources and inclusion. This approach is supported by the independent living models (White et al., 2010) and community-based rehabilitation philosophy (Kee et al., 2020, World Health Organization, 2004a).

13.1.5. Access to resources

From the analysis of the study on environmental factors influencing prevention of SHCs, inaccessible transport, built structure and transport system, and shortage of assistive devices and medicines were barriers to prevention of SHCs. To this effect, access to resources that will support living well with a chronic condition is crucial. Access to the essential resource will assist in addressing social inequities in South Africa (Statistics South Africa, 2019).

13.1.6. Skilled health professionals

Prepared and proactive health professionals are essential to chronic care management (Barr et al., 2003) and render patient-centred care (Pelzang, 2010). The study on environmental factors influencing the prevention of SHCs highlighted the lack of knowledge on SHCs and prevention care among healthcare workers. Training healthcare workers on disability, disability-related needs, SHCs and the importance of preventive care is key to enhancing patient-centred care (Poitras et al., 2018).

The current study adds to the body of knowledge on SCI care, and future research can build on the findings of this study.

13.2. Recommended future research

- Future studies should use transformative research methodologies (community-based participatory action research to identify problems affecting people with SCI and solutions collectively
- The proposed prevention care model needs to be validated. Systems thinking tools (concept mapping, social network analysis, and system dynamics modelling) can be used to model the proposed solutions and to explore the patterns, interlinkages between the identified influencing factors.
- Future research should include telemedicine interventions to assess the effectiveness of telemedicine in improving health outcomes and supporting self-management for people with SCI.
- In the absence of a national disability data and surveillance programme, there is a need for prospective studies to track patients' health outcomes, unmet needs, and care trajectories. Information on unmet needs can inform planning and rehabilitation service delivery.
- Future research to proposed changes in the Rimmers' model is recommended

13.3. Proposed changes to Rimmer's conceptual model

We used Rimmer's conceptual model on onset, course, and secondary conditions outcomes in people with disabilities to conceptualizing key concepts in this study (Rimmer et al., 2011). The analysis of our findings underpinned the adaptation of Rimmers's conceptual model to align with SCI care needs. Figure 13.2 illustrates both Rimmers' model (in the left column) and the proposed prevention models for SHCs (in the right column of the diagram marked A). The proposed key changes to the Rimmers' model include the following concepts/elements: patient-centred care, access to adequate health care, promote health, strengthen rehabilitation care, skilled health professionals and access to resources. These proposed changes require future research.

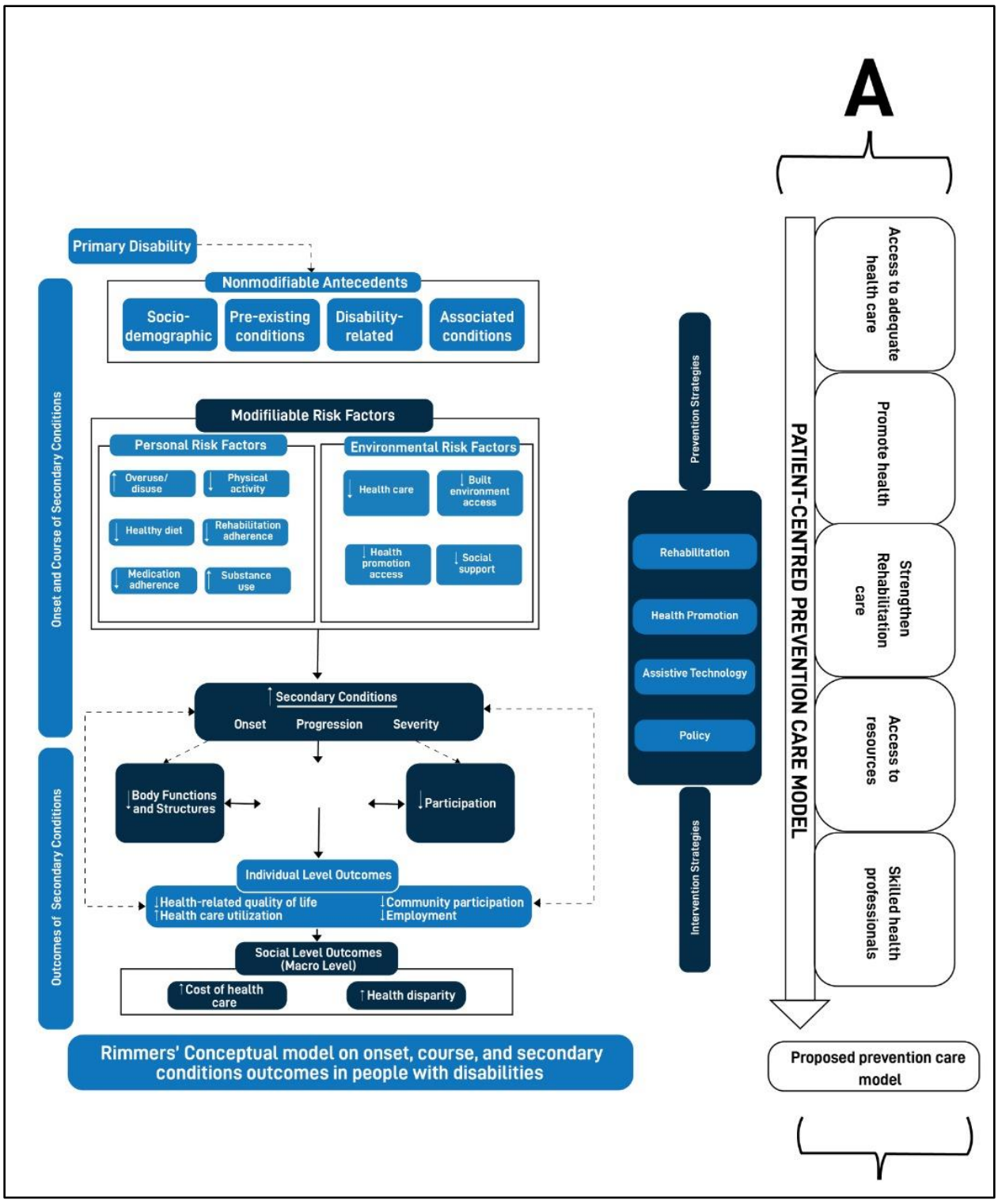


Figure 13:2: Conceptual model on onset, course, and secondary conditions outcomes in people with disabilities (Rimmer et al., 2011)

13.3.1. The Implications arising from the study findings

Practice

It is well established that people with SCI are prone to developing SHCs, so the focus of care needs to shift from solely curative and reactive care practice to be more proactive and preventative focused. Practical strategies that clinicians can implement include:

Patient-centred care

Health professionals are encouraged to incorporate aspects of the patient-centred care approach when managing people with SCI. Health professionals need to listen and validate experiences of illness. Care needs to be holistic, considering contextual factors that influence health. People with SCI must be involved in decision making and planning regarding their health. Interprofessional collaboration must be strengthened to provide holistic care at all levels of care. Interprofessional, collaboration can be introduced during undergraduate training through interprofessional education training and projects to cultivate the culture of working together. Secondly, interprofessional collaboration can be strengthened through research activities that include different stakeholders to enhance patient care.

Health education

People with SCI need health education on SCI, SHCs, prevention strategies and available health-promoting services. Health professionals need to ensure people with SCI understand what SHCs are, risk factors for SHCs, how to minimise their occurrence and, if they occur, how to manage them to prevent further complications. The timing and methods used in education must consider individual needs and abilities. In addition, skills in self-management and resilience must be developed and supported throughout the rehabilitation process.

Support system

Follow-up care post-discharge is recommended to support prevention care. Follow up care can be done through home visits and outreach clinic services to reinforce health education and health maintenance. Support can also be from trained peer mentors. We recommend training and employing peer mentors with SCI in the health system. The peer mentor can work with the

clinicians to educate on SHCs, share experiences, and guide newly injured individuals to live well with the disability.

Screening

We recommend screening for SHCs and risk factors throughout the rehabilitation process: acute care, inpatient rehabilitation and post-discharge during the clinic and home visits. During acute and inpatient rehabilitation, the purpose of screening will be to identify at-risk individuals who can be listed for targeted interventions, follow-up care, and referral. Health screening will help identify SHCs early during clinic and home visits and treat them before becoming worse.

13.3.2. Education of healthcare workers

We recommended inter-professional courses in undergraduate and in-service learning programmes to improve health professionals' competence in SCI and SHCs, prevention care, and patient-centred care.

The courses can include:

- Disability and chronic care: the course can cover different disabilities, health needs, and the importance of health maintenance in chronic care, referral pathways, and available service and how to live well with a chronic condition (health maintenance and preventative care).
- Patient-centred care in SCI and chronic condition management programme can include listening, communication, negotiating and relationship building skills.

13.3.3. Policy

We recommend context-based prevention interventions that consider the socioeconomic status of people with disabilities. Multi-sectoral partnerships between government departments (social development, labour, housing, transport) and community-based non-profit organisations are needed to address systemic barriers to employment for people with disabilities and to create opportunities in developmental programmes such as the Expanded Public Works Programme, Sector Education Training Authorities.

The health system needs to partner with the Road Accident Fund (RAF) in improving health outcomes for motor vehicle accident victims. For example, the rehabilitation hospitals can form a

research committee in partnership with RAF where gaps and opportunities are identified to enhance health outcomes for motor vehicle accident victims with a disability.

Universal accessibility of built structures and the transport system must be promoted as a public good. Respective government departments (public works, housing, transport) must enforce building regulations for all new infrastructure development and change public transport vehicle specifications to make them accessible for wheelchair users. Such initiatives could help implement the United Nations Convention on the Rights of Persons with disabilities Article 9 on universal access and the Sustainable Development Goal 11 on the inclusive and accessible environment.

The lack of a disability database hampers planning for rehabilitation care. To ensure the rights of people with disabilities are achieved, we need to mainstream disability and rehabilitation care at all levels of care. A policy brief and stakeholder engagement activities can be used to bring the study's findings to the attention of the Directorate for Oral Health and Therapeutic Services and the Allied service providers.

13.4. Personal reflection

I have learnt that it is not just the presence of SHCs that affects people with SCI, but the impact it has on their health and wellbeing**.** People with SCI want to be listened to, so we can understand their experiences of illness and their needs. Patients play a critical role in enhancing personal care. They are central to care. They are not passive receipts of care. Therefore, we need to see them as capable of self-managing if equipped and supported.

Although I knew that contextual factors influence health, hearing the specific barriers and facilitators to SHCs prevention helped me understand the complexities around prevention care and the problems faced by people with SCI, caregivers, and service providers. It is not just one problem. The factors are many and layered, requiring many departments to work together to enhance health. However, the different departments work in silos and health is not prioritized in decision-making. As a researcher, lecturer and health professional, I am left with more questions to reflect on. How do we break the practice of working in silos? How do we work together for the common good? What is my role in the change process? My approach to future research needs to

engage the different stakeholders differently. Not in silos, collectively identifying problems and solutions to improve health outcomes for people with disabilities. It would have been better to use transformative and empowering approaches to unpack the problems and collectively design the model. This approach would have helped lay a better foundation for implementing the solutions to improve prevention care.

13.5. Conclusion

People with SCI are vulnerable to preventable SHCs throughout their lifespan affecting health outcomes, independence and inclusion in the community. Prevention care for SHCs is challenging, and for some individuals with SCI, it does not work, leaving them feeling hopeless. There is a need for a paradigm shift in viewing health for people with chronic conditions such as SCI. The context where people live, work, play and access care shapes the experience of disability and health. To live well with a chronic condition such as SCI, our approach to care needs to change from curative and reactive care to a proactive patient-centred care approach. People with SCI need to be empowered to prevent SHCs and be supported in their journey of care related to the prevention of SHCs. To make long-lasting changes in improving health outcomes for people with SCI, we need a new way of thinking and practising care. Systems perspective to care is needed. We need to move away from working in silos and implementing isolated interventions to a broader approach with multisectoral collaboration to enhance and protect health for people with chronic conditions such as SCI.

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APPENDIX A: ETHICS CLEARANCE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research & Post Graduate Affairs)

TO: Ms S Pilusa
School of Therapeutic Sciences
Department of Physiotherapy
Tshwane Rehabilitation Hospital and
Steve Biko Academic Hospital

E-mail: Sonti.Pilusa@wits.ac.za

CC: Supervisor: Professors H Myezwa and J Potterton
<Hellen.Myezwa@wits.ac.za>

FROM: Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 16/01/2018

REF: *R14/49*

PROTOCOL NO: **M170938** *(This is your ethics application study reference number. Please quote this reference number in all correspondence relating to this study)*

PROJECT TITLE: *Prevention care for secondary health conditions amongst people living with spinal cord injuries in the Tshwane Metropolitan Area*

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 the Government funding of the University.

MSWorks2000/Iain0007/Clearscan.wps

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R14/49 Ms S Pilusa

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M170938

NAME: (Principal Investigator)	Ms S Pilusa
DEPARTMENT:	School of Therapeutic Sciences Department of Physiotherapy Tshwane Rehabilitation Hospital and Steve Biko Academic Hospital
PROJECT TITLE:	Prevention care for secondary health conditions amongst people living with spinal cord injuries in the Tshwane Metropolitan Area
DATE CONSIDERED:	29/09/2017
DECISION:	Approved unconditionally
CONDITIONS:	Update to Clearance Certificate issued on 11/12/2017
SUPERVISOR:	Professors H Myezwa and J Potterton
APPROVED BY:	CB Penny Professor CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	16 /01/2018

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

DECLARATION OF INVESTIGATORS

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

I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. in this case, the study was initially reviewed in **September** and will therefore be due in the month of **September** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

2018/01/16
Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

14 November 2018

Sonti Pilusa
Physiotherapy

Sent by email to: sonti.pilusa@wits.ac.za

Dear Mrs Pilusa

Re: **Protocol Ref No: M170938**
Protocol Title: Prevention care for secondary health conditions among people living with Spinal Cord Injuries in the Tshwane Metropolitan Area.
Principal Investigator: Sonti Pilusa
Protocol Amendment: Extension of review period

This letter serves to confirm that the Chairperson of the Human Research Ethics Committee (Medical) has approved the amendment for the above-mentioned protocol, as detailed in your letter, dated 18 October 2018.

The following documents were received:

- Summary Letter
- Protocol

Thank you for keeping us informed and updated.

UNIVERSITY OF THE WITWATERSRAND
OFFICE OF THE DEPUTY VICE CHANCELLOR RESEARCH
14 NOV 2018
RESEARCH OFFICE HREC (Medical)
JOHANNESBURG

Yours Sincerely,

.....
Mr Joshua Ndlangamandla
Administrative Officer
Human Research Ethics Committee (Medical)

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.
- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 03/14/2020.

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee

19/03/2018

Approval Certificate
New Application

Ethics Reference No: 36/2018

Title: Prevention care for secondary health conditions among people living with spinal cord injuries in the Tshwane Metropolitan area

Dear Sonti Pilusa

The **New Application** as supported by documents specified in your cover letter dated 21/02/2018 for your research received on the 13/03/2018, was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 19/03/2018.

Please note the following about your ethics approval:
- Ethics Approval is valid for 2 years
- Please remember to use your protocol number (**36/2018**) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

Ethics approval is subject to the following:
- The ethics approval is conditional on the receipt of **6 monthly written Progress Reports**, and
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

*** Kindly collect your original signed approval certificate from our offices, Faculty of Health Sciences, Research Ethics Committee, Tswelopele Building, Level 4-60*

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

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

012 356 3084 deepeka.behari@up.ac.za / fhsethics@up.ac.za http://www.up.ac.za/healthethics
Private Bag X323, Arcadia, 0007 - Tswelopele Building, Level 4, Room 60 / 61, 31 Bophelo Road, Gezina, Pretoria

APPENDIX B: PERMISSION LETTERS

Permission to access Records / Files / Data base at Steve Biko Academic Hospital

TO:
The [CEO] Chief Executive Officer of Steve Biko Academic Hospital

Re: Permission to do research at Steve Biko Academic Hospital

TITLE OF STUDY: Prevention care for secondary health conditions among people living with spinal cord injuries in the Tshwane Metropolitan area.

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

I am a student at the Department of Physiotherapy at the University of the Witwatersrand. I herewith request permission to conduct a study on the above topic on the hospital grounds. This study involves access to patient records.

The researchers request access to the following information: clinical files, record books and data bases.

We intend to publish the findings of the study in a professional journal and/ or to present them at professional meetings like symposia, congresses, or other meetings of such a nature.

We intend to protect the personal identity of the patients by assigning each individual a random code number.

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

Yours sincerely

Print Name SONTI PILUSA Signature: _____
Principal Investigator

Permission to do the research study at this hospital / clinic and to access the information as requested, is hereby approved, on condition that there will be no cost to the hospital.

Title and name of Chief Executive Officer: Dr SS Mangwane

Name of hospital / clinic: Steve Biko Academic Hospital

Signature: _____ Date: 2018/01/10

GAUTENG PROVINSIALE REGERING
DEPT VAN GESONDHEID
STEVE BIKO AKADEMIESE HOSPITAAL
STEVE BIKO ACADEMIC HOSPITAL
2018 -01- 10
PRIVAATSAK/PRIVATE BAG X160
PRETORIA 0001
GAUTENG PROVINCIAL GOVERNMENT
DEPT OF HEALTH

GAUTENG PROVINCE

REPUBLIC OF SOUTH AFRICA

Annexure 1

Declaration of intent from the clinic manager or hospital CEO

I give preliminary permission (name of researcher) to do his or her SONTI PILUSA

research on (research topic) in PREVENTION CARE FOR SECONDARY HEALTH CONDITIONS AMONG PEOPLE LIVING WITH SPINAL CORD INJURIES IN THE TSHWANE METROPOLITAN AREA

_____ (name of clinic) or

_____ (name of CHC) or

Tshwane Rehabilitation Hospital (name of hospital).

I know that the final approval will be from the Tshwane Regional Research Ethics Committee and that this is only to indicate that the clinic/hospital is willing to assist.

Other comments or conditions prescribed by the clinic or CHC manager or hospital CEO:

Provisional permission is granted by Tshwane Rehabilitation Hospital pending NHRD clearance certificate & operational accomodation at time of data collection. On completion of study, the researcher will be required to present to the clinical staff of Tshwane Rehabilitation Hospital so findings & recommendations can be implemented in support of any evidence based practice

_____

Signature

~~Clinic Manager/CHC Manager~~/CEO

28/3/2018

Date

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Annexure A

Tshwane Rehabilitation Hospital

TEL: 012-3546163

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

DATE: 5 DECEMBER 2017

NAME OF RESEARCHER: SONTI PILLSA

TITLE OF RESEARCH PROJECT:
PREVENTION CARE FOR SECONDARY HEALTH CONDITIONS AMONG PEOPLE LIVING WITH SPINAL CORD INJURIES IN THE TSHWANE METROPOLITAN AREA.

OBJECTIVES OF STUDY (briefly or include a protocol): PROTOCOL ATTACHED

METHODOLOGY (briefly or include a protocol): PROTOCOL ATTACHED

CONFIDENTIALITY OF PATIENT MAINTAINED:
Each participant will be given a unique case number identifier.

COSTS TO HOSPITAL: NONE

APPROVAL BY UNIVERSITY ETHICS (attach proof): ATTACHED

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

APPLICANT SIGN: ..... **DATE:** 9 DECEMBER 2017

PRINT NAME (applicant): SONTI PILLSA **TEL NO (applicant):** 011 717 3715 083 0556190

FOR OFFICIAL PURPOSES ONLY (not to be completed by applicant)
APPROVAL OF HEAD OF DEPT:

	Comments/considerations	Signature of HOD
OPERATIONAL APPROVAL	Recommended, once approved	
NOT APPROVED OPERATIONALLY	arrangements will be done with all departments.	

DATE: 28/3/2017

CEO Tshwane Rehabilitation Hospital

APPROVED	APPROVED WITH AMMENDMENT	NOT APPROVED
	Provisional permission pending NHRD certification & operational accomodation at time of data collection. On completion of study researchers required to present findings & recommendations to clinical staff	

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Annexure C

TSHWANE REHABILITATION HOSPITAL

PLEDGE FOLLOWING COMPLETION OF RESEARCH AT TRH

I, the undersigned SONTI PILUSA,

ID number: 7507010324082

Registered for PHD

With the following Tertiary Institution UNIVERSITY OF THE WITWATERSRAND

Student Number 93 11506 K

I hereby pledge that on successful completion of my research study at Tshwane Rehabilitation Hospital, I undertake to do a formal presentation to all relevant staff and to leave a copy of my Research study including findings for future reference by the institution.

Signature of candidate Pilusa

ON THIS DAY OF 5 MONTH December 20 17

APPENDIX C: PARTICIPANTS INFORMATION SHEET AND CONSENT FORMS

PARTICIPANT'S INFORMATION & INFORMED CONSENT DOCUMENT (PEOPLE WITH SPINAL CORD INJURY)

STUDY TITLE: "Prevention care for secondary health conditions among people living with spinal cord injury in Tshwane Metropolitan area".

SPONSOR: Consortium for Advanced Research Training in Africa

Principal Investigators: SONTI PILUSA

Institution: UNIVERSITY OF THE WITWATERSRAND

DAYTIME AND AFTER HOURS TELEPHONE NUMBER(S):

Daytime numbers: 011 717 3715/ 082 0536190

Afterhours: 082053 6190

DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION: dd/mm/yr/time

Dear Patient

Dear Mr. / Mrs. ..... date of consent …...../…...../…...

1) INTRODUCTION

You are invited to volunteer for a research study. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about all the procedures involved. In the best interests of your health, it is strongly recommended that you discuss with or inform your personal doctor of your possible participation in this study, wherever possible.

2) THE NATURE AND PURPOSE OF THIS STUDY

You are invited to take part in a research study. For this study, my research question is "what are the factors influencing prevention care for secondary health conditions among people living with spinal cord injury in Tshwane metropolitan area?" Secondary health conditions are complications or conditions that can occur due to living with a disability e.g. pressure sores, chronic pain and bladder infection. By doing this research, we wish to learn more about the types of complications that people living with spinal cord injury experience, how people living with spinal cord injury prevent these complications and whether there are factors affecting prevention of these conditions e.g. distance from the home to the hospital, the cost of going to the hospital etc. These conditions can affect health and an understanding of challenges faced when preventing these conditions can help develop a better prevention programme for these conditions.

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

This study involves looking at your hospital file, participating in an in-depth interview and a group discussion. From the hospital file I will identify the type and number of the complications (e.g. pressure sores, chronic pain, bladder infection etc.) and associated factors-these are factors that can increase the risk (chance) of developing the complications e.g. level of the spinal cord injury, how long who have being living with the spinal cord injury, smoking habit etc. From the interview, I would like to collect information on the experiences of secondary health conditions- if you have experienced these complications, how you prevent their occurrence and any factors influencing how you prevent their occurrence. The interview will take 1-1.5 hours and will be audio recorded. From the group discussion, I would like to collect information on the important components of a programme that can be used to prevent these complications and support needed for these complications. The group discussion will take 1 hour and will be audio recorded. The information you contribute should be accurate and detailed. If there is anything you are uncertain about, please inquire with the researcher. You may choose to withdraw from the study at any point without any penalties.

4) *RISK AND DISCOMFORT INVOLVED.*

People living with spinal cord injury

Psychological risks -depression and feelings of stress for patients living spinal cord injury due to sharing the experiences of secondary conditions. To minimize this risk, will make patients with spinal cord injury and their caregivers aware of the social workers services if they need counselling.

Economic risk - will minimize this risk by paying each participants out of pocket expenses. “If I become aware of any unaddressed health issues, I will refer you to the appropriate healthcare provider”

5) **POSSIBLE BENEFITS OF THIS STUDY.**

You will have an opportunity to highlight the health challenges faced by people living with spinal cord injury and the gaps/needs in the health services especially when it comes to prevention of diseases and health promotion. Understanding how people living with a spinal cord injury experience complications and needs related to prevention can enable us to treat you if you should have problems.

6) I understand that if I do not want to participate in this study, I will still receive standard treatment for my illness.

7) I may at any time withdraw from this study.

If you choose to participate in this research study you will be asked to sign an informed consent form, give permission for your hospital files to be reviewed, to be interviewed and to participate in a group discussion.

8) **HAS THE STUDY RECEIVED ETHICAL APPROVAL?**

This Protocol was submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria and the University of the Witwatersrand and written approval has been granted by these committees. The study has been structured in accordance with the Declaration of Helsinki (last update: October 2013), which deals with the recommendations guiding health professional in biomedical research involving human/subjects. A copy of the Declaration may be obtained from the investigator should you wish to review it.

9) INFORMATION If I have any questions concerning this study, I should contact:

Mrs Sonti Pilusa tel: 011 717 3715 or cell: 082 053 6190 sonti.pilusa@wits.ac.za

Research supervisors:

Professor Hellen Myezwa Hellen.Myezwa@wits.ac.za 011 717 3702

Professor Joanne Potterton Joanne.Potterton@wits.ac.za 011 717 3702for reporting of complaints / problems: Prof P Cleaton Jones, Tel 011 717 2301, email peter.cleaton-jones1@wits.ac.za, Ms Z Ndlovu Administrative Officers 011 717 2700/2656/1234/1252 zanele.ndlovu@wits.ac.za

Contact details of Health Sciences Research Ethics Committee, University of Pretoria

Tel 012 356 3084 email deepeka.behari@up.ac.za

10) CONFIDENTIALITY

All records obtained whilst in this study will be regarded as confidential. Results will be published or presented in such a fashion that patients remain unidentifiable. Data will be kept for fifteen years if published or if not published, after this period the will be destroyed. In the event of data sharing with other researchers for academic purposes written permission will be sought from Human Research Ethics Committee (Medical).

11) CONSENT TO PARTICIPATE IN THIS STUDY.

I have read or had read to me in a language that I understand the above information before signing this consent form. The content and meaning of this information have been explained to me. I have been given opportunity to ask questions and am satisfied that they have been answered satisfactorily. I understand that if I do not participate it will not alter my management in any way. I hereby volunteer to take part in this study.

I have received a signed copy of this informed consent agreement.

Patient name:……	Date:.....
Patient signature:……..	Date:…….
Investigator's name:……	Date:…….
Investigator's signature:……	Date:…….
Witness name and signature:…….	Date:…….

PATIENT INFORMED CONSENT (applicable when patients cannot read or write)

I, the undersigned, ……..…, have read and have explained fully to the patient, named …….. And/or his/her relative, the patient information leaflet, which has indicated the nature and purpose of the study in which I have asked the patient to participate. The explanation I have given has mentioned both the possible risks and benefits of the study and the alternative treatments available for his/her illness. The patient indicated that he/she understands that he/she will be free to withdraw from the study at any time for any reason and without jeopardizing his/her treatment.

I hereby certify that the patient has agreed to participate in this study

Patient's Name:…… (Please print)

Patient's Signature ……Date:…….

Investigator's Name:……. (Please print)

Investigator's Signature:…… Date :……

Witness's Name:…….Witness's Signature:……..Date:……..

(Please print**)**

(Witness - sign that he/she has witnessed the process of informed consent)

PARTICIPANT'S INFORMATION & INFORMED CONSENT DOCUMENT (CAREGIVER)

STUDY TITLE: "Prevention care for secondary health conditions among people living with spinal cord injury in Tshwane Metropolitan area".

SPONSOR: CARTA (Consortium for Advanced Research Training in Africa)

Principal Investigators: SONTI PILUSA Institution: UNIVERSITY OF THE WITWATERSRAND

DAYTIME AND AFTER HOURS TELEPHONE NUMBER(S):

Daytime numbers: 011 717 3715/ 082 0536190Afterhours: 082053 6190

DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION: dd/mmm/yr/Time

Dear Participant

Dear Mr. / Mrs. ..... date of consent …...../…...../…....

1) INTRODUCTION

You are invited to volunteer for a research study. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in this study, you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about all the procedures involved. In the best interests of your health, it is strongly recommended that you discuss with or inform your personal doctor of your possible participation in this study, wherever possible.

2) THE NATURE AND PURPOSE OF THIS STUDY

You are invited to take part in a research study. For this study, my research question is "what are the factors influencing prevention care for secondary health conditions among people living with spinal cord injury in Tshwane metropolitan area?" Secondary health conditions are complications or conditions that can occur due to living with a disability, e.g. pressure sores, chronic pain and bladder infection. By doing this research, we wish to learn more about the types of complications that people living with spinal cord injuries experience, how people living with spinal cord injuries prevent these complications and whether there are factors affecting the prevention of these conditions. These conditions can affect health and an understanding of challenges faced when preventing these conditions can help develop a better prevention
programme for these conditions.

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

From the interview, I would like to collect information on secondary health conditions experienced by people with spinal cord injury, how people with spinal cord injury prevent their occurrence and any factors influencing how people with spinal cord injuries prevent their occurrence. The interview will take 1-1.5 hours and will be audio recorded. From the group discussion, I would like to collect information on the important components of a programme that can be used to prevent these complications and the support needed for these complications. The group discussion will take 1 hour and will be audio recorded. The information you contribute should be accurate and detailed. If there is anything you are uncertain about, please inquire with the researcher. You may choose to withdraw from the study at any point without any penalties

4) RISK AND DISCOMFORT INVOLVED.

People living with spinal cord injury

Psychological risks -depression and feelings of stress for patients living spinal cord injury due to sharing the experiences of secondary conditions. To minimize this risk, we will make patients with spinal cord injury and their caregivers aware of the social workers services if they need counselling.

Economic risk - will minimize this risk by paying each participant out of pocket expense. “If I become aware of any unaddressed health issues, I will refer you to the appropriate healthcare provider”

5) POSSIBLE BENEFITS OF THIS STUDY

You will have an opportunity to highlight the health challenges faced by people living with spinal cord injury and the gaps/needs in the health services, especially when it comes to the prevention of diseases and health promotion. Understanding how people living with a spinal cord injury experience complications and needs related to prevention can enable us to treat people living with spinal cord injury.

6) I understand that if I do not want to participate in this study, I will still receive standard treatment for my illness.

7) I may at any time withdraw from this study. If you choose to participate in this research study you will be asked to sign an informed consent form, give permission for your hospital files to be reviewed, to be interviewed and to participate in a group discussion.

8) HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This Protocol was submitted to the Faculty of Health Sciences Research Ethics Committee, the University of Pretoria and the University of the Witwatersrand and written approval has been granted by these committees. The study has been structured in accordance with the Declaration of Helsinki (last update: October 2013), which deals with the recommendations guiding health professional in biomedical research involving human/subjects. A copy of the Declaration may be obtained from the investigator should you wish to review it.

9) INFORMATION: If I have any questions concerning this study, I should contact: Mrs. Sonti Pilusa tel: 011 717 3715 or cell: 082 053 6190/ Sonti.pilusa@wits.ac.zaResearch supervisors:

Professor Hellen Myezwa Hellen.Myezwa@wits.ac.za 011 717 3702

Professor Joanne Potterton Joanne.Potterton@wits.ac.za 011 717 3702

Administrator and chair – for reporting of complaints / problems: Prof P Cleaton Jones, Tel 011 717 2301, email peter.cleaton-jones1@wits.ac.za, Ms Z Ndlovu Administrative Officers 011 717 2700/2656/1234/1252 zanele.ndlovu@wits.ac.za. *Contact details of Health Sciences Research Ethics Committee, University of Pretoria Tel 012 356 3084 email deepeka.behari@up.ac.za*

10) CONFIDENTIALITY

All records obtained whilst in this study will be regarded as confidential. Results will be published or presented in such a fashion that patients remain unidentifiable. Data will be kept for fifteen if published or not published, after this period the will be destroyed. In the event of data sharing with other researchers for academic purposes written permission will be sought from Human Research Ethics Committee (Medical).

11) CONSENT TO PARTICIPATE IN THIS STUDY.I have read or had read to me in a language that I understand the above information before signing this consent form. The content and meaning of this information have been explained to me. I have been given an opportunity to ask questions and am satisfied that they have been answered satisfactorily. I understand that if I do not participate, it will not alter my management in any way. I hereby volunteer to take part in this study.

I have received a signed copy of this informed consent agreement.

Patient name:…… Date:.....

Patient signature:…….. Date:…….

Investigator's name:……

Date:…….Investigator's signature:……

Witness name and signature:……. Date:…….

VERBAL PATIENT INFORMED CONSENT (applicable when participant cannot read or write)

I, the undersigned, ……..…, have read and have explained fully to the patient, named …….. and/or his/her relative, the patient information leaflet, which has indicated the nature and purpose of the study in which I have asked the patient to participate. The explanation I have given has mentioned both the possible risks and benefits of the study and

the alternative treatments available for his/her illness. The patient indicated that he/she understands that he/she will be free to withdraw from the study at any time for any reason and without jeopardizing his/her treatment.

I hereby certify that the patient has agreed to participate in this study.

Patient's Name:…… (Please print) Patient's Signature:…… Date:…….Investigator's Name:…….. (Please print) Investigator's Signature….....: Date:……

Witness's Name:…….Witness's Signature:……Date:……..

(Please print)

(Witness - sign that he/she has witnessed the process of informed consent)

PARTICIPANT'S INFORMATION & INFORMED CONSENT DOCUMENT (HEALTH PROFESSIONALS AND REHABILITATION MANAGER)

STUDY TITLE: "Prevention care for secondary health conditions among people living with spinal cord injury in Tshwane Metropolitan area".

SPONSOR: CARTA (Consortium for Advanced Research Training in Africa)

Principal Investigators: SONTI PILUSA

Institution: UNIVERSITY OF THE WITWATERSRAND

DAYTIME AND AFTER HOURS TELEPHONE NUMBER(S):

Daytime numbers: 011 717 3715/ 082 0536190

Afterhours: 082053 6190

DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION: dd/mmm/yr/Time

Dear Participant

Dear Mr. / Mrs. ..... date of consent …...../…...../….....

1) INTRODUCTION

You are invited to volunteer for a research study. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about all the procedures involved.

2) THE NATURE AND PURPOSE OF THIS STUDY

You are invited to take part in a research study. For this study, my research question is what are the factors influencing prevention care for secondary health conditions among people living with spinal cord injury in Tshwane metropolitan area? Secondary health conditions are complications or conditions that can occur due to living with a disability e.g. pressure sores, chronic pain and Urinary tract infection (bladder infection). By doing this research we wish to learn more about the types of complications that people living with spinal cord injury experience, how people living with spinal cord injury prevent these complications and whether there are factors affecting the prevention of these conditions. These conditions can affect health, and an understanding of challenges faced when preventing these conditions can help develop or improve the prevention model of care for these conditions.

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

This study involves participating in an in-depth interview and a group discussion. From the interview, I would like to collect information on the secondary health conditions in people living with spinal cord injury, how they prevent their occurrence and any factors influencing how they prevent their occurrence. The interview will take 1-1.5 hours and will be audio recorded. From the group discussion, I would like to collect information on the best way to develop a prevention programme and support for these complications. The main aim of this group discussion is to develop a prevention model of care for secondary health conditions. The group discussion will take 1 hour and will be audio recorded. The information you contribute should be accurate and detailed. If there is anything you are uncertain about, please inquire with the researcher. You may choose to withdraw from the study at any point without any penalties.

4) RISK AND DISCOMFORT INVOLVED.

Loss of time risk- minimized by arranging interviews during lunch time or after hours

5) POSSIBLE BENEFITS OF THIS STUDY.

You will have an opportunity to highlight the health challenges faced by people living with spinal cord injury, gaps in the health care services especially when it comes to prevention of diseases and health promotion. Understanding how people living with a spinal cord injury experience complications and needs related to prevention can enable us to treat people living with spinal cord injury in a more holistic manner.

6) I understand that if I do not want to participate in this study, I will still receive standard treatment for my illness.

7) I may at any time withdraw from this study.

If you choose to participate in this research study you will be asked to sign an informed consent form, give permission for your hospital files to be reviewed, to be interviewed and to participate in a group discussion.

8) HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This Protocol was submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria and the University of the Witwatersrand and written approval has been granted by these committees. The study has been structured in accordance with the Declaration of Helsinki (last update: October 2013), which deals with the recommendations guiding health

professional in biomedical research involving human/subjects. A copy of the Declaration may be obtained from the investigator should you wish to review it.

9) INFORMATION If I have any questions concerning this study, I should contact:

Mrs Sonti Pilusa tel: 011 717 3715 or cell: 082 053 6190 Sonti.pilusa@wits.ac.za

Research supervisors:

Professor Hellen Myezwa Hellen.Myezwa@wits.ac.za 011 717 3702

Professor Joanne Potterton Joanne.Potterton@wits.ac.za 011 717 3702

Administrator and chair – for reporting of complaints / problems: Prof P Cleaton Jones, Tel 011 717 2301, email peter.cleaton-jones1@wits.ac.za, Ms Z Ndlovu Administrative Officers 011 717 2700/2656/1234/1252 zanele.ndlovu@wits.ac.za

Contact details of Health Sciences Research Ethics Committee, University of Pretoria

Tel 012 356 3084 email deepeka.behari@up.ac.za

10) CONFIDENTIALITY

All records obtained whilst in this study will be regarded as confidential. Results will be published or presented in such a fashion that patients remain unidentifiable. Data will be kept for fifteen years if published or not published, after this period the will be destroyed. In the event of data sharing with other researchers for academic purposes written permission will be sought from Human Research Ethics Committee (Medical).

11) CONSENT TO PARTICIPATE IN THIS STUDY.

I have read or had read to me in a language that I understand the above information before signing this consent form. The content and meaning of this information have been explained to me. I have been given opportunity to ask questions and am satisfied that they have been answered satisfactorily. I understand that if I do not participate it will not alter my management in any way. I hereby volunteer to take part in this study.

I have received a signed copy of this informed consent agreement.

Patient name:…… Date:.....

Patient signature:…….. Date:…….

Investigator's name:…… Date:…….

Investigator's signature:…… Date:…….

Witness name and signature:……. Date:…….

VERBAL PATIENT INFORMED CONSENT (applicable when participant cannot read or write)

I, the undersigned, ……..…, have read and have explained fully to the patient, named …….. and/or his/her relative, the patient information leaflet, which has indicated the nature and purpose of the study in which I have asked the patient to participate. The explanation I have given has mentioned both the possible risks and benefits of the study and the alternative treatments available for his/her illness. The patient indicated that he/she understands that he/she will be free to withdraw from the study at any time for any reason and without jeopardizing his/her treatment.

I hereby certify that the patient has agreed to participate in this study.

Patient's Name:…… (Please print)

Patient's Signature:…… Date:…….

Investigator's Name:…….. (Please print)

Investigator's Signature….....: Date:……

Witness's Name:…….Witness's Signature:……Date:……..

(Please print)

(Witness - sign that he/she has witnessed the process of informed consent)

Permission for audio recording.

I am asking for permission to audio record the interview/ group discussion.

I agree that Mrs Sonti Pilusa may tape record my interview/group discussion with her and that she will take out any name and places that we talk about when the interview is typed up.

…… …….. ……

(Signature of participant) (Date) (Printed name)

……
……

APPENDIX D: SEMI-STRUCTURED INTERVIER GUIDE FOR PARTICIPANTS LIVING WITH SPINAL CORD INJURY

Good morning/afternoon. Thank you for giving your time for this interview. My name is Sonti Pilusa and I am a PhD student at the University of the Witwatersrand. Today, I would like to learn from you about secondary health conditions you might have experienced and how you prevent them. Lastly, I would like to ask you about any factors influencing the prevention of secondary health conditions among people living with spinal cord injury.

This interview should last 1-1.5hours and will be audio recorded. I have specific questions I would like to ask, but feel free to provide additional information. Please ensure the interview you remain anonymous by avoiding the use of your own name. Please try to speak loudly, clearly, slowly so that your comments can all be audio recorded.

Do you have any questions?

Section 1: Identification information

1.1 *Patient identifier:*	**1.3 Name of Interviewer:**
1.2 Date of interview	**1.4 Interview venue**

Section 2: Demographic data sheet for key informants

1.1 Identifier code:		
1.2 Gender		
1.3 Age		
1.4 Disability –date of injury		
1.5 Level of lesion		
1.6 Assistive device		
1.7 Member of NGO for people with disabilities	YES	NO
1.8 Employment status		
1.9 Highest education attained		
1.10Marital status		

1.11 Area in Tshwane Metropolitan (Address)	

Interview guide

	Good day..can you tell me about yourself
Theme 1: Disability	Can you tell me about your disability? Can you tell me about your experience living with a disability? Probe: how and when the disability occurred?
Theme 2: Secondary health conditions experienced by PLSCI	**PLSCI sometimes experience secondary complications** What is your understanding of secondary complications commonly experienced by people with spinal cord injury? Can you tell me about any Secondary complications related to the spinal cord injury Which secondary complications have you experienced? **(PROBE: If specific secondary health condition/s not mentioned will probe e.g. Pain, pressure sores, anxiety, depression etc.)** **Probe: Types and frequency of the conditions** Can you share your experience with these complications in your life (will be specific on the type of secondary health condition)? Can you share with me when you were told you have these complication(s)?

	Why do they happen if you were rehabilitated? (Underlying risk factors?) **Probe: Anything else?** **Probe: why did you experience these conditions?** **Probe: Anything else?**
Theme 3: Prevention Strategies of SHC	How do you prevent or manage secondary complications in your life? Probe: "other people prevent secondary condition e.g. pressure sores by doing regular pressure relief" can you share more on how you prevent secondary conditions from occurring in your life. Can you share more on how you manage/d them when you had secondary conditions?
Theme 4: Factors influencing prevention of SHC among PLSCI	What factors across the continuum of care from hospital to home setting influence the prevention of secondary complications? **Probe: For the patient with a spinal cord injury?** **Probe: Factors from the rehab hospital?** **Probe: Factors from the family? Community?** Can you share a typical scenario where there were factors that made prevention of secondary complications manageable or easy? (Facilitators) **Probe: Why?**

	Can you share a typical scenario where there were factors that made prevention of secondary health conditions difficult? (barriers) **Probe: Why?** Can you share the challenges you have experienced in preventing or managing the secondary health conditions (will be specific on the type of secondary health condition)?
Suggestions	If you had the power to change things … Which solutions or strategies might assist the prevention of secondary health conditions in people living with spinal cord injury? Any THOUGHTS on how prevention care for secondary conditions can be improved in people with spinal cord injury.

Thank you very much for sharing with me.

APPENDIX E: SEMI-STRUCTURED INTERVIER GUIDE FOR CAREGIVERS

Semi structured interview guide for the caregivers' of people with spinal cord injury

Good morning/afternoon. Thank you for giving me the time to interview you. My name is Sonti Pilusa, and I am a PHD student at the University of the Witwatersrand. Today I would like to learn from you about secondary health conditions experienced by people with spinal cord injury and how you assist them to prevent their occurrence. Lastly, I would like to ask you about any factors influencing the prevention of secondary health conditions among people living with spinal cord injuries

This interview should last 1-1.5hours and will be audio recorded. I have specific questions I would like to ask, but feel free to provide additional information. Please ensure the interview you remain anonymous by avoiding the use of your own name. Please try to speak loudly, clearly, slowly so that your comments can all be audio recorded.

Do you have any questions?

Section 1: Identification information

1.1 *Participant identifier:*	**1.3 Name of Interviewer:**
1.2 Date of interview	**1.4 Interview venue**

Section 2: Demographic data sheet for key informants

1.9 Identifier code:	
1.2 Gender	
1.2 Age	
1.4 Caregiver to ?(name of the person with SCI)	
1.5 Level of education	
1.6 Occupation	

Interview Guide

Theme 1: key informant role	Can you tell me a little bit about your care for the ……(participant living with spinal cord injury)?
Theme 2: prevention of secondary health conditions	Tell me about secondary complications that people with spinal cord injury experience PROBE: If not mentioned will give examples of secondary health conditions e.g. Pain, pressure sores anxiety, depression etc. Can you share how these conditions are prevented? Probe: How do you assist in the prevention of secondary health conditions?
Theme 4: Factors influencing prevention of secondary health conditions among PLWSCI	What are some of the things that make the prevention of secondary health conditions hard? (barriers) Why? What are some of the things that make prevention of secondary health conditions manageable or easy? (Facilitators) **Probe: For the patient with a spinal cord injury?** **Probe: Factors from the rehab hospital?** **Probe: Factors from the family? Community?** Can you share a typical scenario where there were factors that made prevention of secondary complications manageable or easy? (Facilitators) **Probe: Why?** Can you share a typical scenario where there were factors that made prevention of secondary health conditions difficult? (barriers)

	Probe: Why? Can you share the challenges you have experienced in preventing or managing the secondary health conditions (will be specific on the type of secondary health condition)?
Suggestions	What are some of the strategies and solutions that might assist prevention of secondary health conditions in people living with spinal cord injury? Do you have any suggestions on how prevention (care) of secondary conditions can be improved?

This concludes the interview. Thank you for your time and input

APPENDIX F: SCOPING REVIEW APPENDICES

PUBMED

Search strategy for PubMed using health promotion concept (7//9/2019)

(("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ((("health promotion" OR "health behaviour*" OR "patient education")) AND ("Health Promotion"[Mesh] OR "Preventive Health Services"[Mesh] OR "Preconception Care"[Mesh] OR "Public Health Nursing"[Mesh] OR "Primary Prevention"[Mesh] OR "Preventive Medicine"[Mesh] OR "Health Education"[Mesh]))

Pubmed	Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ((("health promotion" OR "health behaviour*" OR "patient education")) AND ("Health Promotion"[Mesh] OR "Preventive Health Services"[Mesh] OR "Preconception Care"[Mesh] OR "Public Health Nursing"[Mesh] OR "Primary Prevention"[Mesh] OR "Preventive Medicine"[Mesh] OR "Health Education"[Mesh])) Filters: English; Adult: 19+ years	5
	#7 Search (#6) Filters: English	
	#6 Search (#1 AND #2 AND #5) (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ((("health promotion" OR "health behaviour*" OR "patient education")) AND ("Health Promotion"[Mesh] OR "Preventive Health Services"[Mesh] OR "Preconception Care"[Mesh] OR "Public Health Nursing"[Mesh] OR "Primary Prevention"[Mesh] OR "Preventive Medicine"[Mesh] OR "Health Education"[Mesh]))	10 10
	#5 (#3 AND # 4)	155606
	Search (("health promotion" OR "health behaviour*" OR "patient education")) AND ("Health Promotion"[Mesh] OR "Preventive Health Services"[Mesh] OR "Preconception Care"[Mesh] OR "Public Health Nursing"[Mesh] OR "Primary Prevention"[Mesh] OR "Preventive Medicine"[Mesh] OR "Health Education"[Mesh])	619326
	#4 "Health Promotion"[Mesh] OR "Preventive Health Services"[Mesh] OR "Preconception Care"[Mesh] OR "Public Health Nursing"[Mesh] OR "Primary Prevention"[Mesh] OR "Preventive Medicine"[Mesh] OR "Health Education"[Mesh]	204388
	#3 Search "health promotion" OR "health behaviour*" OR "patient education"	2794
	#2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities"	34202

	#1 Search "Spinal Cord Injuries"	

Search strategy for PubMed using rehabilitation concept (27//8/2019)

Pubmed	Search ((("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ((rehabilitation) AND ("Rehabilitation Research"[Mesh] OR "Neurological Rehabilitation"[Mesh] OR "Psychiatric Rehabilitation"[Mesh] OR "Telerehabilitation"[Mesh] OR "Exercise Therapy"[Mesh] OR "Treatment Outcome"[Mesh] OR "Hospitals, Rehabilitation"[Mesh] OR "Physical and Rehabilitation Medicine"[Mesh] OR "Rehabilitation Centers"[Mesh] OR "Rehabilitation Nursing"[Mesh] OR "Rehabilitation, Vocational"[Mesh] OR "Rehabilitation"[Mesh]))) Filters: English; Adult: 19+ years	54
	# 7 Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ((rehabilitation) AND ("Rehabilitation Research"[Mesh] OR "Neurological Rehabilitation"[Mesh] OR "Psychiatric Rehabilitation"[Mesh] OR "Telerehabilitation"[Mesh] OR "Exercise Therapy"[Mesh] OR "Treatment Outcome"[Mesh] OR "Hospitals, Rehabilitation"[Mesh] OR "Physical and Rehabilitation Medicine"[Mesh] OR "Rehabilitation Centers"[Mesh] OR "Rehabilitation Nursing"[Mesh] OR "Rehabilitation, Vocational"[Mesh] OR "Rehabilitation"[Mesh])) Filters: English	87
	#6 Search (#1 AND #2 # 5) Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ((rehabilitation) AND ("Rehabilitation Research"[Mesh] OR "Neurological Rehabilitation"[Mesh] OR "Psychiatric Rehabilitation"[Mesh] OR "Telerehabilitation"[Mesh] OR "Exercise Therapy"[Mesh] OR "Treatment Outcome"[Mesh] OR "Hospitals, Rehabilitation"[Mesh] OR "Physical and Rehabilitation Medicine"[Mesh] OR "Rehabilitation Centers"[Mesh] OR "Rehabilitation Nursing"[Mesh] OR "Rehabilitation, Vocational"[Mesh] OR "Rehabilitation"[Mesh]))	88
	#5 Search (#3 AND #4) Search (rehabilitation) AND ("Rehabilitation Research"[Mesh] OR "Neurological Rehabilitation"[Mesh] OR "Psychiatric Rehabilitation"[Mesh] OR "Telerehabilitation"[Mesh] OR "Exercise Therapy"[Mesh] OR "Treatment Outcome"[Mesh] OR "Hospitals, Rehabilitation"[Mesh] OR "Physical and	327416

	Rehabilitation Medicine"[Mesh] OR "Rehabilitation Centers"[Mesh] OR "Rehabilitation Nursing"[Mesh] OR "Rehabilitation, Vocational"[Mesh] OR "Rehabilitation"[Mesh])	
	#4 Search "Rehabilitation Research"[Mesh] OR "Neurological Rehabilitation"[Mesh] OR "Psychiatric Rehabilitation"[Mesh] OR "Telerehabilitation"[Mesh] OR "Exercise Therapy"[Mesh] OR "Treatment Outcome"[Mesh] OR "Hospitals, Rehabilitation"[Mesh] OR "Physical and Rehabilitation Medicine"[Mesh] OR "Rehabilitation Centers"[Mesh] OR "Rehabilitation Nursing"[Mesh] OR "Rehabilitation, Vocational"[Mesh] OR "Rehabilitation"[Mesh]	1258547
	#3 Search rehabilitation	594332
	#2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities"	2794
	#1 Search "Spinal Cord Injury"	34202

SEARCH FOR ASSISTIVE DEVICE

Search (((("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND "spinal cord injury") AND ("assistive device" OR "assistive technology" OR "self help device") Filters: English

Pubmed	Search (((("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND "spinal cord injury") AND ("assistive device" OR "assistive technology" OR "self help device") Filters: English; Adult: 19+ years	2
	#5 Search (((("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND "spinal cord injury") AND ("assistive device" OR "assistive technology" OR "self help device") Filters: English	5

	#4 ((#1 AND #2 AND #3) Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ("assistive device" OR "assistive technology" OR "self help device")	2975
	# 3 "assistive device" OR "assistive technology" OR "self help device"	2794
	#2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities"	34202
	#1 Search "Spinal Cord Injury"	

POLICY

Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND (((policy OR guidelines OR protocol)) AND ("Policy"[Mesh] OR "Environmental Policy"[Mesh] OR "Nutrition Policy"[Mesh] OR "Organizational Policy"[Mesh] OR "Health Policy"[Mesh] OR "Guideline Adherence"[Mesh] OR "Social Control Policies"[Mesh] OR "Public Policy"[Mesh] OR "Economics"[Mesh]))

Pubmed	Search Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND (((policy OR guidelines OR protocol)) AND ("Policy"[Mesh] OR "Environmental Policy"[Mesh] OR "Nutrition Policy"[Mesh] OR "Organizational Policy"[Mesh] OR "Health Policy"[Mesh] OR "Guideline Adherence"[Mesh] OR "Social Control Policies"[Mesh] OR "Public Policy"[Mesh] OR "Economics"[Mesh])) Filters: English	2
	# 6 (#1 AND 2 AND 5)	2
	#5 ((#3 OR #4)	230607
	# 4 Search "Policy"[Mesh] OR "Environmental Policy"[Mesh] OR "Nutrition Policy"[Mesh] OR "Organizational Policy"[Mesh] OR "Health Policy"[Mesh] OR "Guideline Adherence"[Mesh] OR "Social Control Policies"[Mesh] OR "Public Policy"[Mesh] OR "Economics"[Mesh]	713061
	#3 Search policy OR guidelines OR protocol	1062841

	#2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities" #1 Search "Spinal Cord Injury"	2794 34202

PHYSICAL ACTIVITY

"physical activity" OR "exercise therapy"

Pubmed	earch ((("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ("physical activity" OR "exercise therapy")) Filters: English; Adult: 19+ years #5 (#4) LANGUAGE Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ("physical activity" OR "exercise therapy") Filters: English # 4 (#1 AND#2 AND#3) Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ("physical activity" OR "exercise therapy") #3 Search "physical activity" OR "exercise therapy" #2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities" #1 Search "Spinal Cord Injury"	15 28 28 142381 2794 34202

Self-management

"self management" OR "self care" search date 7/9/2019

Pubmed		

	#5 (#4) Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ("self management" OR "self care") Filters: English; Adult: 19+ years	15
	# 4 (#1 AND#2 AND#3)	28
	#3 Search "self management" OR "self care"	1528
	#2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities"	51633
	#1 Search "Spinal Cord Injury"	2796
		34271

Peer mentoring

Pubmed	# 4 (#1 AND#2 AND#3)	0
	Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND "peer mentoring"	350
	#3 Search "peer mentoring"	2794
	#2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities"	34202
	#1 Search "Spinal Cord Injury"	

Motivational interviewing

Pubmed	# 4 (#1 AND#2 AND#3) Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND "motivational interviewing"	0
	#3 Search "motivational interviewing"	4101
	#2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities"	2794
	#1 Search "Spinal Cord Injury"	34202

PUBMED

Search strategy for PubMed using health promotion concept (7//9/2019)

(("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ((("health promotion" OR "health behaviour*" OR "patient education")) AND ("Health Promotion"[Mesh] OR "Preventive Health Services"[Mesh] OR "Preconception Care"[Mesh] OR "Public Health Nursing"[Mesh] OR "Primary Prevention"[Mesh] OR "Preventive Medicine"[Mesh] OR "Health Education"[Mesh]))

Pubmed	Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ((("health promotion" OR "health behaviour*" OR "patient education")) AND ("Health Promotion"[Mesh] OR "Preventive Health Services"[Mesh] OR "Preconception Care"[Mesh] OR "Public Health Nursing"[Mesh] OR "Primary Prevention"[Mesh] OR "Preventive Medicine"[Mesh] OR "Health Education"[Mesh])) Filters: English; Adult: 19+ years	5 10
	#7 Search (#6) Filters: English	10
	#6 Search (#1 AND #2 AND #5)	

	(("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ((("health promotion" OR "health behaviour*" OR "patient education")) AND ("Health Promotion"[Mesh] OR "Preventive Health Services"[Mesh] OR "Preconception Care"[Mesh] OR "Public Health Nursing"[Mesh] OR "Primary Prevention"[Mesh] OR "Preventive Medicine"[Mesh] OR "Health Education"[Mesh])) #5 (#3 AND # 4) Search (("health promotion" OR "health behaviour*" OR "patient education")) AND ("Health Promotion"[Mesh] OR "Preventive Health Services"[Mesh] OR "Preconception Care"[Mesh] OR "Public Health Nursing"[Mesh] OR "Primary Prevention"[Mesh] OR "Preventive Medicine"[Mesh] OR "Health Education"[Mesh]) #4 "Health Promotion"[Mesh] OR "Preventive Health Services"[Mesh] OR "Preconception Care"[Mesh] OR "Public Health Nursing"[Mesh] OR "Primary Prevention"[Mesh] OR "Preventive Medicine"[Mesh] OR "Health Education"[Mesh] #3 Search "health promotion" OR "health behaviour*" OR "patient education" #2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities" #1 Search "Spinal Cord Injuries"	155606 619326 204388 2794 34202

Search strategy for PubMed using rehabilitation concept (27//8/2019)

Pubmed	Search ((("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ((rehabilitation) AND ("Rehabilitation Research"[Mesh] OR "Neurological Rehabilitation"[Mesh] OR "Psychiatric Rehabilitation"[Mesh] OR "Telerehabilitation"[Mesh] OR "Exercise Therapy"[Mesh] OR "Treatment Outcome"[Mesh] OR "Hospitals, Rehabilitation"[Mesh] OR "Physical and Rehabilitation Medicine"[Mesh] OR "Rehabilitation Centers"[Mesh] OR "Rehabilitation Nursing"[Mesh] OR	54

	"Rehabilitation, Vocational"[Mesh] OR "Rehabilitation"[Mesh]))) Filters: English; Adult: 19+ years	
	# 7 Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ((rehabilitation) AND ("Rehabilitation Research"[Mesh] OR "Neurological Rehabilitation"[Mesh] OR "Psychiatric Rehabilitation"[Mesh] OR "Telerehabilitation"[Mesh] OR "Exercise Therapy"[Mesh] OR "Treatment Outcome"[Mesh] OR "Hospitals, Rehabilitation"[Mesh] OR "Physical and Rehabilitation Medicine"[Mesh] OR "Rehabilitation Centers"[Mesh] OR "Rehabilitation Nursing"[Mesh] OR "Rehabilitation, Vocational"[Mesh] OR "Rehabilitation"[Mesh])) Filters: English	87 88
	#6 Search (#1 AND #2 # 5) Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ((rehabilitation) AND ("Rehabilitation Research"[Mesh] OR "Neurological Rehabilitation"[Mesh] OR "Psychiatric Rehabilitation"[Mesh] OR "Telerehabilitation"[Mesh] OR "Exercise Therapy"[Mesh] OR "Treatment Outcome"[Mesh] OR "Hospitals, Rehabilitation"[Mesh] OR "Physical and Rehabilitation Medicine"[Mesh] OR "Rehabilitation Centers"[Mesh] OR "Rehabilitation Nursing"[Mesh] OR "Rehabilitation, Vocational"[Mesh] OR "Rehabilitation"[Mesh]))	327416
	#5 Search (#3 AND #4) Search (rehabilitation) AND ("Rehabilitation Research"[Mesh] OR "Neurological Rehabilitation"[Mesh] OR "Psychiatric Rehabilitation"[Mesh] OR "Telerehabilitation"[Mesh] OR "Exercise Therapy"[Mesh] OR "Treatment Outcome"[Mesh] OR "Hospitals, Rehabilitation"[Mesh] OR "Physical and Rehabilitation Medicine"[Mesh] OR "Rehabilitation Centers"[Mesh] OR "Rehabilitation Nursing"[Mesh] OR "Rehabilitation, Vocational"[Mesh] OR "Rehabilitation"[Mesh])	1258547 594332
	#4 Search "Rehabilitation Research"[Mesh] OR "Neurological Rehabilitation"[Mesh] OR "Psychiatric Rehabilitation"[Mesh] OR "Telerehabilitation"[Mesh] OR "Exercise Therapy"[Mesh] OR "Treatment Outcome"[Mesh] OR "Hospitals, Rehabilitation"[Mesh] OR "Physical and Rehabilitation Medicine"[Mesh] OR "Rehabilitation Centers"[Mesh] OR "Rehabilitation Nursing"[Mesh] OR "Rehabilitation, Vocational"[Mesh] OR "Rehabilitation"[Mesh]	2794 34202

	#3 Search rehabilitation #2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities" #1 Search "Spinal Cord Injury"	

SEARCH FOR ASSISTIVE DEVICE

Search ((("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND "spinal cord injury") AND ("assistive device" OR "assistive technology" OR "self help device") Filters: English

Pubmed	Search ((("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND "spinal cord injury") AND ("assistive device" OR "assistive technology" OR "self help device") Filters: English; Adult: 19+ years #5 Search ((("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND "spinal cord injury") AND ("assistive device" OR "assistive technology" OR "self help device") Filters: English #4 ((#1 AND #2 AND #3) Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ("assistive device" OR "assistive technology" OR "self help device") # 3 "assistive device" OR "assistive technology" OR "self help device"	25 5 2975 2794 34202

	#2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities" #1 Search "Spinal Cord Injury”	

POLICY

Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND (((policy OR guidelines OR protocol)) AND ("Policy"[Mesh] OR "Environmental Policy"[Mesh] OR "Nutrition Policy"[Mesh] OR "Organizational Policy"[Mesh] OR "Health Policy"[Mesh] OR "Guideline Adherence"[Mesh] OR "Social Control Policies"[Mesh] OR "Public Policy"[Mesh] OR "Economics"[Mesh]))

Pubmed	Search Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND (((policy OR guidelines OR protocol)) AND ("Policy"[Mesh] OR "Environmental Policy"[Mesh] OR "Nutrition Policy"[Mesh] OR "Organizational Policy"[Mesh] OR "Health Policy"[Mesh] OR "Guideline Adherence"[Mesh] OR "Social Control Policies"[Mesh] OR "Public Policy"[Mesh] OR "Economics"[Mesh])) Filters: English # 6 (#1 AND 2 AND 5) #5 ((#3 OR #4) # 4 Search "Policy"[Mesh] OR "Environmental Policy"[Mesh] OR "Nutrition Policy"[Mesh] OR "Organizational Policy"[Mesh] OR "Health Policy"[Mesh] OR "Guideline Adherence"[Mesh] OR "Social Control Policies"[Mesh] OR "Public Policy"[Mesh] OR "Economics"[Mesh] #3 Search policy OR guidelines OR protocol #2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities" #1 Search "Spinal Cord Injury”	2 2 230607 713061 1062841 2794 34202

PHYSICAL ACTIVITY

"physical activity" OR "exercise therapy"

Pubmed	earch ((("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ("physical activity" OR "exercise therapy")) Filters: English; Adult: 19+ years	15 28
	#5 (#4) LANGUAGE Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ("physical activity" OR "exercise therapy") Filters: English	28
	# 4 (#1 AND#2 AND#3)	142381
	Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND ("physical activity" OR "exercise therapy")	2794 34202
	#3 Search "physical activity" OR "exercise therapy"	
	#2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities"	
	#1 Search "Spinal Cord Injury"	

Self-management

"self management" OR "self care" search date 7/9/2019

Pubmed	#5 (#4) Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR	15

	"secondary complications" OR "secondary disabilities")) AND ("self management" OR "self care") Filters: English; Adult: 19+ years	28
	# 4 (#1 AND#2 AND#3)	1528
	#3 Search "self management" OR "self care"	51633
	#2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities"	
	#1 Search "Spinal Cord Injury"	

Peer mentoring

Pubmed	# 4 (#1 AND#2 AND#3)	0
	Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND "peer mentoring"	350
	#3 Search "peer mentoring"	2794
	#2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities"	34202
	#1 Search "Spinal Cord Injury"	

Motivational interviewing

Pubmed	# 4 (#1 AND#2 AND#3)	0
	Search (("spinal cord injury") AND ("secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities")) AND "motivational interviewing"	4101

	#3 Search "motivational interviewing"	2794
	#2 Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities"	34202
	#1 Search "Spinal Cord Injury"	

Appendix IV: Excluded studies and reasons for exclusion

Mittmann, Hitzig and Craven, 2014	Title: Predicting health preference in chronic spinal cord injury Study reported on the health preference only	not specific to prevention of SHCs
Guilcher et al., 2012	Title: Application of the Andersen's health care utilization framework to secondary complications of spinal cord injury: A scoping review research priority areas related to secondary complications	not specific to prevention of SHCs
Weaver et al., 2019	Title: Department of Veterans Affairs Quality Enhancement Research Initiative for Spinal Cord Injury Research gaps related to prevention of SHCs	not specific to prevention of SHCs
Jörgensen, Ginis and Lexell, 2017	Title: Leisure time physical activity among older adults with long-term spinal cord injury Focused on leisure time physical participation	not specific to prevention of SHCs
Teo et al., 2011	Title: Health of people with spinal cord injury in Singapore: implications for rehabilitation planning and implementation focussed on the health of people with SCI in Singapore and formulate recommendations for long-term rehabilitation planning and implementation –	Not aimed at presenting prevention of secondary health conditions.
Gagnon et al., 2017	Title: Satisfaction and perception upon completion of a locomotor training program with an overground robotic exoskeleton – Study focused on the training program satisfactions	not specific to prevention of SHCs
Laubacher et a., 2014l	Work-rate-guided exercise testing in patients with incomplete spinal cord injury using a robotics-assisted tilt-table. Focused on Robotics-assisted tilt-table (RTT) technology for cardiopulmonary training and assessment	not specific to prevention of SHCs
Terwoude et al 2006	Title: Passive leg movements and passive cycling do not alter arterial leg blood flow in subjects with spinal cord injury Focus was blood circulation	not specific to prevention of SHCs

Houlihan et al., 2011	Title: Empowering Adults With Chronic Spinal Cord Injury to Prevent Secondary Conditions Focus was on the development of the peer led community based telephone intervention for prevention of SHCs	not specific to prevention of SHCs
Stuifbergen et al., 2010	Title: Benefits of wellness interventions for persons with chronic and disabling conditions: a review of the evidence Focus of study was on benefits of wellness interventions on people with chronic conditions	not specific to prevention of SHCs
Houlihan et al., 2017	Title: RCT of peer-led phone-based empowerment intervention for persons with chronic spinal cord injury improves health self-management Focus was on self-management and quality of life.	not specific to prevention of SHCs
Löfvenmar et al., 2017	Title: Outcomes after acute traumatic spinal cord injury in Botswana: From admission to discharge common complications were reported but not management and prevention.	not specific to prevention of SHCs
Munce, Fehlings, et al., 2014	Title: Views of people with traumatic spinal cord injury about the components of self-management programs and program delivery : a Canadian pilot study Focus was on the about self-management technique in the management of SCI	not specific to prevention of SHCs
Munce, Webster, et al., 2014	Perceived barriers and facilitators to self-management techniques in the management of SCI Focused on self-management	not specific to prevention of SHCs
van der Woude et al., 2013	Title: Active Lifestyle Rehabilitation interventions in aging spinal cord injury (ALLRISC): a multicentre research program It was a research program and protocol	not specific to prevention of SHCs
Hirche et al., 2011	Title: Chronic disease self-management for individuals with stroke, multiple sclerosis and spinal cord injury Focus was on the experience of The programme.	not specific to prevention of SHCs
Kroll et al., 2007	Title: Secondary conditions in spinal cord injury: Results from a prospective survey Predictors of SHCs	not specific to prevention of SHCs

Lundström et al., 2017	Title Participation in activities and explore the relationship with secondary complications among persons aging with a traumatic spinal cord injury (SCI) Focus was on participation and factors that limited participation	not specific to prevention of SHCs
Boninger et al., 2018	Title: Research progress from the SCI Model Systems (SCIMS): An interactive discussion on future directions Described current and future directions in spinal cord injury (SCI) research.	not specific to prevention of SHCs
Fries 2005	Title: Critical Rehabilitation of the Patient With Spinal Cord Injury Review of the management procedure of SCI including secondary health conditions	not specific to prevention of SHCs
Schließmann et al 2018	Title: Trainer in a pocket - proof-of-concept of mobile, real-time, foot kinematics feedback for gait pattern normalization in individuals after stroke, incomplete spinal cord injury and elderly patients Gait training post spinal cord injury and stroke	not specific to prevention of SHCs
Löfvenmark et al., 2017	Title: Outcomes 2 years after traumatic spinal cord injury in Botswana: A follow-up study Focused on the clinical and functional outcomes not on prevention of SHCs	not specific to prevention of SHCs
Sekulić et al 2017	Title: Analysis of the factors influencing development of urinary tract infections in patients with spinal cord injuries Focus was mainly on the risk factors for UTI	not specific to prevention of SHCs
Gallagher &Belle 2016	Title: Combining Adult Learning Theory with Occupational Therapy Intervention for Bladder and Bowel Management after Spinal Cord Injury: A Case Report Adult learning theory and Independent bowel and bladder control in SCI	not specific to prevention of SHCs
Wahman et al, 2019	Title: Prevalence of secondary complications after traumatic spinal cord injury during acute care and rehabilitation Reported the prevalence of SHCs	not specific to prevention of SHCs
Krause et al., 2010	Title: Center for the Prevention of Secondary Conditions After Spinal Cord Injury: Background and Overview of Coordinated Activities Administrative oversight of the centre for prevention of	not specific to prevention of SHCs

	secondary health conditions associated with SCI	
Atkins et al., 2012	Title: Secondary complications in SCI across the continuum: Using operations research to predict the impact and optimize management strategies Hospital costs of SHC. Administrative oversight.	not specific to prevention of SHCs
Lavela et al 2017	Title: Relational empathy and holistic care in persons with spinal cord injuries. Focus was on holistic care and relational empathy	not specific to prevention of SHCs
Guest et al., 2015	Title: Factors predicting resilience in people with spinal cord injury during transition from inpatient rehabilitation to the community Focused on predictors of resilience	not specific to prevention of SHCs
Nardone et al, 2017	Title: Passive cycling in neuro-rehabilitation after spinal cord injury: A review. Reviewed studies passive cycling animal and human subjects with spinal cord injury	The review included animal and human subjects
Flinn and Street, 2015	Title: A medical home for persons with disabilities: Improved health and patient engagement, decreased cost. Outcome measured were general health, patient activation measure and self-efficacy in patient engagement	not specific to prevention of SHCs
Flinn and Street, 2015	Title: The nuts and bolts of a disability-knowledgeable primary care model. Outcomes did not include SHCs –health needs, general health	not specific to prevention of SHCs
Lofton et al., 2015	Title: Acute spinal cord injury rehabilitation in pregnancy: A case report. Focus was on pregnancy care for women with acute spinal cord injury rehabilitation	not specific to prevention of SHCs
Brown, Deriso and Tansey, 2012	Title: From contemporary rehabilitation to restorative neurology. Contemporary rehabilitation methods enhance function	not specific to prevention of secondary health conditions
Heather et al.,2012	Title: Strategies for successful implementation and sustainability of best practices in SCI rehabilitation Focus was on the description of the Spinal Cord Injury Knowledge Mobilization Network project	not specific to prevention of SHCs

Wolfe et al., 2004	Title: Overcoming challenges: The role of rehabilitation in educating individuals with SCI to reduce secondary conditions.	Could not find
Chiodo et al., 2007	Title: Spinal Cord Injury Medicine. 5. Long-Term Medical Issues and Health Maintenance Description of the educational and clinical activities related to spinal cord injuries health maintenance	not specific to prevention of SHCs
Roopchand-Martin et al., 2018	Title: Physical activity levels, perceived barriers to exercise and development of secondary conditions in community dwelling persons with spinal cord injury. Study reported on the physical activity levels and SHCs. No association done between exercise and SHCs	not specific to prevention of SHCs
Maher, McMillan& Nash, 2017	Title: Exercise and Health-Related Risks of Physical Deconditioning After Spinal Cord Injury Focused on exercise in SCI	not specific to prevention of SHCs
Galea 2012	Title: Spinal cord injury and physical activity: preservation of the body Focus of review was to present the role of physical rehabilitation in the management of SCI and not prevent SHCs	not specific to prevention of SHCs
Charlifue, Jha, Lammertse 2010	Title: Aging with spinal cord injury Discussed the presence of secondary health conditions without prevention strategies and it is mainly directed at aging with SCI generally.	not specific to prevention of SHCs
Ginis et al., 2008	Title: Establishing evidence-based physical activity guidelines: Methods for the Study of Health and Activity in People with Spinal Cord Injury (SHAPE SCI) Focused on physical activity guidelines	not specific to prevention of SHCs
Lavis, Scelza and Bockenek, 2007	Title: Cardiovascular Health and Fitness in Persons with Spinal Cord Injury. Focus was on cardiovascular not prevention of SHCs	not specific to prevention of SHCs
Rimmer and Schiller et al., 2006	Future directions in exercise and recreation technology for people with spinal cord injury and other disabilities	Could not find
Dudley-Javoroski and Shields, 2006	Title: Assessment of physical function and secondary complications after complete spinal cord injury. The study reported only on the physical function scores and the occurrence of SHCs	not specific to prevention of SHCs

Chase et al., 2004	Reflection on physical activity, health, and wellness: Developments and advancements for people with spinal cord injury.	Could not find
Washburn et al.,1998	Physical activity and chronic cardiovascular disease prevention in spinal cord injury: A comprehensive literature review.	Could not find
Lennox et al., 2018	Experiences with navigating and managing information in the community following spinal cord injury. Study results focused on information sources and management of information	not specific to prevention of SHCs
Tederko et al., 2017	Determinants of health knowledge and health perceptions from the perspective of health-related education of patients with spinal cord injury: a systematic review Review focus was not prevention of SHCs	not specific to prevention of SHCs
Koller et al.,2016,	Two patients with transition needs: A case study Focus was on the role of the rehabilitation nurses in SCI	not specific to prevention of SHCs
Stampas and Tansey, 2014	Spinal Cord Injury Medicine and Rehabilitation Case report on incomplete SCI not on management of SHCs	not specific to prevention of SHCs
Capoor and Stein, 2005	Aging with spinal cord injury Focus of the review was on aging and physiological changes related to aging	not specific to prevention of SHCs
Thomason 2004	SCI nurses make waves for healthy people with disabilities 2010: focus on health promotion and preventing secondary complications.	Could not find
Glitter 2004	Acute Rehabilitation in Cervical Spinal Cord Injury.	Could not find
Wolfe et al., 2011	Spinal cord injury knowledge mobilization network. Focus was on the description of the project	not specific to prevention of SHCs
Potter et al.,2004	Title: Challenges in educating individuals with SCI to reduce secondary conditions	Could not find
Colony et al., 2002	Title: Teaching for life: integrating aging into the rehabilitation education program	Could not find
Lindsey et al., 2002	Title: Providing SCI education during changing times.	Could not find
Lindsey 1998	Title: Designing patient education materials to increase independence	Could not find

Betts et al., 1989	Title: Rehabilitation Research and Training Center for the prevention and treatment of secondary complications of spinal cord injury Grant application for SCI research	not specific to prevention of SHCs

APPENDIX G: INVITATION TO PARTICIPATE IN A FOCUS GROUP DISCUSSION TO INFORM THE PREVENTION MODEL OF CARE FOR SECONDARY HEALTH CONDITIONS IN PEOPLE WITH SPINAL CORD INJURY.

Re: Invitation to participate in a group discussion to inform the development of a prevention model of care for secondary health conditions in people with spinal cord injury.

Good day

My name is Sonti Pilusa, my overall study focus is on factors influencing the prevention of secondary health conditions in people with spinal cord injury.

Brief Background

People with spinal cord injury develop preventable secondary complications/ secondary health conditions e.g. pressure sores, pain, urinary tract infection etc., increasing hospital readmission and decreasing quality of life. There is a need to strengthen prevention care for secondary health conditions in this population group. The current study aims to identify services and interventions that can be part of a model of care for the prevention of secondary health conditions in people with spinal cord injury. A model of care defines how services and interventions are rendered to a specific population.

I am asking for your input/recommendations/ideas to answer this question: **Which services and interventions are needed to prevent secondary health conditions among people with spinal cord injury throughout their life span?**

Participation is voluntary and you may withdraw from the discussion at any stage or choose not to participate without any penalty. The discussion will be kept confidential and the information gathered will be used for research only and scientific publication.

This study has ethical clearance from the Human Research Ethics Committee, University of the Witwatersrand.

If you have any questions concerning this study, contact:

Mrs. Sonti Pilusa Tel: 011 717 3715 or cell: 082 053 6190 sonti.pilusa@wits.ac.za

Research supervisors: Professor Hellen Myezwa Hellen.Myezwa@wits.ac.za 011 717 2063 and

Professor Joanne Potterton Joanne.Potterton@wits.ac.za 011 717 3702

Human Research Ethics Committee, University of the Witwatersrand 011 717-700/2656/1234/1252 zanele.ndlovu@wits.ac.za

Please complete the following section if you are willing to participate

I hereby volunteer to take part in this study.

Participant: _____ _____

(name and surname) signature

Date: _____

Audio recording permission

I agree that Mrs Sonti Pilusa may tape record my group discussion with her and that she will take out any name and places that we talk about when the interview is typed up.

_____ _____ _____

(Signature of participant) (Date) (Printed name)

Please complete the Demographic data table

Participant name:	
Date of interview:	
Gender	
Date of Birth	
Level of education	
Occupation	
Institution & Department	

APPENDIX H: THE CONTRIBUTOR ROLES TAXONOMY (CREDIT)

The Contributor Roles Taxonomy (CRediT) (Allen et al., 2019b) was used to outline the authors' contribution to the study.

. The full explanation of the terms:

Term	**Definition**
Conceptualization	Ideas; formulation or evolution of overarching research goals and aims
Methodology	Development or design of methodology; creation of models
Validation	Verification, whether as a part of the activity or separate, of the overall replication/ reproducibility of results/experiments and other research outputs
Formal analysis	Application of statistical, mathematical, computational, or other formal techniques to analyse or synthesize study data
Data curation	Management activities to annotate (produce metadata), scrub data and maintain research data (including software code, where it is necessary for interpreting the data itself) for initial use and later re-use
Writing – original draft	Preparation, creation and/or presentation of the published work, specifically writing the initial draft (including substantive translation)
Writing – review and editing	Preparation, creation and/or presentation of the published work by those from the original research group, specifically critical review, commentary or revision – including pre- or post-publication stages
Visualization	Preparation, creation and/or presentation of the published work, specifically visualization/data presentation
Supervision	Oversight and leadership responsibility for the research activity planning and execution, including mentorship external to the core team
Funding acquisition	Acquisition of the financial support for the project leading to this publication

APPENDIX I: DATA COLLECTION TOOL FOR THE PREVALENCE STUDY

Record ID	_____
Data Collection date	_____
Hospital name	◯ Tshwane Rehab Hopistal ◯ Steve Biko Hospital
Participant hospital number	_____
DEMOGRAPHIC DATA	
Date of Birth	_____
Age	_____
Gender	◯ Female ◯ Male
Race	◯ Black ◯ White ◯ Indian ◯ Coloured
Employed	◯ Yes ◯ No
Type of employment	☐ Paid employment ☐ Self-employed ☐ Other
Specify other employment type	_____
Means test classification - income	◯ H0 -Social grant ◯ H1: R0-R70 000 per annum (single income)/ R0-R10(000/annum (household income) ◯ H2: R70 000-R250 000/annum (single income)/ R10(000 -R350 000/annum (household income) ◯ H3: > R250 000/annum (single income)/> R350 000/annum (household income) ◯ P(MVA) ◯ Not stated
Level of education	◯ No schooling completed ◯ Primary school (
Marital status	◯ Single ◯ Married

Home province &township	_____
DISABILITY INFORMATION	
Date of injury (Disability)	_____
Duration since injury	_____
Type of lesion	◯ Traumatic ◯ Nontraumatic
Cause of Spinal cord injury	◯ Motor vehicle accidents ◯ Falls ◯ Acts of violence (Gunshot/stab) ◯ Sports-related injuries ◯ Medical / surgical ◯ Diseases
Diseases causing Spinal cord injury	☐ Degeneration of the spinal column ☐ Infections ☐ Cancer/tumors ☐ Inflammation ☐ Congenital medical issues ☐ TB ☐ Other
Specify other types of diseases	_____
Level of injury	_____
Neurological level of injury	◯ Upper cervical (C2-C4) ◯ Lower cervical (C5-C8) ◯ Upper thoracic (T1-T6) ◯ Lower thoracic (T7-T12) ◯ Lumbar (L1-L5) ◯ Sacral (S1-S5)
lesion level and completeness	◯ Paraplegia/incomplete ◯ Paraplegia/complete ◯ Tetraplegia/incomplete ◯ Tetraplegia/complete ◯ Other
specify other lesion level	_____

ASIA Scale	☐ Grade A: Complete. No sensory or motor function is preserved in the sacral segments S4-S5. ☐ Grade B: Sensory incomplete. Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5 (light touch, pin prick at S4-S5 or deep anal pressure), AND no motor function is preserved more than three levels below the motor level on either side of the body. ☐ Grade C: Motor incomplete. Motor function is preserved below the neurological level and more than half of key muscle functions below the single neurological level of injury (NLI) have a muscle grade less than 3 ☐ Grade D: Motor incomplete. Motor function is preserved below the neurological level and at least half of key muscle functions below the NLI have a muscle grade of 3 or greater. ☐ Grade E: Normal sensation ☐ Not stated
Presence of other disabilities	◯ Yes ◯ No
state type of disability	_____
RISK FACTORS	
Smoking	◯ Yes ◯ No ◯ Not stated
Alcohol consumption	◯ Yes ◯ No ◯ Not stated
Metabolic factors	◯ Underweight ◯ Normal ◯ Overweight ◯ Not stated
Drug use	◯ Yes ◯ No ◯ Not stated
Other risk factors	_____
CHRONIC DISEASES	
Chronic disease present	☐ YES ☐ NO ☐ NOT STATED
Cancer	◯ Yes ◯ No ◯ Not stated
Diabetes	◯ Yes ◯ No ◯ Not stated
Hypertension	◯ Yes ◯ No ◯ Not stated
Hypercholestrol levels	◯ Yes ◯ No ◯ Not stated
Specify other chronic disease	_____

SECONDARY HEALTH CONDITIONS	
PRESSURE SORES	
Pressure sore present	○ Yes ○ No ○ Not stated
Pressure sore location- Sacral	○ Yes ○ No
Pressure sore location Heels	○ Yes ○ No
Pressure sore location- Ankles	○ Yes ○ No
Pressure sore location-Scapula	○ Yes ○ No
specify other pressure sore location	_____
Specifiy grade (Pressure sore)	☐ Grade1: most superficial type of ulcer. The affected area of skin appears discoloured and is red in white people, and purple or blue in people with darker coloured skin ☐ Grade II: some skin loss or damage involving the top-most skin layers ☐ Grade III - necrosis (death) or damage to the skin patch, limited to the skin layers ☐ Grade IV - necrosis (death) or damage to the skin patch and underlying structures, such as tendon, joint or bone. ☐ Not stated
PAIN	
Presence of Pain	○ Yes ○ No ○ Not stated
Neurogenic pain	☐ yes ☐ No ☐ Not stated
LOCATION OF NEUROGENIC PAIN	_____
Muscular pain	☐ yes ☐ No ☐ Not stated
LOCATION OF MUSCULAR PAIN	_____
Joint pain	☐ yes ☐ No ☐ Not stated
LOCATION OF JOINT PAIN	_____
specify other (Pain)	_____
Circulatory problems	

Circulatory problems	☐ Yes ☐ No ☐ Not stated
DVT	☐ Yes ☐ No ☐ Not stated
Pulmonary embolus	☐ Yes ☐ No ☐ Not stated
Orthostatic hypotension	☐ Yes ☐ No ☐ Not stated
Swelling of feet	☐ Yes ☐ No ☐ Not stated
Autonomic hyperreflexia	☐ Yes ☐ No ☐ Not stated
Fatigue and Sleep	
Extreme fatigue/persistent tiredness	☐ Yes ☐ No ☐ Not stated
Sleep problems	☐ Yes ☐ No ☐ Not stated
INJURIES	
Presence of Injuries	☐ Yes ☐ No ☐ Not stated
Burns	☐ Yes ☐ No ☐ Not stated
Falls	☐ Yes ☐ No ☐ Not stated
Fractures	☐ Yes ☐ No ☐ Not stated
Specify other injury	_____
Location of injury	_____
SKELETAL PROBLEMS	
Skeletal complications	☐ Yes ☐ No ☐ Not stated
Osteoporosis	☐ Yes ☐ No ☐ Not stated
Spinal deformity	☐ Yes ☐ No ☐ Not stated
Kyphosis	☐ Yes ☐ No ☐ Not stated
Scoliosis	☐ Yes ☐ No ☐ Not stated
Lordosis	☐ Yes ☐ No ☐ Not stated
Heterotopic bone ossification	☐ Yes ☐ No ☐ Not stated

RENAL PROBLEMS	
Renal problems	○ Yes ○ No
Urinary tract infection	☐ Yes ☐ No ☐ Not stated
Incontinence	☐ Yes ☐ No ☐ Not stated
State other renal problem	_____
Bowel problems	
Bowel problems	○ Yes ○ No
Constipation	☐ Yes ☐ No ☐ Not stated
Diarrhea	☐ Yes ☐ No ☐ Not stated
Bowel incontinence	☐ Yes ☐ No ☐ Not stated
Specify other bowel problems	_____
Respiratory problems	
Respiratory problems	☐ YES ☐ NO ☐ NOT STATED
Pneumonia	☐ YES ☐ NO ☐ NOT STATED
Bronchitis	☐ YES ☐ NO ☐ NOT STATED
Sleep apnea	☐ YES ☐ NO ☐ NOT STATED
Flu	☐ YES ☐ NO ☐ NOT STATED
Asthma	☐ YES ☐ NO ☐ NOT STATED
If other, specify	_____
Contractures and Spasticity	
Presence of contractures	☐ Yes ☐ No ☐ Not stated

Location of contracture	☐ elbow joints ☐ fingers ☐ wrists ☐ Shoulders ☐ ankles ☐ knees ☐ Not stated
Spasticity	☐ Yes ☐ No ☐ Not stated
Type of spasticity	☐ increased intermittent or sustained involuntary somatic reflexes (hyperreflexia) ☐ clonus ☐ painful muscle spasms ☐ hypertonus ☐ not stated
Location of spasticity	_____
Sexual problems	
Sexual problems	☐ yes ☐ No ☐ Not stated
Sexual problems type	☐ Loss of libido ☐ erectile dysfunction ☐ Ejaculatory problems ☐ other ☐ not stated
State, other sexual problems	_____
Post traumatic Syringomyelia	☐ yes ☐ No ☐ Not stated
MENTAL HEALTH	
Mental health problems	☐ yes ☐ No ☐ Not stated
Mental health problem type	☐ Serious episodes of anxiety ☐ Depression ☐ Stress ☐ not stated
Other secondary conditions	_____

Prevention strategies for secondary health conditions in people with spinal cord injury: a scoping review protocol

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ABSTRACT

Objective: The objective of the review is to map existing evidence and to provide an overview of the prevention strategies for secondary health conditions that have been reported in people with spinal cord injuries.

Introduction: Spinal cord injury is a physical disability caused by a lesion in the spinal cord resulting in a loss of sensory and motor function below the affected area. In the lifespan of a person living with spinal cord injury, at least one preventable secondary health condition will develop. These conditions can be predictable and potentially prevented.

Inclusion criteria: This review will consider studies that include participants 18 years and over with spinal cord injury and report on prevention strategies for secondary health conditions (e.g. pressure sores, urinary tract infection, pain) at all levels of disease prevention (primary, secondary and tertiary level). Studies of any design conducted in a clinical (hospital and primary healthcare facility), home or community-based setting will be considered.

Methods: A three-step search strategy will be used in this review, with an initial search of MEDLINE (PubMed) and CINAHL. Databases to be searched include: PubMed, PEDro, CINAHL, Embase, Scopus, Health Source: Nursing/Academic Edition and SPORTDiscus. Government resources (Department of Health website), World Health Organization, Google Scholar and OpenGrey will be searched for unpublished studies. Titles and abstracts will be screened by two independent reviewers. Studies that meet the inclusion criteria will be retrieved and assessed. Results will be presented in narrative and tabular form.

Keywords Prevention strategies; secondary complications; secondary conditions; secondary health conditions; spinal cord injury

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Introduction

Spinal cord injury (SCI) is a physical disability caused by a complete or incomplete lesion in the spinal cord resulting in a loss of sensory and motor function below the affected area. It is more prevalent in the adult population.[1,2] People with SCI experience preventable secondary health conditions, which negatively impact their health, quality of life and participation in life, as well as increasing re-hospitalization rates.[3-5] Secondary health conditions are preventable complications, such as urinary tract infections and pressure sores, that a person living with disability is predisposed to in their lifetime as a result of living with a disability.[6-8] Different researchers have used different terminologies for these health conditions, namely secondary conditions, secondary medical problems, secondary impairments, secondary participation limitation, secondary complications and secondary disabilities.[6,7,9] For the purpose of this study, the term secondary health conditions will be used.

In the lifespan of a person living with SCI, at least one preventable secondary health condition will develop. Adriaansen *et al.*[5] assessed the occurrence of secondary health conditions in persons living with SCI at different periods in the journey of care. The study reported a high prevalence, with 98.5% of participants having had at least one secondary health condition. The most common secondary health conditions were musculoskeletal pain, neuropathic pain,

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pressure ulcer, urinary tract infection and edema. Similar findings were noted in an earlier longitudinal study by Adriaansen *et al.*[8] that looked at the occurrence of secondary health conditions and their potential risk factors in persons with SCI, one to five years post discharge. These secondary health conditions are known to affect people with SCI, thus they are predictable and preventable.[8]

Prevention care for a person with SCI must be at primary, secondary and tertiary levels, starting during inpatient rehabilitation and continuing after hospital discharge in the community.[10-12] Prevention care at a primary level focuses on stopping the health condition from occurring; secondary level prevention focuses on early detection and treatment of the condition to prevent its progression; and tertiary level prevention care aims to manage the condition to prevent its consequences.[13] Throughout the lifespan of disability, a person with SCI must be able to prevent secondary health conditions and manage them when they have occurred. However, research indicates that the prevention care needs of people living with SCI are not being fully met.[14,15] A study by Van Loo *et al.*[15] described the care received and extra care needs related to secondary conditions experienced by people living with SCI at home. Thirty percent of the care received focused on treatment for the most problematic secondary health conditions, namely pressure sores, pain, spasms, bladder and bowel problems.[15] The fact that such a high percentage of participants received treatment for secondary conditions could indicate that most of the preventive care occurs after secondary conditions have already developed. In addition, the study found that 41% of the participants still needed extra care related to secondary conditions, mostly in the form of treatment care, psychosocial care and access to information.[15] This finding indicates a need to strengthen prevention care at all levels to minimize the risk of developing preventable secondary health conditions and their consequences. Similarly, a study by Mashola *et al.*[16] looked at hospital readmission rates and reasons for readmissions for persons with SCI. The study found that 80% of readmissions were due to secondary health conditions, with pressure sores and urinary tract infections being the leading causes.[16]

Prevention strategies for secondary health conditions must be holistic in their approach in order to meet the needs of people living with SCI. Prevention strategies are interventions or approaches that aim to address risk factors that predispose an individual to ill health in order to minimize the chance of developing or minimizing progression of a health condition.[13] Prevention strategies can be targeted at a primary, secondary or tertiary level. Previous studies have considered prevention strategies in isolation, such as role of physical activity and the use of assistive devices in preventing secondary conditions.[17,18] Social support networks[19] and self-management have also been highlighted as important preventive care strategies for secondary conditions.[20,21] Some studies have looked at strategies to enhance self-efficacy in self-management for secondary health conditions through peer mentoring, education and motivational interviewing.[22-25] Although there are studies that have reported on strategies to prevent secondary health conditions, when assessed against frameworks for prevention studies such as Rimmer *et al.*'s,[7] the range of prevention strategies is still unknown. Rimmer *et al.*[7] developed a conceptual model for identifying, preventing and managing secondary conditions in people with disabilities. This conceptual model proposed elements of a prevention and intervention strategy for secondary conditions which included health promotion, rehabilitation, assistive devices and policy.[7]

There are limited studies that review these key concepts for the prevention of secondary health conditions, specifically in people living with SCI. A scoping review to map the evidence will be useful because it will give a broad overview of types of prevention strategies for secondary health conditions that have been reported in the literature and any gaps that exist.

A preliminary search was conducted in the Cochrane Database of Systematic Reviews and the *JBI Database of Systematic Reviews and Implementation Reports*, and no scoping reviews or systematic reviews on this topic was identified.

Review question

What kind of prevention strategies for secondary health conditions have been reported for people with SCI?

Inclusion criteria

The inclusion criteria for this scoping review will be guided by the population, concepts and context (PCC) approach.

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Population

This review will consider studies that include people with SCI. Both non-traumatic and traumatic SCI will be included, with no limitation on the duration of living with SCI, severity or the level of the lesion. Studies with female or male participants who are 18 years and over will be included.

Concept

This review will consider papers that report on different prevention strategies for secondary health conditions (e.g. pressure sores, urinary tract infection, pain) at all levels of disease prevention (primary, secondary and tertiary level) including, but not limited to, rehabilitation, health promotion, assistive technology and policy. Examples of prevention strategies include physical activity or exercise therapy, self-management intervention, peer mentoring, health education and motivational interviewing.

Definition of concepts

Health promotion is a "process of enabling people to increase control over, and to improve, their health".[26(para.3)] Health promotion interventions can include exercise interventions, health literacy, self-efficacy skills training, social support, peer support and accessibility of the environment.

Policy can be guidelines and/or frameworks that advocate for the health care of a person with a disability, as illustrated in the coverage for power assisted wheelchairs, and health insurance coverage.[7,27]

Rehabilitation is a process across the continuum of care in the lifespan of a person with a disability that aims to maximize function and participation in key aspects of life within the individual's environment.[7,28] Rehabilitation intervention can include patient-orientated therapy, exercises training, family support, counseling, modification to the environment and self-management strategies.

Assistive devices are equipment used to enhance the functional ability of an individual with a disability and facilitate participation in life events such as power-assisted wheelchairs, prostheses and specialized computer software.[7,29]

Context

The review will consider studies on prevention strategies for secondary health conditions experienced by people with SCI conducted in a clinical (hospital and primary health care facility), home or community-based setting. The context will not be limited to specific geographic locations or racial or gender-based interests.

Type of sources

This review will consider all study designs including descriptive cross-sectional, experimental, systematic reviews, meta-analysis and qualitative. Opinion letters and conference papers will also be included.

Methods

This scoping review will identify the range of available evidence and relevant literature (published and unpublished) following JBI methodology.[29]

Search strategy

A three-step search strategy will be used to search the databases. The initial search of MEDLINE (PubMed) and CINAHL will be conducted, followed by an analysis of the text words contained in the title and abstract of retrieved papers, and of the index terms used to describe the articles. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference lists of all identified reports and articles will be searched for additional relevant studies. If more information is required, the authors of primary studies or reviews will be contacted. The proposed search strategy is outlined in Appendix I. All relevant literature on the kinds of prevention strategies for secondary health conditions experienced by people with SCI (published and unpublished) from inception to the present date in English will be considered.

Information sources

Databases to be searched include: PubMed, PEDro, CINAHL, Embase, Scopus, Health Source: Nursing/Academic Edition, and SPORTDiscus. Government resources (Department of Health website), World Health Organization, Google Scholar and OpenGrey will be searched for unpublished studies.

Study selection

Following the search, all identified studies will be managed using Mendeley (Mendeley Ltd., Elsevier, Netherlands) and duplicates will be removed. Titles

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and abstracts will be screened by two independent reviewers for assessment against the inclusion criteria. Potentially relevant studies will be retrieved and assessed. Studies that do not meet the inclusion criteria will be excluded. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram will outline the search process and the number of articles identified, included and excluded, with reasons.[30]

Data extraction

The resulting articles will be retrieved and examined for the author, year of publication, country of origin, study aim, sample (size, age, and sex) and study outcomes against the inclusion criteria. Studies will be classified according to study design using Evans' Hierarchy of Evidence, a framework for ranking evidence evaluating healthcare interventions.[31] Data extraction will be conducted by the primary reviewer using the data charting table (Appendix II). A second reviewer will confirm the accuracy of the extraction process based on the inclusion criteria. Where there is a disagreement, a third reviewer will aid in the decision. Charting the results is an iterative process; therefore, the charting table will be updated throughout the reviewing process.

Data presentation

Results will be presented in a tabular form to map existing evidence on kinds of prevention strategies for secondary health conditions, level of prevention and level of evidence. A narrative summary will describe how the tabulated results related to the review question.

Acknowledgments

Dr Tunde Adajidahun for reading this protocol and offering feedback. This scoping review will contribute toward completion of a doctoral degree in physiotherapy for author SP.

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Appendix I: Search strategy for PubMed

search conducted July 19, 2019

Search	Query	Records retrieved
#7	Search (#6) Filters: English	25
#6	Search (#1 AND #2 AND #5)	26
#5	(#3 OR # 4)	663,579
#4	Search "Health Promotion"[Mesh] OR "Preventive Health Services"[-Mesh] OR "Primary Prevention"[Mesh] OR "Preventive Medicine"[Mesh] OR "Health Education"[Mesh] OR "Public Health Nursing"[Mesh] Sort by: PublicationDate	615,322
#3	Search "health promotion" OR "health behaviour*" OR "patient education" Sort by: PublicationDate	203,202
#2	Search "secondary health conditions" OR "secondary conditions" OR "secondary medical problems" OR "secondary impairments" OR "secondary participation limitation" OR "secondary complications" OR "secondary disabilities" Sort by: PublicationDate	2781
#1	Search "Spinal Cord Injuries"[Mesh] Sort by: PublicationDate	46,609

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Appendix II: Data extraction tools

Level 1: Study details	
Author (year published)	
Title	
Study aim	
Country	
Context (clinical, home, community)	
Participants (age, gender, type of SCI, level of injury, duration of living with SCI)	
Study design	
Data collection methods	
Level of evidence	
Key findings	
Reviewers' summary	
Level 2: Results extracted from the study	
Prevention strategy used for secondary health conditions: i) Health promotion ii) Rehabilitation iii) Policy iv) Assistive device v) Other prevention strategies	
Level of prevention i) Primary ii) Secondary ii) Tertiary	

SCI: spinal cord injury.

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APPENDIX K: DECLARATION: STUDENT'S CONTRIBUTION TO ARTICLE (S) AND AGREEMENT OF CO-AUTHOR(S)

Declaration: Student's contribution to article(s) and agreement of co-author(s)

I, SONTI IMOGENE PILUSA, student number, 9311506K declare that this Thesis Report is my own work and that I contributed adequately towards research findings published in the article(s) stated below, which are included in my Thesis.

Signature of Student _____ **Date:** 30 April 2021

Name of Primary Supervisor: Hellen Myezwa

Signature of Primary Supervisor ..... **Date** 02/05/2021

Name of Secondary Supervisor: Joanne Potterton

Signature of Primary Supervisor ..... **Date** 02/05/2021

Agreement by co-authors: By signing this declaration, the co-authors listed below agree to the use of the article(s) by the student as part of her Thesis. In cases where the student is not the 1st author of a published article, the primary supervisor must explain (under comments) why the student is entitled to use the paper for her degree purposes.

Article 1: Title: Experiences of secondary health conditions amongst people with spinal cord injury in South Africa

Journal name, year, volume and page numbers: South African Journal of Physiotherapy, 2021, 77(1) 1-8. doi:https://doi.org/10.4102/sajp.v77i1.1530

Authors	Name	Signature	Date
1st author	Pilusa, S.		30 April 2021
2nd author	Myezwa, H.		30 April 2021
3rd author	Potterton, J.		30 April 2021

Comments by primary supervisor:

This publication is as a result of original work conducted by the candidate Ms Sonti Pilusa, supervised by Professor Hellen Myezwa and Professor Joanne Potterton

Article 2: Title: 'I forget to do pressure relief': Personal factors influencing the prevention of secondary health conditions in people with spinal cord injury, South Africa

Journal name, year, volume and page numbers: *South African Journal of Physiotherapy, 77*(1), 1-9 .doi:https://doi.org/10.4102/sajp.v77i1.1493

Authors	Name	Signature	Date
1st author	Pilusa, S.		30 April 2021
2nd author	Myezwa, H.		30 April 2021
3rd author	Potterton, J.		30 April 2021

1

Comments by primary supervisor:

This publication is as a result of original work conducted by the candidate Ms Sonti Pilusa, supervised by Professor Hellen Myezwa and Professor Joanne Potterton

Article 3: Title: Prevention strategies for secondary health conditions in people with spinal cord injury, Prevention strategies for secondary health conditions in people with spinal cord injury, protocol

Journal name, year, volume and page numbers: JBI Evidence Synthesis: October 24, 2019 - Volume Online First - Issue -doi: 10.11124/JBISRIR-D-18-00015

Authors	Name	Signature	Date
1st author	Pilusa, S.		30 April 2021
2nd author	Myezwa, H.		30 April 2021
3rd author	Potterton, J.		30 April 2021

Comments by primary supervisor:

This publication is as a result of original work conducted by the candidate Ms Sonti Pilusa, supervised by Professor Hellen Myezwa and Professor Joanne Potterton

Article 4: Title: Prevention care for secondary health conditions among people living with spinal cord injuries: research protocol.

Journal name, year, volume and page numbers: *BMC Res Notes* 12, 179 (2019). https://doi.org/10.1186/s13104-019-4202-7

Authors	Name	Signature	Date
1st author	Pilusa, S.		30 April 2021
2nd author	Myezwa, H.		30 April 2021
3rd author	Potterton, J.		30 April 2021

Comments by primary supervisor:

This publication is as a result of original work conducted by the candidate Ms Sonti Pilusa, supervised by Professor Hellen Myezwa and Professor Joanne Potterton

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UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FACULTY OF HEALTH SCIENCES

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

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PREVENTION CARE FOR SECONDARY HEALTH CONDITIONS AMONG PEOPLE WITH SPINAL CORD INJURY IN THE TSHWANE METROPOLITAN AREA

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