

Secondary health conditions and their impact on the wellbeing of people with spinal cord injury, South Africa: Patients perspective.

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Abstract

Background Long-term rehabilitation that includes preventive care for people with spinal cord injury is key to promoting health. There is evidence that secondary health conditions (SHCs) are prevalent complications across the continuum of care for people with spinal cord injury, leading to recurrent hospitalization and poor quality of life. In order to develop a context-based prevention model of care and strategies in South Africa, there is a need to understand the lived experiences of people with spinal cord injury (SCI).

Aim To describe people with spinal cord injury's experiences of secondary health conditions and the impact these have on their wellbeing.

Methods A qualitative descriptive design using semi-structured interviews was adopted. Purposive sampling was used to collect data from 17 participants with SCI who attend outpatient medical care at a tertiary rehabilitation hospital in Gauteng, South Africa. Primary data were collected from August 2018-July 2019. All interviews were transcribed verbatim and analysed using a thematic analysis approach.

Results People with spinal cord injury experience a range of secondary health conditions, of which pain, bowel and bladder issues were the most common. The presence of SHCs had an impact on the psychological, physical and social wellbeing of the participants.

Conclusion There is a need for prevention interventions (health education and screening) for SHCs throughout the continuum of care and at all levels of prevention. Further research on factors influencing the prevention and management of SHCs is needed.

Background

Spinal cord injury (SCI) is a physical disability caused by a complete or incomplete lesion in the spine either due to trauma (gunshot, vehicle accidents, sports-related injuries and falls) or diseases like HIV, cancer, arthritis, cancer, and tuberculosis (TB) (1–3). The prevalence of SCI was estimated to range from 698–827 per million population among high-income countries and 220–519 per million people in low-income countries (4). The disparity is probably due to epidemiological data on disability from low-income countries not being monitored (3,5,6). Surveillance data indicate an incidence of spinal cord injury of 75.6 people per million in South Africa, mainly caused by injury in the form of assault (59.3%) motor vehicle accidents (26.3%) (7). Although the incidence of SCI seems low, the three main causes of SCI namely HIV, TB and injuries, contribute significantly to the burden of disease in South Africa even if there is limited research on these causes (8,9). Given that there is no cure for SCI, research on the health needs and care gaps for this group of people is imperative as advocated by global and national initiatives such as the Rehabilitation 2030 and Sustainable Development Goal number 3 "healthy lives and promotion of the well-being of all"(10,11).

Previous studies have shown that preventable secondary health conditions are common in people with SCI. Secondary health conditions (SHCs) are complications that can occur post-SCI throughout the continuum of care. These complications are not directly caused by the spinal cord injury but are related to living with a disability (12,13). During the acute hospital phase, the prevalence of SHCs ranges between 59%–78% (14,15). Whilst the prevalence of SHCs post-acute phase seems to be even higher (88%–100%) (14,16,17). Also, there is evidence that SHCs co-exist, with clustering of multiple SHCs (18). What this all means is that throughout the continuum there is a need for holistic and targeted prevention strategies such as health education, screening and prevention protocols to minimize the occurrence of these secondary health conditions and their impact on the wellbeing of people living with SCI.

The impact of secondary health conditions is the main issue patients with SCI complain about and must not be underestimated. Secondary health conditions have been reported to limit the quality of life (17,19); health (20); participation at work (21); social life (22) and to be a barrier to self-management (23). There are many studies that have explored lived experiences of SCI (21,24,25) and unmet care needs (24–26). However, the focus on the experiences of SHCs and their impact on wellbeing is limited. Callaway et al (21) conducted a pilot study exploring lived experiences of secondary health conditions in Australia to inform the National Disability Insurance Scheme. The study reported a range of secondary health conditions experienced by people with SCI and their impact in limiting participation. Unfortunately, we cannot generalise the findings of Callaway's study to South Africa because the context is not the same. There is a need for context-based exploration of people with SCI experiences of SHCs and their impact on their well-being.

In South Africa, research on the experiences of SHCs in people with SCI across the continuum of care is scarce. A study focusing on patients with traumatic SCI found that 50% of the participants had one or more SHCs (27). The most common SHCs reported in the study were pressure ulcers, pulmonary complications and urinary tract infection. This study focused only on patients with traumatic SCI during acute hospital phase. On the same note, Mashola and Mothabeng,(28) reported the association between health behaviour, SHCs and quality of life (QOL) in people with SCI discharged from a private rehabilitation hospital. The top three SHCs that had a significant effect on activity and independence were chronic pain (47%), spasms (36%) and joint and muscle pain (22%). The presence of SHCs affected neuro-musculoskeletal health behaviour and the presence of chronic pain affected health and QOL. The majority of those with significant pain reported needing medical treatment to function in their daily life. Even though the results of the study are informative, the study represents a small population that supposedly has access to health insurance to cover high private health care costs. The reality in South Africa is that the majority (84%) of South Africa's population don't have access to health insurance so they depend on the already strained public health system sector (29). Therefore, research on patients with SCI accessing public health care system in South Africa is imperative, to understand their illness journey and care needs.

Health providers and patients see illness through different lenses. Kleinman's' explanatory model of illness states that views on illness are shaped by how people perceive the causes, symptoms, severity,

expected consequences, appropriate treatment, anticipated outcomes, experiences related to the illness and coping mechanisms (30). If we are to fully understand the journey of people living with spinal cord injury, the complications they experience and their impact, we need to listen to patients' narratives of their experiences. Therefore, the objective of this study is to describe the experiences of SHC among people with spinal cord injury and the impact of SHC on their wellbeing.

Methods

Study setting

The study was undertaken at a public tertiary rehabilitation hospital in South Africa. The hospital has 79 beds offering rehabilitation services to patients with stroke, spinal cord injury, amputation, and head injuries to achieve their highest functional ability through therapy, education programmes, peer support and work-oriented visits. The disciplines available include occupational therapy, physiotherapy; speech therapy, dietetics, social work and psychology. The outpatient (OPD) services include doctor consultation; wound care management and collection of repeat medication and consumables; wheelchair seating clinic; individual therapy and wheelchair repairs; testing for HIV and non-communicable diseases. This rehabilitation hospital caters for the patients from other provinces due to lack of tertiary hospitals in those provinces.

Study Population

The key-informants were patients with SCI who attend outpatient medical care at the rehabilitation hospital once every three months. The inclusion criteria for the patients were a diagnosis of spinal cord injury, patients 18 years and above and must be a patient at the tertiary rehabilitation hospital. The key informants were recruited using purposive sampling.

Data collection

A qualitative descriptive design approach was used to give clarity and deeper understanding of the phenomenon of experiences of SHC among people with spinal cord injury and the impact of SHC on wellbeing (31). Semi-structured interviews were conducted using an interview guide that was developed, informed by literature on possible secondary health conditions which people with spinal cord injury experience. Part A of the interview guide included questions on sociodemographic information including age, sex, and injury date, cause of injury, level of the lesion, occupation, use of an assistive device for mobility and marital status. Part B of the interview guide included broad questions with probes on spinal cord injury and experiences of secondary health conditions. The interview guide was piloted with a researcher experienced in qualitative methods. Prior to the interview, written informed consent for the interviews and audio recordings was obtained. Semi-structured interviews lasting approximately 50 minutes were conducted by the principal researcher in the language the participant was comfortable in and the interviews continued until data saturation was reached. All the interviews were audio-recorded and transcribed verbatim for data analysis. Data were collected between June 2018 and July 2019.

Data analysis

In total, 17 interviews were conducted. The interviews were transcribed verbatim and the eleven interviews conducted in IsiZulu and Setswana were transcribed and then translated to English. All the transcripts were stored in a Microsoft Word document file. All the transcripts were read and spelling errors and mistranslation were removed prior to analysis. All the transcript were exported to MAXQDA version 2018.1 for analysis. Using thematic analysis coding was done inductively and deductively (32). One interview transcript was coded and a codebook was developed with the co-authors which was used for all the transcripts. Categorizing the codes was done both manually and using MAXQDA version 2018.1. Categorizing of the codes was done manually with the co-authors to identify the themes related to the study objectives. Recoding was conducted by the principal investigator and the results were compared.

Rigor

To ensure the trustworthiness of data the following strategies were be conducted (33). All the interviews were audio-recorded and debriefing sessions were conducted to discuss the research process, findings and data analysis with the co-authors with experience in qualitative research design. For transferability, the context and the demographic data of the participants were explained in detail. To ensure dependability a detailed description of the data collection, analysis and interpretation were outlined and code-recode procedure was employed- coding of a segment of data in two separate sessions and the results compared. To improve inter-coder reliability, a public health specialist with experience in health promotion and qualitative data analysis coded one transcript and the categories were compared.

Results

Characteristics of the participants

Seventeen patients with spinal cord injury were interviewed and the demographic information of the patients is presented in Table 1. The mean age of the participants was 44.7 ± 13 years with the age range of 27–72 and the majority were male 14(82%). The main cause of spinal cord injury was motor vehicle accidents 7(41%) and the mean duration since injury was 9 ± 7 years. Only 6(35%) of the participants were married and 14(82%) were using a wheelchair for mobility.

Table 1: Demographic information for patients with spinal cord injury (n=17)

Age in years (Mean, SD)	44.8 ± 13.6
Age range (years)	27-72
Gender	n (%)
Female	3(18)

Male	17(82)
Currently employed	5(31)
Marital status	
Single	11(65)
Married	6(35)
Time since injury (range in years)	1-30
(Mean, SD)	9±7
Cause of injury	
Trauma	14(82)
Motor vehicle accident	7(41)
Fall	3(18)
Gunshot	4(23)
Non trauma	3(18)
TB spine	1(6)
Tumour	1(6)
Vitamin B deficiency	1(6)
Type of SCI	
Paraplegia	13(76)
Quadriplegia	3(18)
Hemiplegia	1(6)
Completeness of the injury	
Complete	13(76)
Incomplete	4(24)
Assistive devices	
Wheelchair	14(82)
Walking aid	2(12)
None	1(6)

The study aimed to describe experiences of SHC among people with spinal cord injury and the impact of SHC on their wellbeing. The three themes that emerged from the qualitative data analysis were the “range of secondary health conditions experienced”; “co-occurrence of secondary health conditions” and the

“impact of secondary health conditions on wellbeing”. The range of secondary health conditions is presented in Table 2 followed by the qualitative narrative of the top two common secondary health conditions, co-occurrence of secondary health conditions and the impact of SHC on wellbeing.

Range of secondary health conditions experienced

Participants reported a range of secondary health conditions across the continuum of care, some SHCs occurring during the acute hospital phase and some in the post-discharge rehabilitation phase. The secondary health conditions experienced included pain; bowel and bladder problems; pressure sores; spasms; psychological problems (depression & worry); injuries; contractures; osteoporosis; respiratory problems; sleep disturbance; sexual problems and fatigue (presented in Table 2). The most common secondary health conditions were pain, depression and bowel and bladder problems.

Table 2: Range of secondary health conditions experienced n=17

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 prolapse	1(6)
	Bloating	1(6)
Psychological problems (depression, worry, 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)
Sleep disturbances		6(35)
Fatigue		4(24)
Skeletal problems	Osteoporosis	2(12)
	Arthritis	1(6)
	Myositis ossificans	1(6)
Respiratory problems		1(6)

Further probing revealed the nuanced experience of the common secondary conditions as shown in the qualitative results. The two most common secondary health conditions experienced by patients with spinal cord injuries are discussed below.

Pain

Ninety four percent of the participants experienced pain. The dimensions of pain expressed were the type, intensity, location and factors that worsened and eased the pain. Participants experienced “sharp burning pain”, joint pains and muscle pains. For some participants, the pain symptom was constant whilst a few had intermittent pain. Pain intensity ranged from unbearable to manageable and it was worsened by spasms and cold weather.

"Out of 10 my pain level is always 7.5, sometimes 9, sometimes 10. That is the biggest, biggest challenge." Female paraplegic 61 years.

"I have constant pain. I have pain daily ...if the pain can stop I will know that I'm no longer alive"

Male paraplegic 44 years.

Pain symptom was mostly managed by pain medication (tramadol) prescribed at the hospital. In addition, to ease the pain, some participants exercised, practised mindfulness, “ignored the pain”, accepted pain as part of their lives and kept busy so that they don’t focus on the pain.

Bowel and Bladder problems

Participants described bowel and bladder problems experienced and how they manage them. For bowel problems, participants experienced incontinence, diarrhoea and constipation. To manage bowel movements most patients used Coloplast, and to relieve constipation medication (Dulcolax) was used. Bladder problems included urinary tract infection, urine leaking and few had bladder stones. Participants expressed fear of accidentally leaking urine leading to restriction of water consumption and increasing the risk of urinary tract infection.

"I don't drink a lot of water because I feel, I can't keep urine for a long time"

Male paraplegic 39 years.

And another thing is that going to the bathroom, you can't feel whether you need to urinate or to do number 2, that's another stressful issue"

Male paraplegia 38 years

From the data analysis, there were patterns of co-occurrences of secondary health conditions. The co-occurrence of secondary health conditions noted was for osteoporotic bones and fractures; spasms and pain; spasm and sleep disturbance illustrated in Table 3.

Table 3: Co-occurrence of secondary health conditions

Themes	Category	Quote
Co-occurrence of Secondary health conditions	Some SHCs cluster/coexist	<i>I am now 30 years (living with spinal cord injury), sometimes, like not sleeping at night and you have spasms and your legs are kicking and you can't sleep. It's very demoralising when your foot goes like this all night, and just when you fall asleep, it feels like somebody is just giving you a pull in your foot like that. So you can't sleep,"</i> Male quadriplegic 50 years.

The impact of SHCs on wellbeing is illustrated in Table 4 using pain as an example

Table 4: Impact of secondary health conditions on wellbeing.

The presence of a secondary health condition had an impact on the psychological, physical and social wellbeing of the participants.

Themes	Category	Quote
Impact of Secondary health conditions on wellbeing	Psychological wellbeing	<i>"Phew, my neuropathic pain is the reason why I was in, the primary reason why I was always thinking about suicide, is that pain. Out of 10 my pain level is always 7.5, sometimes 9, sometimes 10. That is the biggest, biggest challenge"</i> Female paraplegic 61years.
	Physical wellbeing	<i>"Pain is on the back on the spine. So I am back on the wheelchair, some days the pain is unbearable, I can't hold my crutches..."</i> Female paraplegic 38 years.
	Social wellbeing	<i>"The issue of pains, when you at work you won't be happy when you have pain even... even if people make jokes when the pain comes you won't be happy.. it stresses me"</i> Female paraplegic 27 years

Discussion

The purpose of this study was to explore and describe experiences people with spinal cord injury have with secondary health conditions and the impact of SHC on their wellbeing. Using a descriptive qualitative approach three themes emerged, the range of secondary health conditions experienced, the co-occurrences of secondary health conditions and the impact of secondary health conditions on the wellbeing. Patients with SCI experienced a range of SHCs in agreement with previous studies on secondary health conditions occurring throughout the continuum of care, during inpatient hospital, (14,15,27) and post-hospital discharge (17,21,34). In comparison to local studies, the findings of this study are not surprising. Joseph et al (27) reported 50.3% of patients with SCI in acute tertiary care in Cape Town, had one or more secondary health conditions. Whilst Mashola and Mothabeng (28) reported a range of SHCs experienced by patients with SCI from a private rehabilitation hospital. There is a need for longitudinal research tracking the occurrence of SHCs and factors influencing the prevention of these SHCs in people with SCI throughout the continuum of care.

Similar to other studies on SHCs, pain, bowel and bladder problems were the most common complications experienced by people with SCI (21,25). A study by Piatt et al (35) described problematic secondary health conditions among adults with SCI and the impact on social participation and daily life. Pain and bowel regulation issues were ranked in the top problematic complications affecting social participation and daily life regardless of the majority of the participants having had attended a wellness programme (35). Similar findings were reported in a study by Fuseini, Aniteye and Alhassan, (36) on the experiences of spinal cord injury in Ghana. The experience of SCI included physical effects such as pain, bowel and bladder problems and pressure sores. Even though the study used different terminology to describe “physical effects of SCI”, in essence, these are the complications that can occur post-SCI collectively termed secondary health conditions. The presence of such diverse descriptions indicates the need to establish clearer terminology for secondary health conditions for research, planning and setting priorities for care for people with SCI.

There was co-occurrence of some of the secondary health conditions (Figure 1: Co-occurrence of secondary health conditions). For example spasms at night can disturb sleep patterns, leading to fatigue. Similar findings were reported by Brinkhof et al (18) indicating that some secondary health conditions cluster together such as pain and spasticity. There is a need for research to understand in detail the co-occurrence of SHCs and how they influence each other. The understanding of clustering of SHCs can be used to inform intervention strategies to not only focus on one SHC. In terms of clinical practice, clinicians must be aware of SHCs that coexist and screen for them during medical check-ups.

SHCs were found to have a negative impact on the psychological, physical and social well-being of patients with SCI. Pain symptom was used to illustrate the impact of SHCs on the wellbeing. Pain in the life of a person with a disability such as SCI is a common symptom in all the phases of care. The reported prevalence range between 34%–92% (16,18,35,37) with the type of pain (neuropathic or joint or muscle pain) influenced by the level of the lesion and the duration of the spinal cord injury (38). The presence of pain at times is related to the presence of other SHCs such as spasticity, pressure sore, contractures, urinary tract infection (21,37). Pain has an impact on many dimensions of health namely

quality of life (17,37); health (20); occupation (21); social life (22) and is a barrier to self-management (23). In agreement with the literature, the participants in this study expressed how pain made them worry, affected their sleep and mobility and limited their social participation. Clearly, focusing only on the health problem presence of pain and quantifying pain doesn't fully give a picture of the illness. To fully understand illness and health outcomes we need to focus on the impact of illness on the broader domains of health such as functional activities and participation in the community. For that reason, clinicians should be encouraged to use biopsychosocial framework such as the International Classification of Functioning, Disability and Health for assessment and treatment purposed throughout the rehabilitation process to fully capture the picture of illness and health.

Conclusions

This study aimed to describe people with spinal cord injury's experiences of secondary health conditions and the impact these have on their wellbeing. People with SCI experience a range of SHCs across the journey of care which has an impact on their psychological, physical and social wellbeing. The most commonly reported SHCs were pain, bowel and bladder problems. Given that SCI is a permanent disability, requiring a holistic approach to care throughout a continuum there is a need to strengthen prevention care within the rehabilitation process. Understanding the patients with SCI experiences of SHCs and their impact can be used to strengthen patient-oriented approaches to care. In addition, the findings of this study also highlight the need to encourage screening for SHCs during the medical check-up and develop targeted health education programmes that will empower patients with SCI to prevent the occurrence SHCs or minimize their impact on wellbeing.

Implications

In order to develop a context-based prevention model of care for SHC which encourage patient-oriented rehabilitation care, an understanding of lived experiences of secondary complications related to SCI is imperative. This study has added to the body of knowledge on secondary complications post-SCI. The study results will help clinicians understand priority health problems in patients with SCI and inform rehabilitation care throughout the continuum.

Recommendations

Further research on contextual factors influencing prevention care for secondary health conditions in people with spinal cord injuries is needed to understand what are the barriers and facilitators to preventing SHCs. Lastly, there is a need for research on the occurrence of secondary health conditions in terms of the types of SHCs and the risk factors associated with the co-occurrence.

Limitations of the study

This study was a descriptive qualitative design, thus generalization of the findings to the SCI population will be limited. The study participants were mostly men, paraplegics and traumatic SCI. Future research

must focus on women with SCI and on non-traumatic SCI. However, to the researchers' knowledge, this is the first study to listen to patients with SCI narratives on their experiences on experiences with secondary health conditions and the impact they have on their wellbeing in a public health care facility in South Africa.

List Of Abbreviations

SHC- Secondary health condition

SCI-Spinal cord injury

OPD-Outpatient

TB-Tuberculosis

Declarations

Ethical considerations and consent to participate

Ethical approval was obtained from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (M170938) and the study was registered with the South African National Health Research Database (reference GP201712036). Permission to use the study site for data collection was granted by the tertiary rehabilitation hospital. The study was explained to the participants as well as their rights to withdraw their participation at any stage. Interviews were conducted with patients who gave informed consent prior to the interview and permission to audio record the interview. To protect anonymity, the patients with SCI will be labelled using their gender, type of SCI and age.

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Author's contributions:

This study was part of the SP doctoral dissertation at the University of the Witwatersrand (South Africa).

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

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Figures

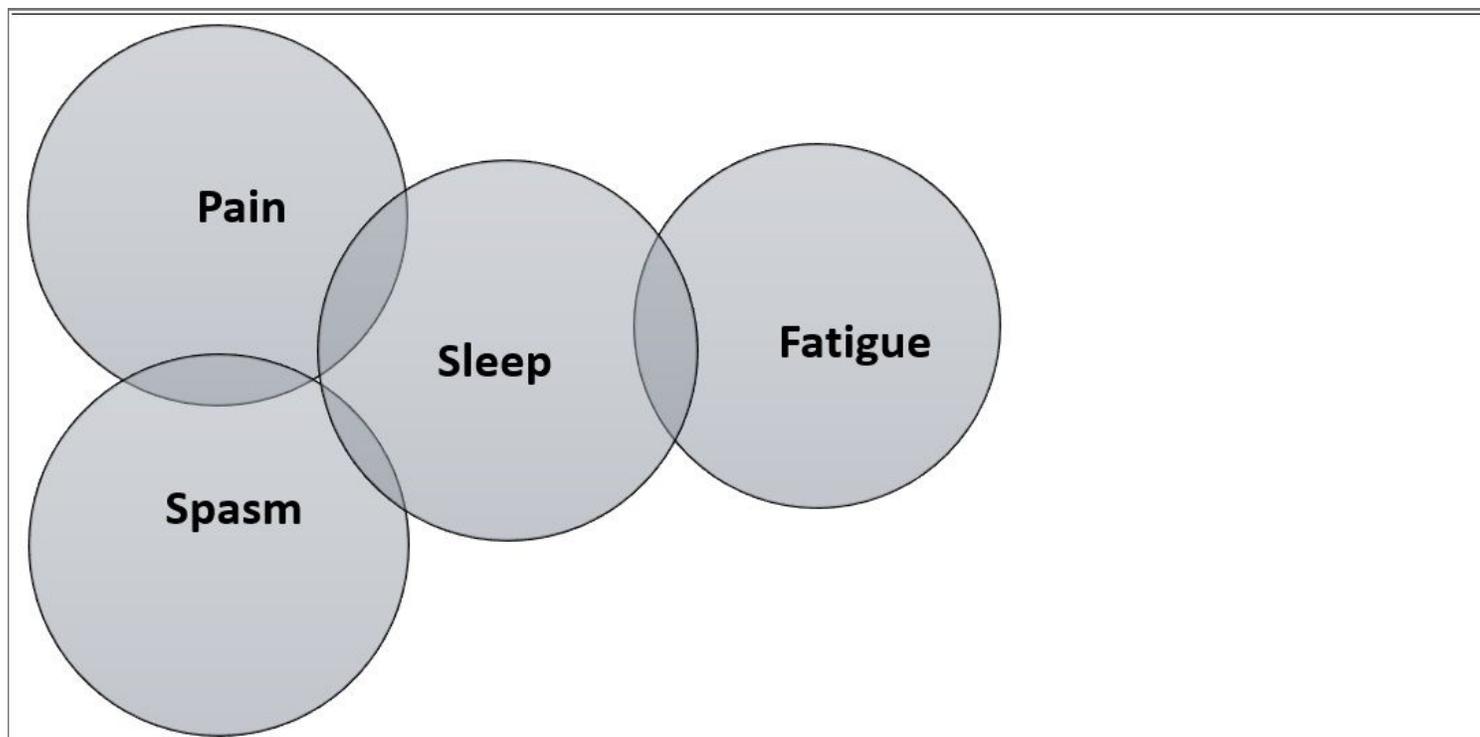


Figure 1

Co-occurrence of secondary health conditions