

**The survival status of People with Spinal Cord Afflictions following
discharge from a Gauteng Provincial Government Hospital**

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DECLARATION

I, EM Burger declare that this dissertation is my own, unaided work. It is being submitted for the Degree of Master of Science (Medicine) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

_____ day of _____ 2017

DEDICATION

*“To all the patients that I had the privilege to meet during my career -
you enriched me and made me the person that I am today”*

ABSTRACT

Background: A spinal cord affliction is defined as an insult to the spinal cord, and encompasses both traumatic and non-traumatic disruption to the spinal cord. There is a dearth of information on the epidemiology of spinal cord afflictions in low- and middle-income countries (LMIC) or the survival status of these individuals following discharge from hospitals. This study was conducted to determine the survival status of patients with spinal cord afflictions following discharge from a South African public sector academic hospital.

Study design: This was a cross-sectional study, consisting of a five-year retrospective record review for the period 1 January 2008 until 31 December 2012, and follow up of surviving patients at their homes.

Objectives: The objectives of the study were to: describe the demographic profile of People with Spinal Cord Afflictions (PSCA) discharged from the Dr George Mukhari Hospital Academic (DGMAH) Spinal Unit; determine the medical background information of all PSCA discharged; describe the environmental conditions faced by PSCA after discharge; and determine the survival status of PSCA following discharge from hospital.

Setting: A public sector academic hospital, the DGMAH, in the Gauteng Province of South Africa.

Methods: Using a cross-sectional study design, a record review was conducted of **all** PSCA admitted and treated at the DGMAH spinal unit for the period 1 January 2008 until 31 December 2012. A structured, pre-tested questionnaire was used to obtain demographic, medical and environmental information of PSCA. The patients admitted during the study period and known to be alive were contacted. During a home visit, a semi-structured questionnaire was completed with PSCAs. Descriptive data analysis was done using Microsoft Excel and Statistica[®] 13.

Results:

A total of 264 records were reviewed and 55/264 (20.8%) of patients passed away during hospital stay. The mean age of all patients discharged during the review period was 37, standard deviation (SD) 15.3. The majority of patients discharged were male (66.3 %). In terms of medical profile, 45 % (94) had a TSCA and 48.3% (101) a NTSCA, with 6.7% (14)

unknown. The leading cause of TSCA was road traffic accidents (RTAs) at 63.7%, while tuberculosis (TB) was the leading cause for NTSCA at 43.3%. An additional 19 patients are known to have died following discharge from hospital. There was very high non-response rate of 57.8 % (n: 152) and only 19 patients were visited in their homes

Conclusion: Patients with TSCAs were on average 10 years younger than those with NTSCAs. The study found that RTAs and TB were the leading causes of TSCAs and NTSCAs respectively, suggesting the need for a broader public health approach with prevention at its core. The high non-response rate suggests the need for improved hospital information systems to monitor patient outcomes after discharge.

Key words: Spinal cord affliction, non-traumatic, traumatic, demographic, medical, environmental,

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LIST OF ABBREVIATIONS AND ACRONYMS

ADL	Activities of daily living
AIDS	Acquired Immune Deficiency Syndrome
ASIA	American Spinal Injury Association Impairment Scale
BOD	Burden of Disease
DGMAH	Dr George Mukhari Academic Hospital
DALYs	Disability-Adjusted Life Years
ICF	International Classification of Function and Disability
ICD	International Classification of Diseases
ICHI	International Classification Health Intervention
ISCoS	International Spinal Cord Society
FICA	Financial Intelligence Centre Act
GHD	Gauteng Health Department
GNI	Gross National Income
GSW	Gunshot wound
GSWs	Gunshot wounds
HIC	High Income Countries
HIV	Human Immunodeficiency Virus
ISCOS	International Spinal Cord Injury Society
LMIC	Low, and Middle Income Countries
NCDs	Non communicable diseases
NSCISC	National Spinal Cord Injury Statistical Centre
NTSCA	Non – traumatic Spinal Cord Affliction
NTSCAs	Non – traumatic Spinal Cord Afflictions
OT	Occupational Therapy
PwD	Persons with Disabilities
PSCA	People with spinal cord afflictions
PT	Physiotherapy
RTA	Road traffic accident
RTAs	Road traffic accidents
SA	South Africa
SCA	Spinal Cord Affliction
SCAs	Spinal Cord Afflictions
SD	Standard deviation

SDG	Sustainable Development Goals
SDH	Social determinants of health
TBI	Traumatic Brain Injury
TSCA	Traumatic Spinal Cord Affliction
TSCAs	Traumatic Spinal Cord Afflictions
TB	Tuberculosis
WHO	World Health Organisation
WSPH	Wits School of Public Health
YLL	Years of Life Lost
YLD	Years Lived With Disability

CHAPTER 1: INTRODUCTION

1.1 Background

There is increasing global emphasis on the causes, management and impact of disability, as well as measures to ensure that the human rights of people living with disabilities are respected (1). A spinal cord affliction (SCA), is defined as an insult to the spinal cord that leads to severe functional limitations and secondary problems related to various body functions such as bowel and bladder, making the condition an important contributor to disability (2). A SCA encompasses both traumatic and non-traumatic disruption to the spinal cord. A traumatic spinal cord affliction (TSCA) is a result of road traffic accidents (RTAs), gunshot wounds (GSWs) and sports injuries. A non-traumatic spinal cord affliction (NTSCA) refers to a SCA that involves an underlying pathology, such as tuberculosis or cancer of the spine (3).

According to the World Health Organisation (WHO): *“The symptoms of spinal cord lesion depend on the extent of the injury or non-traumatic cause, but they can include loss of sensory or motor control of the lower limbs, trunk and the upper limbs, as well as loss of autonomic (involuntary) regulation of the body. This can affect breathing, heart rate, blood pressure, temperature control, bowel and bladder control, and sexual function”* (3):6. All these factors make a person with a SCA vulnerable to secondary complications and premature mortality (4).

Worldwide, there is a paucity of data on both the incidence and prevalence of SCA, but more information is available on TSCA, because of the relative ease of comparison of data across different settings. Globally the incidence of all SCAs is estimated at between 40-80 new cases per million of population per year (3). The global incidence rate of TSCA varies between 13-53 per million (3), whereas the prevalence, derived from six High Income Countries (HIC), is estimated to be between 280 - 1298 per million (5-8).

Estimates of incidence rates for NTSCA are difficult to compute because of different definitions and hence difficulties of comparing data across different country settings. The information gap on SCAs is even more acute in low- and middle-income countries (LMIC), despite the fact that 80 percent of the world’s population live in these countries (3). Hence the

WHO continues to advocate for improvements in both the quality and quantity of data collection (3).

There are also information gaps in South Africa, where there is a dearth of information on the aetiology, prevalence and incidence of SCA and the factors influencing the survival of people with spinal cord afflictions (PSCAs). It is important to address the knowledge gaps in the context of South Africa's quadruple burden of disease (BOD) which consists of communicable diseases (such as HIV and tuberculosis (TB), child and maternal mortality, non-communicable diseases and intentional and unintentional injuries (9), which can manifest as SCAs (10, 11).

In light of limited information on SCAs, the aim of this research study was to generate new knowledge on the survival status of PSCAs treated in a Gauteng Provincial Government Hospital. The remainder of this chapter sets the scene for the study that was conducted by: describing the study setting, outlining the problem statement and study rationale, and presenting the conceptual framework for the research. The chapter concludes with the study aim and objectives.

1.2 Overview of the study setting

The study was conducted at the Dr George Mukhari Academic Hospital (DGMAH), a large public sector, central, academic hospital in Gauteng Province. The latter is the most densely populated urban province in South Africa with the smallest land mass (1.45%) (12). In 2016, Gauteng had a population of 12.3 million or 20% of the total population of South Africa (13). It is the economic powerhouse of the country, generating around one third of the country's gross domestic product (14).

There are 35 public sector hospitals in Gauteng Province, of which four are central hospitals. These central hospitals provide tertiary services and serve as teaching hospitals linked to university health science faculties, as well as referral centres for primary health care facilities, district and regional hospitals and surrounding provinces. DGMAH is located in the Tshwane Metropolitan district in Ga-Rankuwa in Northern Gauteng (see Figure 1).

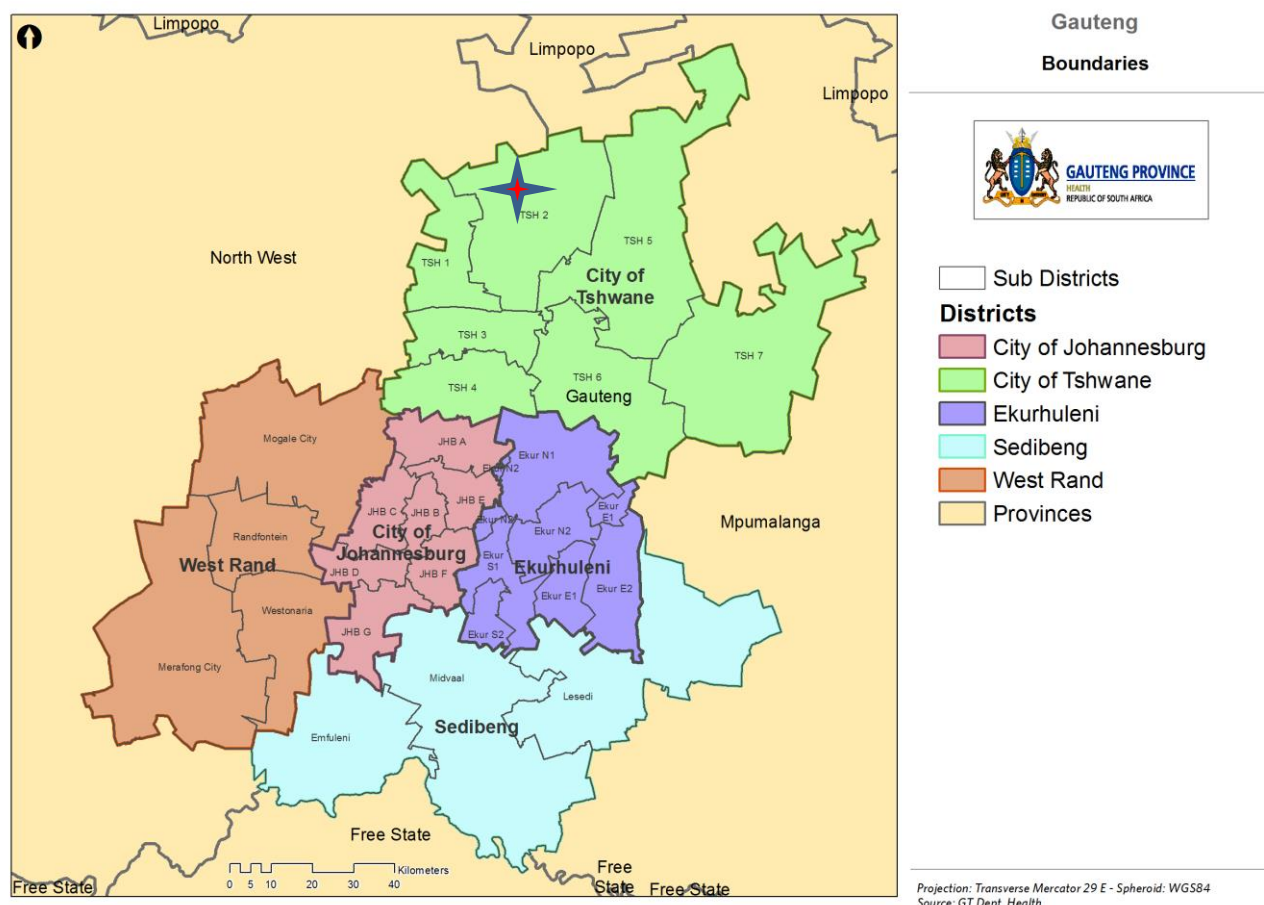


Figure 1.1: Map of Gauteng with approximate location of DGMAH

Source: Gauteng Department of Health.

Note: Star shows approximate hospital location

At the time of the study DGMAH served as the teaching hospital of the University of Limpopo MEDUNSA campus. In 2015, the hospital became the teaching hospital of the Sefako Makgatho Health Sciences University. DGMAH has 1 200 beds, including a 19-bed spinal unit that started in 1995. The hospital serves Northern Gauteng (urban) as well as the rural neighbouring provinces of North West and Limpopo (15).

The DGMAH was selected as it has the only dedicated spinal injury unit in the Gauteng Province. In instances where the unit is full, patients are admitted into general wards. Both TSCAs and NTSCAs are treated in the unit and overflow wards. There are four other rehabilitation units within the province, which cater for a range of disabilities and not PSCAs only.

Patients from outlying areas are stabilised in referring hospitals and are transferred to the unit as soon as possible, whilst patients within the catchment area of the hospital are admitted directly into the spinal unit. The unit is a “one stop service” and caters for both the acute management of patients and their rehabilitation. If all beds are occupied, patients are accommodated in general wards and are transferred to the unit as soon as space is available (Van Rensburg, E, personal communication Jan 2015).

1.3 Problem statement and study rationale

In an overview of conditions facing PSCA in LMIC, Rathore paints a dreary picture, suggesting that the prognosis for patients sustaining a SCA in a LMIC is bleak from the onset (16). PSCA have to cope with a severe injury and then have to face the added challenges of poor evacuation protocols and pre-hospital care, inadequate radiology imaging services, and the lack of specialised, rehabilitation services (16).

In this dissertation, survival status means whether the individual is alive or dead. There is little empirical information on the survival status of PSCA in South Africa. In addition, there is little information on the demographic and medical profile of those individuals who are alive, as well as the environmental factors that they have to deal with.

This lack of information on SCA poses challenges to health service planning, as health policy-makers need accurate information to plan for primary prevention initiatives, comprehensive medical and rehabilitation services and appropriate resource allocation (3). In Gauteng Province, there are 117 long terms rehabilitation beds of which the majority are used for PSCA (17). Patients receive intensive rehabilitation services and the estimated average length of stay for a PSCA at the Tshwane Rehabilitation Hospital is 53 days (Khelawon P, CEO Tshwane rehab hospital, Personal Communication, November 2016). However, little is known on the survival status of the PSCA following discharge from hospitals.

There were several reasons for doing this study. Firstly, there is insufficient information on the demographic and medical profile of PSCA admitted in different Gauteng hospitals. It was envisaged that this study will begin to address this knowledge gap at one large public sector hospital in the province. Secondly, there is insufficient information on whether service delivery is meeting the needs of patients and whether steps need to be taken to facilitate better outcomes for patients. It was envisaged that the study would provide local, context specific

information to enable managers at DGMAH to implement possible interventions to prevent or reduce mortality following discharge from hospital. Lastly, it was envisaged that the study would provide empirical information on the survival status of PSCA, albeit in a small study population. This could assist the Gauteng Health Department (GHD) with baseline information to plan a much larger study that could inform health policies, service planning and resource allocation for PSCA in the province.

1.4 Conceptual model

There are various conceptual models to examine SCA and disability (18, 19). The medical model focuses on the individual and their impairments, disability and handicaps, as well as search for a possible cure. The medical model locates the problem primarily with the patient and has been criticized for not giving consideration to external factors that may impact on the patient or their outcomes (20).

The social model views disability in a more inclusive manner, taking numerous factors into account, amongst others the physical barriers in the environment, e.g. stairs (21). Exclusion from the built environment, educational institutions as well as attitudinal barriers, are important barriers identified by the social model. The focus of this model is thus on external barriers and society, rather than on the individual patient. However, some critiques of the social model suggest that it does not pay sufficient attention to medical factors and that the degree of impairment plays a critical role and should therefore feature more prominently (22).

The social adapted model incorporates both aspects of medical status and the social model to ensure that services are viewed in the wider context of Persons with Disabilities (PwD) (23). This model acknowledges that the impact of impairments on the integration of PwD into society may be more significant than acknowledged by the social model (22). Hence, this study used the social adapted model as a guiding framework (22). Furthermore, in light of the global emphasis on the social determinants of health (SDH), these were also incorporated into the social adapted model (24), shown in the diagram below.

Social Adapted Model

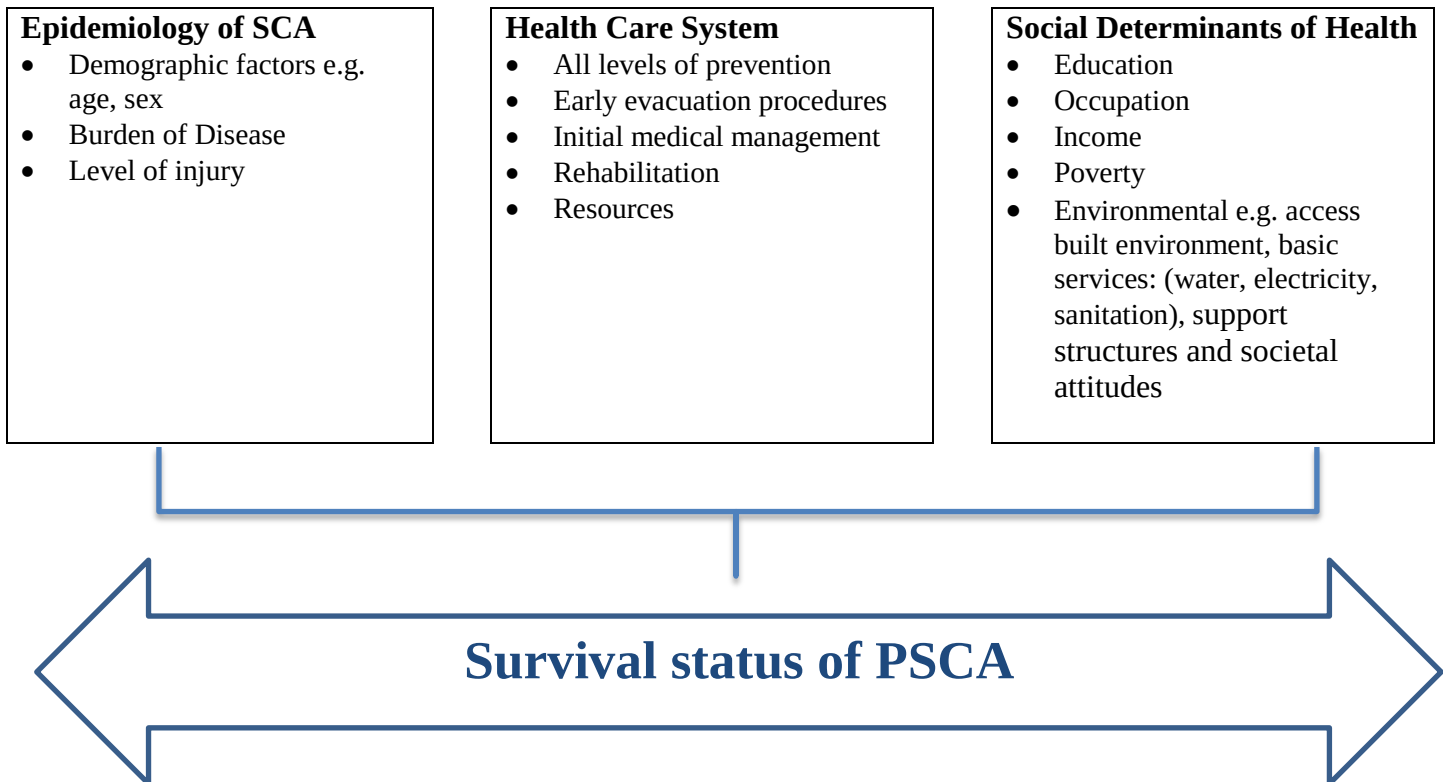


Figure 1.2: Social adapted model used to guide the research study

Source: Adapted from: (22)

1.5 Research question

What is the survival status (i.e. alive or dead) of PSCA following discharge from a Gauteng Provincial government hospital?.

1.6 Aim and objectives

The aim of the study was to determine the survival status of PSCA following discharge from an academic hospital spinal unit, for a five year period from 1 January 2008 until 31 December 2012. The specific objectives of the study were to:

- 1.6.1 Describe the *demographic profile* of all PSCA treated at the spinal unit of the DGMAH specifically: date of admission; gender; age at admission; education level at admission; and employment status at admission.
- 1.6.2 Describe the *medical background information* on all PSCA treated: aetiology (traumatic vs non-traumatic); level of injury in the spinal cord; length of stay in ward; assistive devices provided (e.g. wheelchair and type of wheelchair).

- 1.6.3 Determine the *environmental conditions* faced by PSCA after discharge, such as wheelchair access at entrance of dwelling and bathroom, availability of, and distance to running water, and availability of electricity
- 1.6.4 Determine the *status* of PSCA post-discharge, i.e. whether the individuals were alive or dead.
- 1.6.5 Determine whether there is an association between survival status post-discharge and the demographic, medical background and/or environmental variables obtained.

CHAPTER 2: LITERATURE REVIEW

2.1.Introduction

This chapter summarises the literature on SCA, relevant to this dissertation, using the conceptual framework presented in the previous chapter. It begins with the definition of terms used, prior to presenting available global data for each of the three pillars in the conceptual framework (section 2.3). Thereafter data from South Africa is summarised (section 2.4) and the chapter concludes with a summary of studies on the survival status of PSCA (section 2.5).

2.2.Definitions of terms

The American Spinal Injury Association International Standards for Neurological Classification of SCA (ASIA) is a standard for assessing and classifying the neurological level and extent of the SCA (3). Both motor and sensory levels are measured according to five grades (25).

- *ASIA Grade A* - Complete lack of motor and sensory function below the level of injury (including the anal area)
- *ASIA Grade B* - Some sensation below the level of the injury (including anal sensation)
- *ASIA Grade C* - Some muscle movement is spared below the level of injury, but 50 percent of the muscles below the level of injury cannot move against gravity.
- *ASIA Grade D* - Most (more than 50 percent) of the muscles that are spared below the level of injury are strong enough to move against gravity.
- *Asia Grade E* - All neurologic function has returned.

Disability adjusted life years (DALYs) is the sum of the Years of Life Lost (YLL) due to premature mortality in the population and the Years Lost due to Disability (YLD) for people living with the health condition or its consequences (26).

Years of life lost (YLL) are years lost due to premature mortality and are calculated by subtracting the age at death from the longest possible life expectancy for a person at that age (26).

Years lived with a disability (YLD) is years lived with disability, but it can also be described as years lived in less than ideal health (26).

Incidence: The number of new people that acquire a SCA over a period of a year in a population, described by the number of new cases per million of the population per year (3).

Country Income classifications: Countries are classified according to geographical region, income group, and by the operational lending categories of the World Bank Group (27).

- *Low-income countries:* Those with a gross national income (GNI) per capita of \$1,025 or less in 2015 as per the World Bank Atlas (27).
- *Middle income countries* Those gross national income of US\$1,026 to \$12,475 (2011) as per the World Bank Atlas (27) *High income countries:* Those with a GNI per capita of \$12,476 or more according to World Bank Atlas (27).

Non-traumatic spinal cord affliction (NTSCA) refers to a spinal affliction that develops over time and is due to an underlying pathology. There is no standard classification for NTSCAs. The most common categories of NTSCAs are: vascular, cancerous, inflammatory infections, such as TB, degenerative and other (28).

Paraplegia: Is an impairment in motor and/or sensory function of the lower extremities due to afflictions in either the thoracic, lumbar, or sacral regions of the spine (29).

Prevalence: Is the number of people living with SCA at a given time and it is influenced by risk and duration of condition (3).

Social determinants of health (SDH): The conditions in which people are born, work, and grow old, and the power and resources that influence these daily living conditions (30).

Spinal cord affliction (SCA) is an affliction to the spinal cord, conus medullaris and cauda equina (3).

Tetraplegia is paralysis affecting all the limbs and the torso that is caused by illness or injury. It results in the partial or total sensory or motor loss of the use of all the limbs and torso (29).

Traumatic spinal cord affliction (TCSA) refers to a sudden insult to the spinal cord caused by an event such as a RTA, GSW, sports injury or stabbing (28).

2.3.The profile of SCA at a global level

2.3.1. Epidemiology of SCA

Globally, insufficient epidemiological information on many diseases, injuries and risk factors remains a challenge to appropriate public health interventions for improved population health outcomes (31). The 2010 global BOD study provides a comprehensive description of the causes of premature deaths, including the major shifts in the causes of disability adjusted life years (DALYs) lost between 1990 and 2010 (31). Although HIV & AIDS and malaria continue to account for many DALYs, there has been an overall decline in “communicable, maternal, neonatal, and nutritional conditions relative to non-communicable diseases” (31):451. RTAs increased by one third between 1990 and 2010, while self-harm and falls were among the top 25 leading diseases and injuries that contributed to DALYs (31).

The epidemiological profile of SCA needs to be viewed within the context of the global BOD. SCAs could result from arthritis, cancer, TB, HIV & AIDS, falls, RTA or GSW, thus placing SCAs in the categories of NCDs, communicable diseases, and/or injuries (3, 11). In the case of HIV & AIDS this is caused by vacuolar myelopathy (32).

WHO has highlighted that SCAs are relatively rare compared to other conditions, but “*life altering and costly and with a high mortality risk that varies by income status and depends on the availability of quality clinical care and rehabilitation services*” (3): 14. Hence, a scholarly focus on SCAs is important, especially in resource-constrained settings.

In the case of SCAs, reliable global epidemiological information is scarce, (16, 33), and this problem is worse in LMIC. Within SCAs, the majority of the cases remain TSCAs (3, 34, 35) but NTSCAs are on the increase due to ageing and changing disease profiles (36, 37). However, the classification of NTSCAs is not the same across different studies, thus complicating a comparative analysis of the results of NTSCAs

Although the functional outcomes for NTSCAs and TSCAs could be similar (35), existing evidence suggests that individuals with TSCAs are more likely than NTSCAs to suffer from secondary complications such as neurogenic bladder/bowel, pressure ulcers and spasticity (34). In contrast, the onset of a NTSCA illness is more difficult to determine compared to a

TSCA (35). Comparisons among countries regarding NTSCAs are difficult as common classifications are often not used (36).

Although some authors have cautioned against the use of SCA incidence and prevalence data (34), the International Spinal Cord Society (ISCoS) Prevention Committee has produced various global maps for TSCA epidemiology and estimated global incidence and prevalence rates (10). The prevalence rate was reported as being between 236 to 4187 per million (10). In 2007, a global incidence rate was estimated at 23 TSCA cases per million or 179 312 cases per annum (38).

Similar maps were produced for NTSCAs. However, unlike with TSCAs, the committee found a general lack of data on incidence rates in different countries (37). The incidence rates for North America and Western Europe ranged between 6 and 76 per million per year, whilst Canada and the USA had an incidence rate of 68 and 80 per million per year respectively. However, the data for the USA date back to 1999 (37, 39).

The estimates for the SCA incidence rates for the various WHO regions are shown in the table below.

Table 2.1: Estimated SCA incidence rates for WHO regions

WHO region	TSCA incidence per million	NTSCA incidence per million	Comment on data quality
North America	40	76	Regional data available
Western Europe	16	6	Regional data available
Australia	15	26	Regional data available
Asia-Central	25	Not available	Extrapolation
Asia-South	21	Not available	Extrapolation
Caribbean	19	Not available	Extrapolation
Latin America, Andean	19	Not available	Extrapolation
Latin America, Central	24	Not available	Extrapolation
Latin America-Southern	25	Not available	Extrapolation
Sub-Saharan Africa-Central	29	Not available	Extrapolation
Sub-Saharan Africa-East	21	Not available	Extrapolation

Source: Lee et al, 2013 (10), New et al, 2013 (37)

Although the table provides some information SCA incidence rates for different regions, very few empirical studies were conducted, and the estimates are based on modelling or extrapolation of data from a few countries.

Existing evidence suggests that the gender distribution for TSCAs follows a similar pattern in all countries, irrespective of income levels. In the case of TSCAs, the majority of individuals are male (33, 40, 41). In contrast the male and female distribution for NTSCAs is fairly equal and in some instances slightly higher for females (33).

Individuals with mean age of injury was 32.4 years (42). In LMIC, the most affected age group was between the ages of 20-30 years. TSCAs tend to be younger compared to those with NTSCAs because of the onset of NCDs at a later age (35).(35). In a systematic review on TSCAs in 28 LMIC the mean age at injury was 23.4 years (42). The mean age for NTSCAs tends to be higher, and in Mexico and Australia, the mean age ranged between 45 and 67 years (43, 44).

In the USA, the life expectancy of PSCA remains below that of the general population and respiratory complications is the leading cause of death (45). This in spite of the fact that health care, especially in HIC such as the USA has improved (3).

It is not clear whether marital status plays a role in the survival of patients, but it is a factor to consider in terms of the status of patients post-discharge. Therapists reported that next of kin are trained to carry out caregiving tasks and that it is often the patients' spouse that shoulders this responsibility (Van Rensburg personal communication, Sep 2015). TSCAs tend to be single at the time of injury, but this might be related to the younger age of these individuals (under 30) at the time of injury (46). In contrast, NTSCA patients tend to be married, but this might be a reflection of the time of onset in an older group of individuals (35, 44).

However, the probability of staying married or getting married after a TSCA is lower, when compared with the general population. Both the divorce rate and marital rate reportedly increase over the years and at 30 years post-injury the respective rates are 21.3% and 38.9% as opposed to 11.1% and 21.3% at time of injury (47).

RTAs, falls and violence are the leading causes of TSCAs in HIC (3), with RTAs being the leading cause (46 -57%) of TSCA in North America, Europe as well as in Australia (10). The 2015 report from the National Spinal Cord Injury Statistical Centre (NSCISC) indicated that the four leading causes of TSCAs were RTAs (39.1%), falls (9.5%), violence (14.4%), and sports (8.4%), and that the remaining 8.6% were due to other factors. Even in HIC such as Spain where extensive efforts have been put in place to curb RTAs, these remain the leading cause of the TSCA at 41% (48). The leading causes for TSCAs in LMIC follow a similar pattern, namely RTAs and violence, notably GSWs and stab injuries. These countries reported differences in the rankings of the causes (33, 41, 49). Many studies exclude fatalities from injuries, which may also influence the results.

In all countries, the causes of NTSCAs include spinal stenosis, tumours, multiple sclerosis, degenerative and vascular diseases (35, 50). However, in LMIC such as Kenya (1975), Ethiopia and Malawi (1966), TB was found to be a major cause of NTSCA (51-53). Recent information on NTSCA in these countries is not available.

The level of injury and the severity of the affliction influence the survival status of PSCA. Data for TSCA from the NTSCISC in 2016 reflects that the majority of patients (58.3%) were tetraplegic and 41.3% were paraplegic (47). Data on the severity of injury for TSCA from Australia, Canada and the USA show that the majority of tetraplegics had an incomplete injury (34, 47, 54). The trend for paraplegics differs in these three countries, with only Canada showing a majority of paraplegics being incomplete out of the overall total of the patient group (34, 54). Incomplete tetra- and paraplegia constitute 66% of patients on the NSCISC data base (40), while incomplete paraplegics account for the majority of the NTSCA population in Australia and the USA (35) (50).

Co-morbidities are often undiagnosed and can have an impact on survival: additional injuries such as traumatic brain injuries (TBI) and systemic injuries have a negative impact on mortality and outcome of rehabilitation. The early diagnosis of these factors is crucial for improving survival in an acute care setting (55).

There appear to be no significant differences in mortality between high and low level tetraplegics, but paraplegics are less likely to die than tetraplegics, with the mortality rate being 1.4 times higher for tetraplegics than for paraplegics (56). Patients with incomplete

cervical injuries were found to be less likely to die than those with complete cervical afflictions, while the mortality rate was found to be 1.5 times higher for complete versus incomplete affliction (57). The severity of the SCA plays less of a role in the case of paraplegics (58).

A systematic review done by Rahimi-Movaghar in 28 LMIC and a study done in Pakistan suggested that the majority of patients had complete lesions (16, 42). This systematic review found that paraplegics account for 58.6% of the group (42). This suggests that the lack of quality management, especially evacuation procedures, in the pre-hospital phase might have had a bearing on the high percentage of complete lesions (16, 42, 59).

Time since affliction or time living with affliction is also an important factor when considering the status of patients post-discharge. In a 25-year longitudinal study, Krause found that employment rate and satisfaction improved over time, but that social lives, sex lives and health decreased over time. Participants in this study reported a decline in outings undertaken and visitors received over time. Women were found to have experienced challenges with activities of daily living (ADL) and fatigue, whereas men reported more medical problems (60).

2.3.2. *Medical management of PSCA*

In this section evacuation procedure, medical management and rehabilitation services are discussed.

The first step in the medical management of TSCA is the correct emergency evacuation procedure at the site of injury. This includes the availability of spinal boards and devices to immobilise the patient, well trained staff and the availability of ambulance services, because it is of critical importance that patients are immobilised at the scene of the accident and that they are transported to hospital by ambulance (3). The consequences of the non-availability of optimal evacuation procedures include exacerbation of the condition of the patient, turning an incomplete lesion into a complete lesion, and an increase in mortality (3).

Emergency evacuation procedures differ between HIC and LMIC. In Sweden 4% of patients with TSCA were transferred to hospital in private cars, while the remainder were taken by road ambulance or helicopter, with 83% admitted directly into a tertiary hospital (61). In

Nigeria and Pakistan, between 5.4% and 21.6% were transported to hospital in an ambulance, while the remainder of the evacuations were done by co-workers, local people and family members. In these cases, three-wheeler transport, rickshaws, easy bikes, buses, trucks and private cars were used (59, 62, 63). In addition, patients in LMIC were not transferred on spinal boards (64).

Evacuation-procedures are not a factor in patients with NTSCA, as one can assume that these patients will seek medical attention based on symptoms experienced.

The importance of early comprehensive management has been highlighted. Patients have a much better functional outcome, where comprehensive management commenced within two days after injury, compared to those where comprehensive treatment was delayed by four or more weeks (65). In Sweden patients were admitted within five hours of injury (61). No other data that reflected multiple hospital visits and a delay in admission for HIC could be found.

In LMIC there was on average a 17-22 day delay in admission to a spinal unit. While some patients were found to have sought assistance initially from traditional healers, many were found to have experienced multiple hospital visits at sub-district hospitals, district-level hospitals, or tertiary facilities with no rehabilitation services prior to being admitted into a spinal unit. In Nigeria, only 25% of patients had their first admission directly into spinal units where comprehensive services were available (63, 64, 66).

Varma et al argued that there is a need to allocate resources for trauma prevention and to promote research towards improving the care of acutely injured patients (55).

PSCA are susceptible to secondary complications and have a higher mortality rate than the general population. In 1997, a Danish study showed that diseases such as pneumonia and ischemic heart disease as well as suicide were amongst the most common causes of mortality (67). Pressure ulcers on admission, or developed in hospital or rehabilitation unit ranged from 39% (Pakistan) to 62% (Armenia) and 60% (Nigeria). In Sierra Leone, 50% of the PSCA that passed away following discharge died of the complications from poorly managed pressure sores, an indicator of the quality of care provided (41, 59, 66, 68).

Rehabilitation services form an integral part of service delivery and studies have shown that PSCA in HIC spend between 36 to 72 days in hospital; the majority of these days are spent in rehabilitation. In some instances discharge may be delayed to ensure that all support services, such as home modifications, are in place prior to discharge (69). Tetraplegics with ASIA scores A, B and C (40, 70) accounted for the longer lengths of stay. However, according to the NSCISC there has been a decline in the *length of stay* globally for both the acute admissions and the admissions into rehabilitation units. It is unclear whether the shorter length of stay influence the status of PSCA following discharge (40). The length of stay for persons with NTSCAs seems to be shorter and in Australia, was found to be 21 days (43).

Rehabilitation services are available in some LMIC, but these tend to be limited to a few centres of excellence. In Malawi it was reported that rehabilitation services for PSCA were provided by peer supporters (71).

There are various post-discharge services such as physiotherapy (PT), occupational therapy (OT), recreation therapy, psychology, social work and nursing available in the USA and it might be more extensive than previously thought. The majority of OT and PT services are taking place post-discharge, especially in the first year post-injury (70). This is an area that warrants further research. These services may reflect the continuum of care that is needed as part of optimal management of PSCA, but could also be as a direct result of the reduction in the length of stay (70).

2.3.3. Social Determinants of Health

SCA is a lifelong affliction and there are on-going costs involved for PSCA. Patients need to have continuous access to consumable items such as catheters, wheelchairs and other mobility devices and routine medical check-ups. Lack of access to on-going comprehensive services can lead to a premature death (3).

There is some evidence that PSCA who are poor have a shortened life expectancy, but this might be related both to poor care and risk behaviours such as the use of drugs. However, there is no evidence that PSCA with higher income have a better life expectancy (72).

The socio-economic status of patients in LMIC represents a major barrier to accessing services, as patients are not always covered by some form of health insurance, hence the cost

of on-going care is often carried 'out-of-pocket' by the PSCA. Where the PSCA was the breadwinner prior to the SCA, the subsequent reduction or absence of income has a negative impact on community integration and leave PSCA marginalised, destitute and at high risk. Thus the patient's ability to continue attending long-term medical follow up services might be placed in jeopardy (73).

Ageing has become a factor to consider in the survival status of PSCA because of improved patient outcomes (74, 75). PSCA can experience the effects of ageing much earlier than the general population. There is a decline in health with ageing and an increase in the need for medical services. Fatigue is experienced more quickly and this impacts negatively on independence (75). There is an increase in pain, shoulder problems from overuse, osteoporosis and risks associated with a sedentary lifestyle (74-76).

Patients with a low income and TB of the spine may experience additional challenges as access to long term treatment is required and unaffordable transport may lead to poor compliance with treatment. The situation is made even more difficult if there is a lack of food with which to take medication on a daily basis (77). Non-compliance with TB treatment regimens can lead to catastrophic consequences (78).

In the SCA health survey used in the USA by Krause et al (2010), level of education played a role as PSCA with higher education, showed a lower risk of adverse outcomes such as pressure sores and infection. A higher education level had a positive impact on vocational areas (79). In the NSCISC data base for TSCA, 51,5% had a high school level education in the USA, but the level of education slowly increased over post-injury years (40). Similar results were found in a 25 year longitudinal study done by Krause and Broderick (74). As NTSCA are older and even retired, the education level seem to be less important (35).

Employment may not directly have an influence on survival but it does have a positive impact on community integration and quality of life (80). The majority of PSCA are in their economically productive years of life. Of the TSCA patients in the NSCISC, 57% were employed at the time of the injury, one year later only 12%, but this then increased again and at 20 years later, 34,9% were employed (40). In contrast to this, the majority of NTSCA are likely to be retired (35). Factors such as being employed prior to the affliction, having a

higher level of education and being able to ambulate all influence return to work for PSCA in the USA (81, 82).

Persons employed as manual labourers might find it exceptionally difficult to return to work. At the time of injury 48% of those sustaining a TSCA in Bangladesh were day labourers/farmers and 55.4 % had a very low income (64). A clear link between survival and employment could not be found except for the financial strain that is placed on the family and the difficulties that might occur to access continued medical services.

PSCA need access to basic services such as clean water for intermittent catheterisation and if unavailable, this can lead to bladder infections and ultimate death (83). Environmental factors and access to basic services play a major role in the status of PSCA. Access to housing, public buildings and transport are major factors in community integration of PSCA. In addition, access to health care and appropriate governmental policies are equally important (84).

2.4.Profile of SCA in South Africa

2.4.1. *Epidemiology*

South Africa has a quadruple BOD (85), and three of the four; communicable diseases, non-communicable diseases and injuries, have an impact on SCAs. South Africa also experiences high levels of violence that could lead to TSCAs (10, 86). Communicable diseases cause NTSCAs and both TB and HIV and AIDS lead to affliction of the spine (32, 87).

There is limited data on the epidemiology of PSCAs in general, and information on NTSCAs seems to be especially scarce. In Gauteng Province, data for SCAs from 1994 reflect that 90% of patients had TSCAs and 10% NTSCAs (88). In sharp contrast with this, the 2015 Gauteng Department of Health Physiotherapy annual report of patients seen at hospital level, showed that for PSCA, TSCAs accounted for 46.1% of SCAs while NTSCAs accounted for 53.9% (89).

Incidence rates for TSCA of between 30 and 75.6 per million have been estimated in South Africa but these rates were based on studies in the early 1990s and a study limited to the city of Cape Town (10, 86). No other information on prevalence and incidence could be obtained for South Africa.

Males accounted for between 85.5% – 90% of patients with TSCAs in the Cape Town area with a mean age of 31.7 - 33.5 years (86, 90). In two separate studies at Natalspruit Hospital in Gauteng Province, which included both patients with NTSCAs and TSCAs, males accounted for between 79% - 80% of patients. In these studies, the majority of patients were between 16 – 30 years of age (91, 92).

In KwaZulu Natal in a study limited to patients with TB spine, females made up 58% of patients and in total 32% of the patients were younger than 17 years (87).

In 2000, 57% of afflictions admitted to Natalspruit Hospital in Gauteng Province were violence-related. These injuries stemmed from GSWs and stab wounds (88). Two studies (2012 and 2015) carried out in Cape Town indicated that violence-related injuries remain the leading cause of TSCAs in Cape Town at just under 60% (86, 90). In contrast to this, a 2011 study in Northern Gauteng that included both *private* and *public* health sectors found that RTAs were the leading cause at 70,6% and violence-related injuries were at 19,5% (93).

In the studies carried out in Cape Town with patients with TSCAs, tetraplegics made up between 36% - 53.1% of the total patients group, with the remainder being paraplegic (86, 90). Just over half of the patients had spinal surgery and 57.9 % had associated injuries (86).

In the TB spine study from KwaZulu Natal, affliction to the thoracic spine accounted for the majority (42%) of affliction and only 11% affected the cervical spine (87).

2.4.2. Management of PSCA

There is a paucity of data on emergency evacuation and early comprehensive management of PSCA in South Africa. In the public sector, only three of the nine provinces: Gauteng, North West and Western Cape have dedicated rehabilitation hospitals or units that cater for PSCA (94). The national referral policy determines referrals to SCA units in Gauteng.

Data on medical management is scant but some data is available on length of stay. TB patients stayed an average of 41 days in hospital in Kwa-Zulu Natal and patients with TSCAs stayed on average 36.5 days in Cape Town (86, 87). There is also a lack of information on secondary complications. No data could be found for post-discharge services for South Africa and the continuum of care following discharge.

2.4.3. Social Determinants of Health

A study in northern Gauteng revealed that education of PSCA ranged from 2 to 12 years with a mean of 9.87 years of which 70% completed high school (95). In Tshwane 64% of the patients with TSCAs were single at the time of the injury and 90% lived with families (95).

In South Africa, there is a social grant system and PwDs have access to a disability grant and health care for PwDs is free (96). There is a lack of data on the employment or re-employment of PSCA in South Africa. In Tshwane District in Gauteng, 56.9% of PSCA were employed before the affliction and only 25.6% at the time of the study (95). No differences were found in terms of the incidence of people with TB spine amongst the employed and unemployed patients (87). According to Census 2011 only 0.9% of those employed were people with disabilities (97).

Environmental factors and access to basic services may play a role in survival (83). The 2011 general census carried out in South Africa showed that 77.8% of the population lived in formal dwellings, 89.9% had access to piped water and more than 85.4% had electricity. Lack of access to piped water may have a bearing on survival (98).

In Tshwane District of Gauteng, Mothabeng found that 15% of participants in the study lived in informal dwellings at the time of injury (95). Mothabeng found that participants that have been living with SCA for longer periods and that had a higher level of education, were employed and lived in the suburbs were more satisfied with their quality of life. This study also found that attitudes of members of society, accessibility of the environment and social support played a major role in community integration (95). McLachlan identified that lack of transport, access to water and lack of employment opportunities are major barriers in community integrations of PSCA (90).

2.5. Survival status and mortality of PSCA

Over the preceding 50 years, there has been an improvement in the management of PSCA, with the most noticeable improvements occurring in the 1980s. This has led to an improvement in the outcomes of patients treated in recent years (99). Several factors influence the survival status of PSCA. These include, amongst others, demographic characteristics (age,

sex), time since injury, level and severity of injury, medical management and care following discharge (100, 101).

Detailed information regarding mortality and survival is available for HIC. The median survival rate of persons with TSCAs in England after injury was 32 years. The study found that after 10 years, 85% had survived; after 20 years, 71% has survived; and after 40 years, 35% of these patients had survived (102).

In the USA there is a high mortality risk in the months after a TSCA, although it has decreased for the two-year period after injury. The risk after two years post-injury increases again, which seems to suggest that more attention is given to the patient in the first two years post injury and that this may peter out after two years (72).

In a systematic review on survival rates, Van der Berg *et al* found that survival rates were lower for NTSCAs than for TSCAs (56). However, the aetiology of NTSCAs has an impact on survival and mortality rates. Life expectancy for patients with disc herniation and spinal stenosis is on par with that of the general population (103). Metastatic spinal cord compression (MSCC) of lung, breast and prostate cancer accounted for 50% of MSCC (104). The median survival with patients with MSCC in 2003 was between 2 – 3 months, with those patients with lung cancer having the shortest survival rate (105).

In Denmark for persons with TSCAs, the standard mortality rate for females was higher than that of males and that gender is a contributing factor, but did not venture an explanation for this (99).

Age at injury play also play a role in mortality. For persons, older than 50 at injury, the mortality rates are 9.7 times higher than those injured younger than 30 years of age. Younger patients experience better survival rates (57, 106).

There is a dearth of information for LMIC. In Nigeria a study found that the mortality rate was 16.7% in the first six weeks of admission (63) and mortality in Bangladesh was high post- discharge, with more than half of the PSCA dying within five years of affliction and less than 20% surviving beyond ten years (107). The most common cause of death for a person with TSCA in patients in LMIC was respiratory failure, TBI and post-discharge pressure

ulcers (41, 108). Limited mortality data is available for LMIC, but it is clear that follow-up is limited as a result of amongst others, challenges with transport to access specialised facilities (109).

Data for mortality rates are also sketchy for South Africa. A 14% mortality rate was reported for cervical cord affliction in the first year after injury at the Groote Schuur Hospital in Cape Town, with ventilator dependency accounting for 43% of these deaths (110). There was a mortality rate of 7% during hospitalisation at Natalspruit Hospital (92). The table below summarises the available information on SCAs.

2.6.Conclusion

The review of the literature revealed that there remains a dearth of studies on SCA and PSCA. The majority of studies have been done in HIC, and the epidemiological information is often used to model incidence and prevalence estimates for LMIC, where the context and resource availability are very different. Although there has been an encouraging increase in the number of studies done in LMIC, studies tend to be quite dated, or are small, with different methodological approaches, making generalisations and comparisons difficult.

Table 2.2: Comparison HIC, LIC and South Africa

Country & number pts	Date study period	Author	Type	M and F	Age	Level Tetra complete: TC Tetra Incomplete: TI Para complete: PC Para Incomplete: PI	Aetiology	Mortality	Comments
HIC									
Canada (n: 175)		Rouleau et al (111)	TSCA		36.8 Mean	TC: 16% TI:27% PC: 22% PI : 36%	RTA 52.5% Fall: 15.8% Work: 11.6% Leisure: 5.3% GSW: 3.1% Other: remainder	Not studied	Concluded that treatment must target the sub groups of injuries
			NTSC A		48.8 Mean	TC:10 % TI:46.2% PC: 1.3% PI: 42.5%	Stenosis: : 34.5% Syringomelia: 9.9%, Myeloma: 9.9% Hernia: 9.9% Various Other: remainder		
Scotland (n:1930)	(1994-2013)	McCaughey (112)	TSCA	M; 75.2	47.2	Cerv:60.6%	Fall: 51.7% RTA: 24.9% Sport 10.2% Various Other: remainder	Not studied	Improvement in documentation for NTSCA needed
			NTSC A	M:51.8	68.1	Cerv:28.1%	Vascular:40% Infection 22.7% Vertebral degeneration 16.4% Neoplasm 15.5% Inflammatory : 3.6 Various other		
LMIC									
India (n: 207)	2007	Agarwal P et al(33)	NTSC A	M: 42,3%	In group 20-39	C: 54,5% T: 18,2% L: 27,3%	Various: 12,6%	In hospital: 4	Patients included with no neuro defect.

Country & number pts	Date study period	Author	Type	M and F	Age	Level Tetra complete: TC Tetra Incomplete: TI Para complete: PC Para Incomplete: PI	Aetiology	Mortality	Comments
			TSCA	M: 83,4%	years: 41,5%	C: 50,5% T: 24,3% L: 25,2%	Fall height: 58,9%; MVA: 21,3%; Fall of weight 7,2%		
Bangladesh (n: 371)	2011	Hossain et al (108)	NTSCA TSCA	M: 89,5%	34	TSCA tetra: 40% TSCA para: 54% NTSCA tetra: 0,8% NTSCA para: 4,6%	Not included	In hospital: 21/ 5,7% Post discharged: 54/14,6%	In patient deaths 62% due to respiratory and Post discharge deaths 56% due to pressure ulcers.
AFRICA									
Botswana (n: 49)	2011 - 2013	Lofvenmark et al (113)	TSCA	M: 71%	31-45 years: 39%	C: 59% T: 37% L: 4 %	RTA: 68% Violence: 16% Fall 10% Sport 2% Struck by object 4%	In hospital 10: 20%	Most RTAs were single accidents caused by burst tires.
Nigeria (n: 468)	1992-2006	Obalum DC et al (41)	TSCA	M: 70,1%	21-30 years: 29,1% 31-40 years: 28,6%	C: 30,3% T: 10,3% L: 59,4%	RTA: 77,4% Falls: 9,4% GSW: 7,3% Violence: 2,1% Other: remainder	In hospital :82: (17,5%)	Top 2 causes death: respiratory 39%, associated TBI 29,3%
Nigeria. (n:168)	2009	Ahidjo et al (63)	TSCA	Study limited to mode of transport					Crouched position 27% Presentation ≥24 hours: 17% Multiple hospital presentation: 17% Saloon car(54.2) Commercial bus(24.4) Open truck(13.7) Ambulance(5.4) Motorcycle(2.4)

Country & number pts	Date study period	Author	Type	M and F	Age	Level Tetra complete: TC Tetra Incomplete: TI Para complete: PC Para Incomplete: PI	Aetiology	Mortality	Comments
Ghana (n;185)		Amatefe M et al. (114)	TSCA	M: 76%	36.3	CI: 32% CC: 42% C Intact: 26% TI: 27% TC: 52 T: Intact: 26%	RTA:70.3% Fall:24.3% Industrial: 3.2% Assaults: 2.7%	Not studies	After 6/12 post injury only 26% came for follow up. X-ray 74.1 2/52 after injury. Transportation hospital: ambulance 56.8% Private cars: 25.4% Taxis 8.7% Five airplane
Sierra Leone (n:24)	25002-2004	R. A. Gosselin R, Coppotelli, C (66)	TSCA	M:92 %	30 years	On D: Complete: n = 14 Incomplete: n = 3 All C5 – C7 or T10 – L2	RTA; 46% Fall from tree:42% Wall collapse: 0.8%	In hospital: 29% Post D: 33% Los to follow-up: 17%	Only able to trace 5 17 months post injury
South Africa Gauteng (1203)	Jan 1988 – Dec - 1998	Hart et al (88, 92)	TSCA: 90%	M:80 %	20-29 years: 46%	C: 25% T: 63% L: 12%	Violence: 59% RTA: 25 Fall: 3% NTSCA: 10% Other: 3%	7,4%	HIV status of pts had impact on complications.
			NTSC A:10%	M 50%					
South Africa Gauteng (160)	2011	Mothabeng (95)	TSCA; 90% NTSC A: 10%	M:77.5 %	Mean age 29.2	Tetra: 37.5 Para 62.5	RTA: 70.6% Violence: 19.3% NTSCA: 10%	Not measured	90% lived with own family
South Africa KwaZulu-Natal	March 2005: April 2006	Godlwana L et al (87)	NTSC A: only Tb Spine	M: 42%	0-17 years: 32% Mean 28 years	C:11 % T:42 % L: 30% T/L: 10% L/S: 5%	Tb Spine: 100%	-	44% no neuro deficit 81% unemployed

Country & number pts	Date study period	Author	Type	M and F	Age	Level Tetra complete: TC Tetra Incomplete: TI Para complete: PC Para Incomplete: PI	Aetiology	Mortality	Comments
			included			S: 2			
South Africa Cape town (n: 47)	2008-2009	Maclachlan , M.(90)	TSCA	M; 91%	Mean 31.7	TC:11% TI; 25% PC: 34% PI: 30%	GSW: 28% Stab: 30% RTA: 30% Fall: 6% Sport: 4% Other : 2%	Not measured.	Recommend more follow up, Community barriers huge.
South Africa Cape Town (147)	Sep 2013- Sep 2014	Joseph et al (86)	TSCA	M: 85,5%	Mean 33.5 18-30: 54%	C:53.1 % T:38.6 % L/S: 8.3%	Violence: 59.3% RTA: 26.3% Fall 11.7% Other: 2.7%	Not Included	Violence preventative measures needed

CHAPTER 3: METHODOLOGY

This chapter describes the overall study approach and methods, the study population, study design, sampling, data collection and analysis in line with the study aim and objectives. Section 3.1 presents an overview of the study methods, section 3.2 outlines ethical considerations, section 3.3 describes the record review and section 3.4 the follow-up of PSCA at their homes. Section 3.5 outlines potential research bias and study limitations, and researcher efforts to minimise or ameliorate these.

3.1 Methodological overview

Using a cross-sectional study design, a record review was conducted of **all** PSCA admitted and treated in the DGMAH spinal unit for the period 1 January 2008 until 31 December 2012. A structured, pre-tested questionnaire was used to obtain demographic, medical and environmental information on PSCA. Once the record review was complete, all the patients admitted during the study period and known to be alive, were contacted to determine whether they were willing to participate in the study. During a home visit, a semi-structured questionnaire was completed with PSCA who could be traced and who agreed to be visited and interviewed.

Figure 3.1 summarises the overall approach to the study

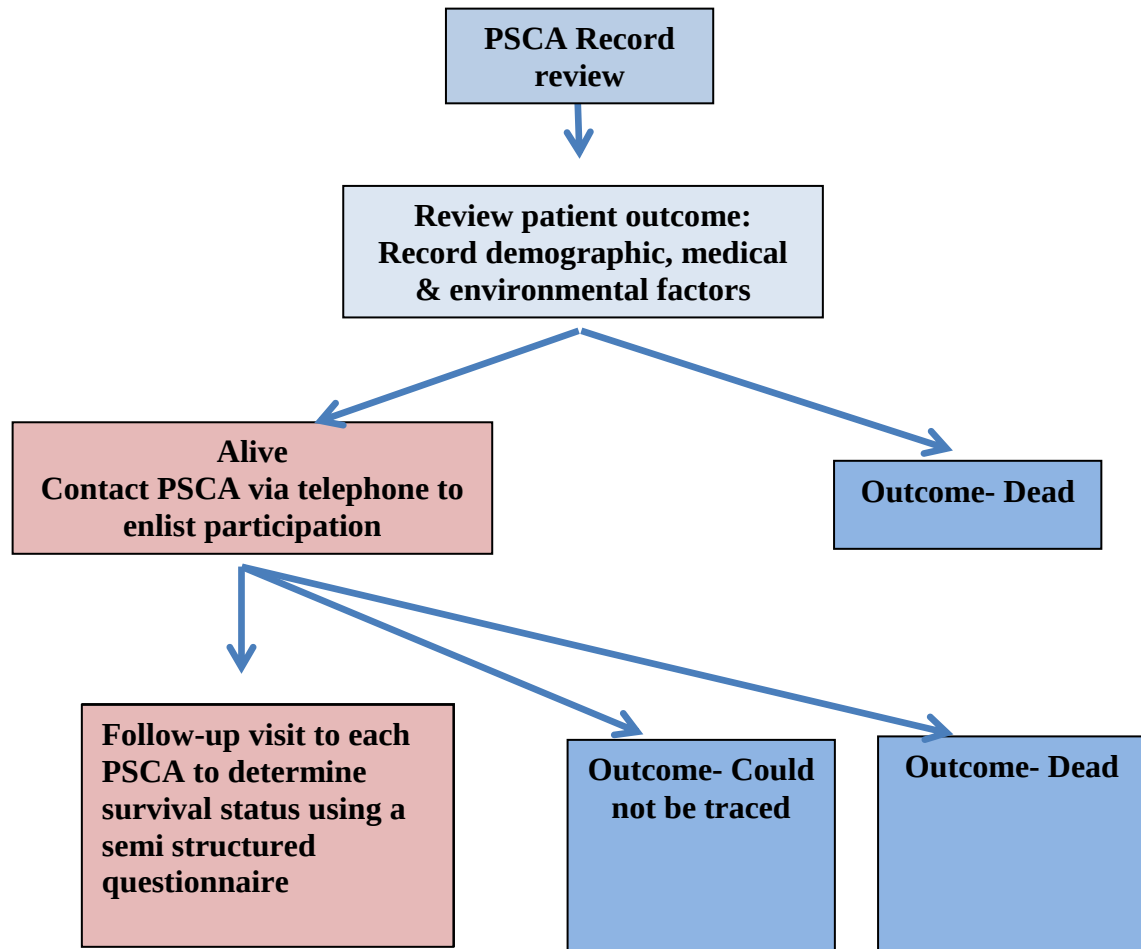


Figure 3.1: Overview of study design to determine survival status of patients

3.2 Ethical considerations

Ethical approval was obtained from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg (Certificate number M140485) (Appendix 1). Further approval was obtained from the CEO of the hospital (Appendix 2) and the Tshwane District Services (Appendix 3). All ethical procedures were adhered to.

The researcher is registered with the Health Professional Council of South Africa as an occupational therapist, and recognises the importance of patient confidentiality and respecting such information. Patient's information was kept confidential and only the researcher had access to the relevant records. Medical records and data collection tools were accessed in a private area and were not left unattended. Each record review form of PSCA admitted was

allocated a unique identification number. The register of the unique numbers and patients identifying information was locked up in the office of the Assistant Director for OT at the DGMAH. All information was kept on a computer that was password protected. The data capturers only had access to unique numbers and not patient identifying information (Appendix 4).

For the follow-up of surviving patients, the researcher contacted each patient with a SCA telephonically to enlist participation in the study.

The research team informed all patients who could be contacted that they were under no obligation to agree to the visit and that they were free to opt out of the research. It was also stressed that there were no benefits from participation in the study.

For the patient interview, an information sheet and a consent form were developed (Appendices 5a, 5b, 6a and 6b). The information sheet and consent form were originally written in English and two different health workers who were fluent in Setswana were requested to assist with translation. One health worker translated the information sheet and consent form English into Setswana and the other was responsible for translating it from Setswana into English. The discrepancies were resolved to ensure that the same information was collected in Setswana as would be the case in English (Appendices 5a, 5b, 6a and 6b).

Two fieldworkers were employed and trained to collect information from patients in their language of choice. This was in anticipation of a large number of people to interview in the second phase of the study. During the training of the field workers the need for confidentiality was emphasised and a guideline was developed for the field workers to use as a reference document (Appendix 7).

Prior to any interview being conducted, the information sheet was discussed with the patient and they were requested to sign the consent form. Patients were again assured of confidentiality at the time of the visit and that their participation was voluntary and that there were no benefits from participation. Thereafter the patient was asked to sign the consent form and the interview was conducted.

During the interviews, a few patients indicated that they needed medical intervention. These patients were referred to a health care facility.

3.3 Record review

3.3.1 Study setting

The study was conducted at the DGMAH in Gauteng Province, a public-sector tertiary hospital that serves as the teaching hospital of the Sefako Makgatho University (see chapter 1). DGMAH has the only dedicated spinal unit in Gauteng Province, whereas other hospitals have mixed rehabilitation wards that admit patients with other conditions, such as cerebrovascular accidents. The hospital serves Northern Gauteng (urban) as well as the neighbouring, more rural provinces of North West and Limpopo (15).

3.3.2 Study population

For the record review component, the study population comprised of all PSCA who were admitted and treated in the dedicated spinal unit as well as the over-flow wards.

3.3.3 Study period

The five-year period from 1 January 2008 and 31 December 2012 was selected to ensure that a sufficient number of records was sampled, and to ensure that sufficient time had passed to determine the survival status of PSCA (i.e. whether the individual was dead or alive).

3.3.4 Questionnaire design: Record review

The record review data collection tool consisted of a structured questionnaire (Appendix 4). All patient records, including OT and PT records were used to collect demographic, medical and environmental information (Appendix 4). This data collection tool was designed originally by the Gauteng Health Department in 2011, to provide information on spinal cord afflictions in the five rehabilitation units of the province. The tool was amended for the study, and all aspects of the form not pertaining to SCA were removed. Apart from the contact details, the data collection sheet only had tick boxes that needed to be completed. The information collected in the record review also took account of the conceptual framework

Following amendment of the Gauteng Provincial Government form, the data collection tool was piloted at another hospital in the province that manages PSCA. The pilot study consisted of a review of eight records, to test the suitability of the tool to meet the study objectives, time

taken for completion, and whether all the information could be obtained from the patient records. The researcher made a few changes to the data collection tool, namely: the sections on wheelchair dexterity and mobility were removed, and a section expanding on pre- morbid causes of SCAs was added.

The form covered three sections, the first being basic information, the second, demographic information that included employment and educational information. The last section on medical background information section included aetiology, level and date of injury, as well as information on discharge and assistive devices issued.

The record review questionnaire thus catered for the first three objectives of the study (Appendix 4).

3.3.5 Review of patient records

Following ethics and hospital study approval, the researcher obtained patients' records with the assistance of the OT and PT departments for the study period to ensure that only the applicable records were accessed.

From September 2014 to November 2015, the researcher collected all data from the records for the study period from 1 January 2008 to 31 December 2012. Where key information was lacking from the therapy records the researcher accessed the hospital records and the MEDICOM electronic information system to ensure a comprehensive record review.

3.3.6 Data processing and analysis

All questionnaires were kept in a safe and secure area. Once data collection was complete, the researcher enlisted the assistance of an external service provider for data capturing. Microsoft Excel was used to capture the data, with double entry for quality control. The researcher took responsibility for overall quality assurance of the data. Following data cleaning and checking, the researcher analysed the data using Microsoft Excel and STATISTICA[®] 12.1. Only descriptive analysis was conducted using data from the record review. Frequency tables, mean, median, ranges and proportions were calculated.

3.4 Field work: Semi structured questionnaire

3.4.1 Study population

For the follow up field work visit the study population consisted of all patients that could be traced, and who lived within a 200-kilometre radius from the DGMAH. This was done because of budgetary constraints, and for logistical reasons.

3.4.2 Semi- structured questionnaire design

A semi-structured questionnaire (Appendix 8a) was aligned to the record review form. A near exact replica of the questionnaire was in use by the GHD rehabilitation hospitals in 2010 as part of the in- patient assessment. Only a small section of the questionnaire was expanded to give more detailed information on access to water. This questionnaire obtained comprehensive information on environmental factors such as transport routes, toilet facilities, access to water and wheelchair accessibility of the house. The questionnaire was designed in English for the follow-up visit with each PSCA. and included The questionnaire was expanded to include open-ended qualitative questions that focused on the type of challenges experienced by patients with SCAs and what would improve their lives and make them happier. The questions were worded as follows;

- What is the most difficult thing for you to cope with now
- Please tell us what will make you happier
- Please tell us what will make your life easier

The form was allocated the same unique number as for the patient record review, in order to link the information collected. The questionnaire was aligned with the conceptual framework.

The semi-structured questionnaire was originally written in English and two different health workers who were fluent in Setswana were requested to assist with translation. One health worker translated the questionnaire from English into Setswana and the other was responsible for translating it from Setswana into English. The discrepancies were resolved to ensure that the same information was collected in Setswana as would be the case in English. Following advice from staff at the DGMAH, the translation of the questionnaire was limited to Setswana as the hospital serves a predominantly Setswana population (Appendix 8b).

3.4.3 *Fieldworker recruitment and training*

Five field workers were recruited from the community with the assistance of hospital staff. The fieldworkers had to be fluent in English and Setswana and be able to drive. The researcher developed a detailed guide for fieldworkers (Appendix 7). The researcher took responsibility for training the field-workers to ensure that they understood the purpose of the study, issues around confidentiality and professional conduct, and ensured overall quality control.

In March 2016 a training workshop was held with the fieldworkers. The researcher explained the research process and provided an overview of the field worker guidelines. The training included an overview of spinal cord affliction and the implications of the condition. However; special attention was given to fieldworker conduct in arranging the interview and during the visit. Each question in the semi-structured questionnaire was discussed and explained. The fieldworkers were requested to provide an explanation of each of the questions as they understood it for quality assurance purposes. The fieldworkers were encouraged to contact the researcher at any time if they needed assistance.

3.4.4 *Data collection*

All patients who could be traced and lived within a 200 km radius of DGMAH were followed up. The distance stretches from the DGMAH to Bela-Bela in the North, Kempton Park in the South, Rustenburg in the West and Bronkhorstspuit in East. This radius was selected because of budgetary constraints, and for logistical reasons. In addition, the literature suggests that the majority of patients tend to utilise the closest health care facility.

The approach followed for the semi-structured interview commenced with the researcher, with limited assistance from some occupational therapists, contacting all the participants telephonically to make arrangements for the field work visit. The researcher explained the reason for the call, the purpose of the study and emphasised that participation was voluntary. The patients were further informed that they will be contacted by a fieldworker for a home visit.

The trained fieldworkers contacted each patient who agreed to be interviewed, and visited them in their homes. Each patient was interviewed, using a semi-structured questionnaire (Appendix 8). During the fieldwork, the researcher provided oversight of the study, supported

the fieldworkers, called them to check progress with the study, and quality checks were done to ensure that there were no errors or missing values on the questionnaire.

3.4.5 Data processing and analysis

The researcher captured the information from each questionnaire on an Excel spread sheet. Following data cleaning and checking, the researcher analysed the data using Microsoft Excel. Only descriptive analysis was conducted, as only 19 patients were visited in their homes. In consultation with a biostatistician, the researcher established that it was not possible to conduct multivariate statistical analysis.

For the open ended questions, content analysis was done (115). In the first step of the analysis, the researcher and the supervisor coded the qualitative data, and then agreed on the codes. The codes were then categorised into the various themes.

3.6 Addressing potential source of bias and study limitations

3.6.1 Bias and remedies

This section outlines potential sources of bias, as well as study limitations and steps taken to address bias or these limitations. Bias results from systematic errors in the research methodology (116). In this study, the potential sources of bias were: selection bias; observation bias; recall bias, and non-respondents.

Selection bias was overcome by reviewing all the records for the five-year period from 1 January 2008 until 31 December 2012. Observation bias results when different interviewers ask or record the questions in a slightly different way. This was overcome by developing a detailed guideline for the fieldworkers (see Appendix 7) and the development of a standardised questionnaire for use during the interview (Appendix 8). The researcher took responsibility for training the fieldworkers to ensure that data collection was standardised across the five fieldworkers. The researcher was in contact with all the fieldworkers, to ensure that any problems were dealt with. As soon as fieldworkers submitted completed questionnaires the questionnaires were checked for accuracy by the researcher.

Recall bias was overcome with by using a semi structured questionnaire, with most of the questions having limited options for participants to choose from, to overcome the possibility of participants not remembering important pieces of information (116).

A major problem encountered in the study was the inability to trace people for the follow-up interviews, resulting in non-respondent bias and incomplete information, as well as the inability to conduct multi-variate analysis. This non-respondent bias could occur for several reasons: death or movement of patients since discharge from hospital in 2012; or inaccurate or changed telephone numbers. The researcher took several steps to reduce non-response of PSCA. All available telephone numbers were captured from the patient records. In some instances, three different phone numbers were captured. Cell phone numbers that went onto voice mail were phoned three times before the patient was classified as non-respondent. The table below highlights the potential issues leading to non-respondent bias information, and the steps taken to overcome these.

Table 3.1: Non-respondent Bias

Non-response	Action to overcome limitation
Patient records with no telephone numbers	MEDICOM system was checked to supplement the missing data
Change in patients' cell phone numbers, incorrect numbers captured.	Financial Intelligence Centre Act (FICA) regulation implemented after the study OT staff captured as many telephone numbers as possible. Some records contained as many as 4 cell phone numbers.
Cell phone re-directing to "Voice Mail"	In these instances, the phone numbers were called three time prior to the patient being deemed as a non-respondent "
	Study period was extended by 9 months, however due to budget constraints and other logistics the study had to be closed.

3.6.2 Study limitations

The study limitations are related to the review of patient records, the selection of one spinal unit in a large academic public sector hospital, in an urban study setting. A further limitation was the inability to trace patients, and the non-respondent bias discussed above.

There were several challenges with the record review such as lost or misplaced records and incompleteness of or missing information contained in the records. All possible avenues were exhausted to overcome challenges to ensure completeness of records as reflected in table 3.3.

Table 3.2: Record review challenges

Challenges	Action to overcome limitation
Patient records	
No central SCA patients register is kept at the hospital	OT records together with all other patient records from the main patient record filing room were accessed as OT records and were filed according to diagnosis and kept for 5 years.
Patients' hospital records could not be traced	All attempts were made to ensure a comprehensive record review
Only basic graphic information is captured on the electronic patient register information system (MEDICOM)	The MEDICOM System complemented the review of physical patient records

The selection of one specialised spinal unit in a large public sector teaching hospital means that findings in the study may not be comparable with studies of patients that were not treated in a specialised unit. This is because all patients were treated by a team of doctors, nurses and therapists that have a higher level of expertise in the field of spinal cord affliction. The study represents patients accessing the DGMAH in the public health sector and not all patients admitted in Gauteng with SCAs. Patients that were followed up were only from urban or semi-urban settings and the environmental factors cannot be generalised to all the patients admitted into the unit.

The large number of patients that had incomplete information and could not be traced was a major study limitation. This also impacted on the researcher's inability to undertake multi-variate analysis, a further study limitation. The very small sample of PSCA in the second phase of the study, and the inability to conduct inferential statistical analysis means that no associations could be established between survival status and demographic, clinical or environmental factors.

The researcher restricted the radius for follow-up to 200 km, because of budgetary and logistical reasons. This meant that 19 patients living outside the 200 kilometres were not interviewed during the second phase of the study, adding to the study limitations, and the inability to reach any generalisable conclusions.

Nonetheless, there are several strengths of this study. This is one of the first studies to examine the survival status of PSCA in a large dedicated spinal unit. Every record of PSCA was reviewed for the five-year period. The record review form and the semi-structured questionnaire could be used by other researchers, who would then be able to compare their findings with those of this study. Lastly, the study findings provide useful information for a five-year period of this hospital spinal unit, and could be used to compare the findings of similar units in other parts of the province, the country or the region, provided that they share the characteristics of this unit. The lessons learned during fieldwork also provide useful pointers to other researchers. These include the need for dedicated financial and human resources, the time taken to conduct the research, and the importance of stakeholder involvement at hospital level.

CHAPTER 4: RESULTS

4.1. Study participants

The researcher reviewed a total of 264 records, which revealed that 55 patients had died in hospital. Of the remaining 209 eligible patients for follow-up, 19 patients had died post-discharge, and 152 patients could not be traced due to incorrect phone numbers, three ‘voice mail’ messages, one refusal and four patients were not contacted. A total of 38 patients were traced and could be followed up, but only 19 patients were interviewed. Nineteen patients were not followed up due to distances exceeding a 200 kilometre radius from the hospital. This is shown in Figure 4.1 below.

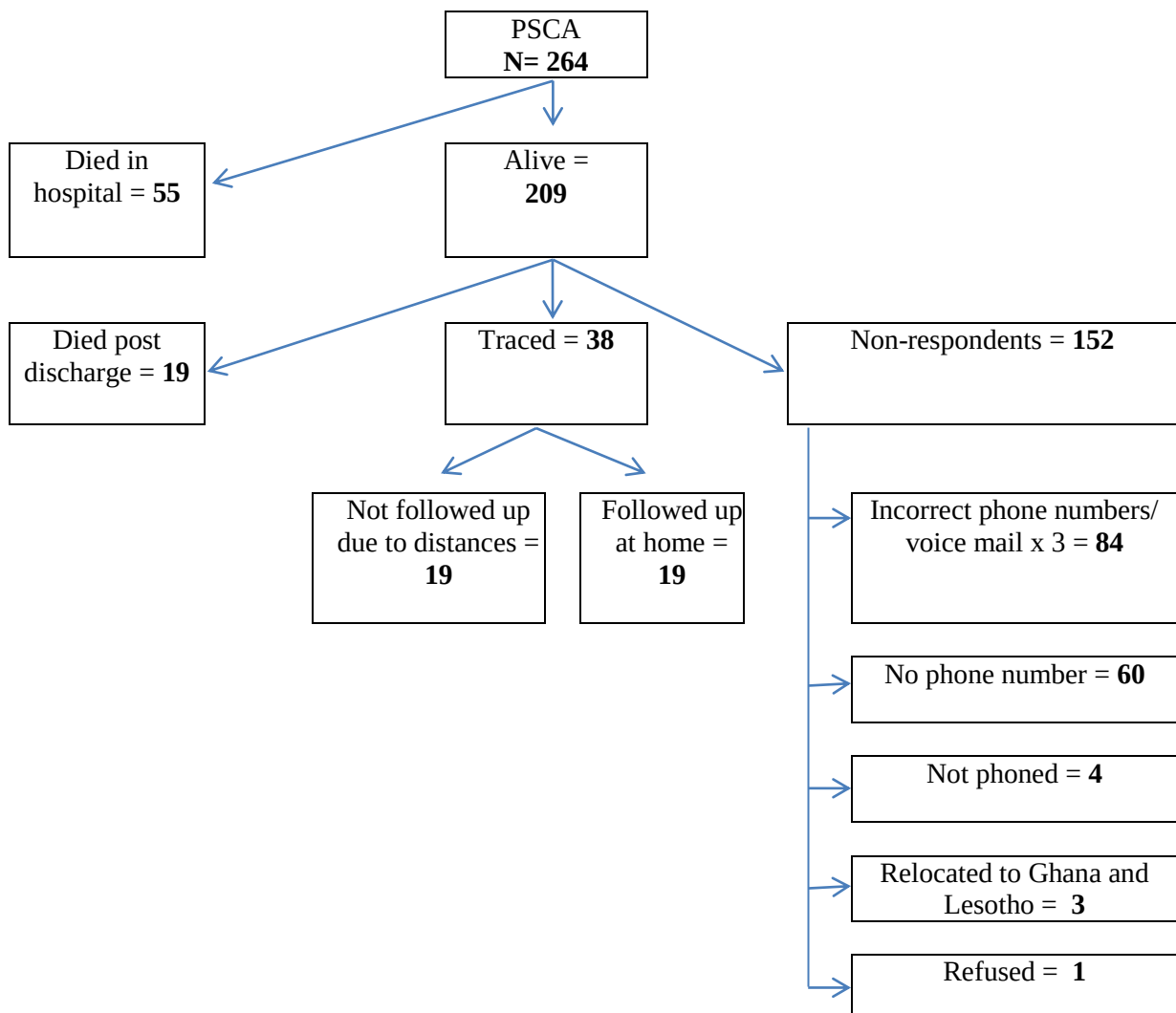


Figure 4.1: Diagrammatic representations of study participants

4.2.Results: Record review

The data in the section reflects the status of patients discharged from hospital (n=209) and excludes those who died in hospital (unless stated otherwise). The STROBE guidelines were followed in presenting the data (117).

4.2.1. Socio-demographic profile of PSCA

There were many missing values in the patient records, which account for the variations in denominators. Table 4.1 provides an overview of the socio-demographic characteristics of PSCA that were discharged from the hospital.

Table 4.1: Socio-demographic characteristics of discharged PSCA

Characteristics	Discharged n (%)
Gender	n:196
Male	126 (64.3)
Female	70 (35.7)
Age	
Total Mean (SD; range)	n: (175) 37 (15.4; 3-81)
Male Mean	n: (109) 37 (15; 5-81)
Female Mean	n: (62) 37 (15.6; 3-78)
Total median (IQR)	n: (175) 35 (27-46)
Male Median (IQR)	n: (109) 35(27-49)
Female Median (IQR)	n: (62) 37 (27-43)
Marital status	
Married	64 (46%)
Widow	2(1.4%)
Single	56 (38.1%)
In relationship	11 (7.9%)
Other	9 (6.5%)
Country of birth	194
South African	177 (87.6%)
Outside South Africa	17 (8.8%)
Province	
Gauteng	90 (50.8%)
North West	45 (25.4%)
Limpopo	23 (12.9%)
Mpumalanga	11 (6.2%)
KZN	6 (3.4%)
Eastern Cape	2 (1.1%)
Education level	37
None	3 (8.1%)
≤ Grade 5	4 (10.8%)
≤ Grade7	4 (10.8%)
≤ Grade10	10 (27%)
≤ Grade12	8 (21.6%)
> Grade 12	8 (21.6%)
Employment	
Yes	68 (47.5%)
No	75 (52.4%)
Category employed	57
Elementary occupation	28 (49.1%)
Machine operators and driver	6 (10.5%)
Clerical and admin	4 (7%)
Sales worker	4 (7%)
Technical and trade worker	1 (1.8%)
Other	14 (24.6%)

* Differences in totals are due to missing values.

The majority (64.3%) of patients discharged were male and 46% were married. The age range of patients was 3 to 81 years. The mean age of all sampled patients was 37.3, while the mean age of patients with TSCA and NTSCA were 32.2 years and 42.3 years respectively. Patients in the NTSCA group were on average 10 years older than those in the TSCA group. (Table 4.1)

In terms of province of residence, 50.8% of patients discharged were from Gauteng; 25.4% from North West, 13% from Limpopo and 6.2% o from Mpumalanga. The country of birth and/or province was not known for 15 patients. Foreign nationals made up 8.8 % of the 194 patients where country of birth was known.

As can be seen from table 4.1 the education level was only known for 37 patients: 29 patients had a grade 12 or less level of education and only eight patients had post-school qualifications.

The employment category was known for 57 patients of the 66 PSCA who were employed. Of these 57 patients, 49.1% worked in elementary category of work, such as gardeners and bricklayers, and a further 10.5% as machine operators.

4.2.2 Medical background information of study participants

Aetiology

The study found that for all patients admitted during the study period (n=264), 41.7% (110) of the SCA were due to TSCA and 51.9 % (137) were due to NTSCA. The cause of the SCA in the remaining 6.4% (n=17) of patients was unknown as the diagnoses were not indicated in the records. However, of the 209 PSCA discharged, 45 % (94) had a TSCA and 48.3% (101) a NTSCA, with 6.7% (14) unknown.

Table 4.2: Aetiology, level of injury and severity

Variable		TSCA n (%)	NTSCA n (%)	*Total n (%)
Aetiology	RTA	58 (63.7%)		58 (63.7)
	Fall	7 (7.7%)		7 (7.7)
	Stab	7(7.7%)		7(7.7)
	GSW	16 (17.6%)		16 (17.6)
	Other	2 (3.3%)		4 (3.3)
	Total TSCA	91(100%)		91(100%)
	Malignancy		24 (26.7%)	24 (26.7%)
	HIV		10 (11.1%)	10 (11.1%)
	TB		39 (43.3%)	39 (43.3%)
	Arthritis		3 (3.3%)	3 (3.3%)
	Vascular		0 (0.0%)	0 (0.0%)
	Other		14 (15.6%)	14 (15.6%)
	Total NTSCA		90 (100%)	90 (100%)
Level of injury	C1-C5	20 (20.6%)	5 (5%)	28 (13.4%)
	C6-C8	9 (9.3%)	9(9%)	20 (9.6)
	Cervical*	(0%)	2(2%)	2 (1)
	<u>Subtotal</u>	<u>(29.9%)</u>	<u>(16%)</u>	<u>(24)</u>
	T1-T6	18 (18.6%)	12 (12%)	30 (14.4%)
	T7-T12	30 (30.1%)	31 (31.%)	65 (31.1%)
	Thoracic*	1 (1.1%)	5 (5%)	6 (2.9%)
	<u>Subtotal</u>	<u>(49.8%)</u>	<u>(50%)</u>	<u>48.4%</u>
	Lumbar	11 (11.3)	14 (14%)	25 (12%)
	Sacral	(0%)	(0)	0
	Unknown	8 (8.2%)	22 (21%)	33 (15.8)
	Total	100	100	
Severity of injury	Complete	58 (65.2%)	17 (21.5%)	79 (44.8%)
	Incomplete	31 (34.8%)	62 (78.5%)	97 (55.1%)
	Total	100	79 (100%)	

* Differences in totals are due to missing values.

As can be seen from Table 4.2, RTAs and TB were the leading cause of all SCAs. The majority (63.7%) of PSCA that sustained a TSCA were involved in a RTA, and 25.3% of patients were involved in violence-related incidences (stab and GSW) that lead to a TSCA. For PSCA that contracted a NTSCA, TB (43.3 %) was the leading cause. The most frequent level for patients with TSCAs and NTSCAs was at the level of T7 – T12. (Table 4.2)

At the time of the study the hospital did not use the ASIA scale consistently. Therefore, the severity of the affliction is reflecting the patient's ability to move any part below the level of affliction and not a complete or incomplete affliction as per the ASIA scale definitions. A total of 55.1% (97/176) of patients discharged had no movement below the level of affliction,

but 65.2% (58/89) of patients with TSCA had no movement and 21.5% (17/79) of patients with NTSCA had no movement.

The record review found that, for both male and female, the three most common causes of SCAs were RTAs, TB and malignancies. Table 4.3 highlights the aetiology by gender.

Table 4.3: Aetiology and gender

Aetiology:	Male n: (%)	Female n (%)
RTA	35(31.3%)	20 (33.3%)
TB	16 (14.3%)	22 (36.7%)
Malignancy	15(13.4%)	8 (13.3%)
GSW	14(12.5%)	1 (1.7%)
Fall	7 (6.3%)	
Stab	7 (6.3%)	
HIV	6 (5.4%)	3 (5.0%)
Arthritis	2 (1.8%)	
Other	10 (8.9%)	6 (10.0%)
* TOTAL	112 (100.0%)	60 (100%)

* Differences in totals are due to missing values.

The record review found that, for both male and female, the three most common causes of SCAs were RTAs, TB and malignancies.

Table 4.4 tabulates the level of affliction and aetiology for patients with NTSCAs.

Table 4.4: NTSCA level of affliction and Aetiology

Level	Aetiology: n (%)					
	HIV	TB	Malig-nancy	Arthritis	Other	Total
C1-C5	1 (20%)	1(20%)			3 (60%)	5 (100%)
C6-C72	1 (11.1%)	2(22.2%)	2 (22.2%)		2 (22.2%)	8 (100%)
T1-T6	2 (16.7%)	5 (41.7%)	4 (33.3%)			13 (100%)
T7-T12	3 (9.7%)	16 (51.6%)	8 (25.8%)	1 (3.2%)	1(3.2%)	31 (100%)
Lumbar	0	6 (42.9%)	3 (21.4%)	1 (7.1%)	1(14.3%)	14 (100%)
Cervical*					1(50%)	2 (100%)
Thoracic**		2 (40%)			1 (20%)	5 (100%)
Total	10	39	24	3	13	

* Cervical was used as an overarching category in cases where the exact level was not indicated

** Thoracic was used as an overarching category in cases where the exact level was not indicated

*** Differences in totals are due to missing values.

From this table it is evident that the majority of afflictions at a thoracic and lumbar level were due to TB.

Table 4.5 reflects level of affliction and aetiology of patients with TSCAs.

Table 4.5: TSCA level of affliction and Aetiology

Level	Aetiology: n (%)					
	RTA	Fall	Stab	GSW	Other	Total
C1 – C 5	11 (55%)	4 (20%)	1 (5%)	3 (15%)	0	100%
C6-C8	4 (44.4%)	1 (11.1%)	3 (33.3%)	0	0	100%
T1 – T6	14 77.78%)	1 (5.5%)	2 (11.1%)	0	0	100%
T7 – T12	19 (65.5%)	0	1 (3.4 %)	8 (27.6%)	0	100%
Lumbar	6 (54.5%)	1 (9.1 %)	0%	3 (27.3 %)	0	100%
Thorasic	0	0	0	1 (50%)	1 (50%)	100%

* Differences in totals are due to missing values.

For patients with TSCA: RTA and GSW most commonly occurred in the T7 – T12 level, falls in the C1-C5 level and stab wounds in the C5 – C8 level (Table 4.5).

Table 4.6 shows the average length of stay for patients by aetiology and level of affliction.

Table 4.6: Length of stay per aetiology and level of affliction injury

Variable		Number	Ave days
Length of stay according to aetiology	Average	164	109
	RTA	47	126
	Fall	6	164
	Stab	5	84
	GSW	15	120
	TSCA Unknown	7	7
	Malignancy	18	90
	HIV	8	82
	TB	35	117
	Arthritis	2	52
	Other	9	101
	NTSCA Unknown	8	8
Length of Stay according to level of injury	C1 – C 5	23	154
	C6-C8	16	116
	Cervical	1	28
	T1 – T6	26	118
	T7 – T12	53	106
	Thoracic	4	44
	Lumbar – Sacral	20	79
	Unknown	21	21
	Total	164	164

The data suggests that patients stayed an average of 109 days in hospital. Conditions that accounted for the highest average length of stay were: falls (164 days); RTAs (126 days); GSWs (120 days) and TB (117 days) at a total average of 126 days. Patients with a C1 – C5 lesion stayed the longest at an average of 154 days. (Table 4.6)

The majority of patients (58/74) with TSCA were reported as having no associated injuries but 10.8%, (8/74 patients), sustained limb fractures and 2.7% TBI (2/74) in addition to their TSCA. Six patients sustained other associated injuries. (Table 4.6)

Source of referral

Information on source of referral to the spinal unit was only available for 48 patients. Of these patients, more than half were referred to the unit from within DGMAH (54.2%),

followed by self-referral (20.8%), private sector (12.5%) and other tertiary and regional hospitals (12.3%).

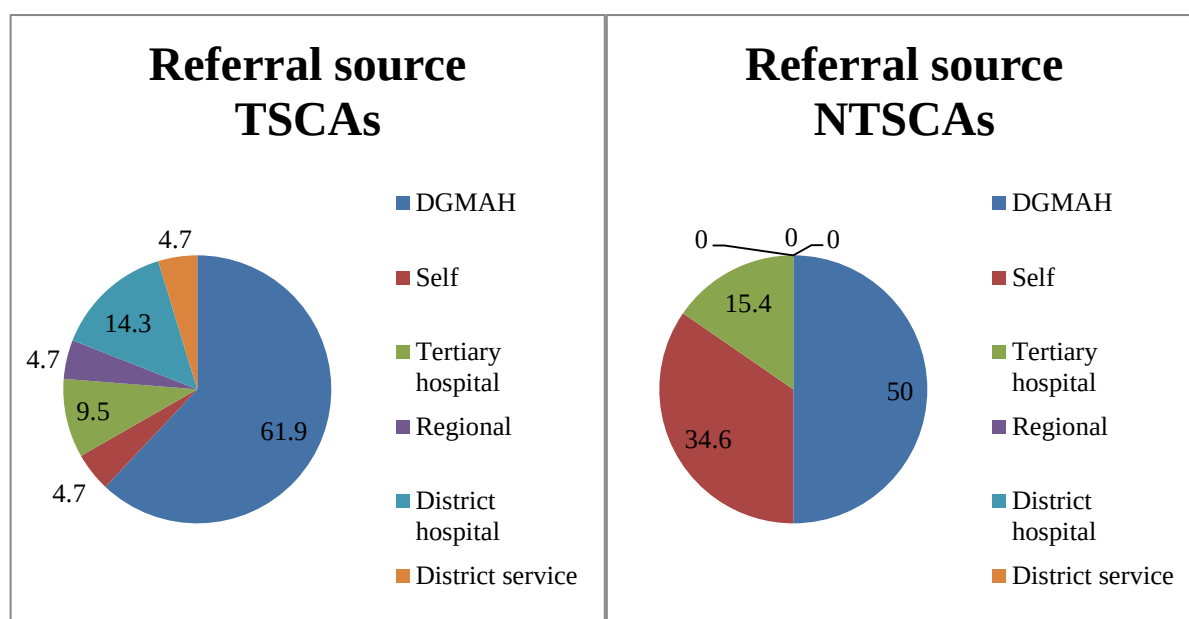


Figure 4.2 Referral source TSCAs and NTSCAs

Mobility status

The occupational therapists indicated that a standardised walking assessment scale was not administered, and that they used clinical judgements to identify certain patients as functional walkers (Table 4.7).

Table 4.7: Mobility status and assistive devices

Variable		Total	TSCA n	NTSCA n
* Mobility status	Full time wheelchair user	100/165 (64.1%)	62/83 (74.7%)	34/ 67 (50.7%)
	Functional walker	35/139 (25.2%)	13/74 (17.6%)	21/61 (34.4%)
	Wheelchair long distances	11/139 (7.9%)	5/74 (5%)	6/61 (10%)
Patients requiring assistive device		120 (81.1%)		
Manual wheelchair		105		
Motorised wheelchair		1		
Cushions		106		
Back slabs, crutches, walking frames		29		

* Differences in totals are due to missing values

As can be seen from the table 4.7, 25% of patients were functional walkers at the time of discharge. For patients with TSCA, 17.6% were functional walkers compared to 34.4% of

patients with NTSCA. A total of 64.1% of patients with were full time wheelchair users. A small proportion used wheelchairs only for long distances.

A total of 81.1% (120) patients received assistive devices, of which 75.6% (101) were manual wheelchairs and one was a powered wheelchair. The remainder of the assistive devices consisted of 29 various walking aids. Some patients received more than one assistive device. All wheelchairs were issued with pressure-care cushions. The records reflect that all patients needing wheelchairs were issued with wheelchairs before discharge and that no patient was placed on a waiting list. Thirty percent of patients were deemed not to need assistive devices.

A total of 78.6% of patients were discharged when rehabilitation was deemed completed, based on clinical judgement, by the multi-disciplinary team. The discharge results of 155 patients are shown in Table 4.8.

Table 4.8: Discharge results

Variable		Total n (%)	TSCA n (%)	NTSCA n (%)
Discharged to	Home	124 (80%)	61 (84.7%)	58 (81.7)
	Referring hospital	17 (11%)	7 (9.7%)	9 (12.7)
	RHT	1 (0.6%)		1 (1.4%)
	Old age home	2 (1.3%)	1 (1.4%)	1 (1.4%)
	NGO	1 (0.6%)		
	Other / not known	10 (6.4)	3 (4.2%)	2 (2.8%)
	TOTAL	155 (100%)	72 (100%)	71 (100%)

The majority of patients were discharged home

Seasonal variations in TSCA

Figure 4.4 below give an indication of the type of TSCA and the time of year that they most commonly occurred.

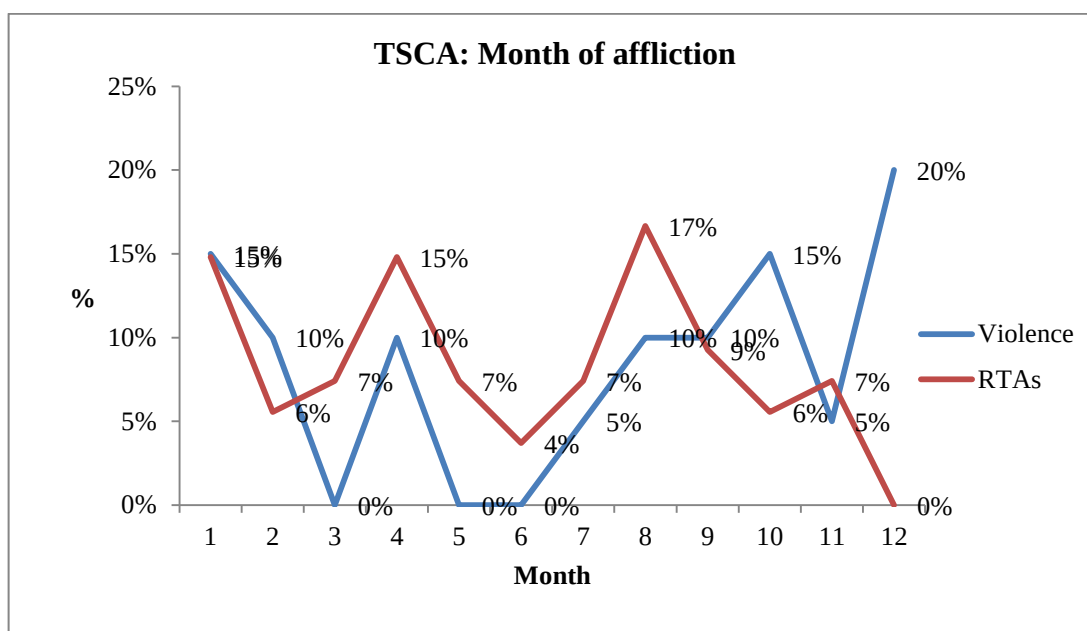


Figure 4.3: TSCA: Month of affliction

The majority of RTAs occurred in the months of January, April, and August. However, 20% of violence related TSCA occurred in December followed by 15% in October and January respectively.

4.2.2. Mortality profile of PSCA admitted to DGMAH

The record review found that 74/ 264 or 28% of patients admitted during the study period passed away. Of these, 55 during their hospital stay and a further 19 following discharge which was discovered when patients were contacted telephonically. Of those patients who passed away during their hospital stay (n=55), the majority (36/ 55= 69.2%) had a NTSCA.

Table 4.9 provides an overview of patients that died in hospital and those where mortality information was obtained during the follow-up. The exact diagnosis was not known for three patients that died in hospital – hence table below is only reflecting information for 52 patients.

Table 4.9 Mortality

	In patient mortality		Post-discharge mortality	
	TSCA: n %	NTSCA: n (%)	TSCA: n (%)	NTSCA: n (%)
deaths total	n=16	n=36	n=9	n=10
n (%)	30.8%	69.2%	47.4%	52.6 %
Gender				
Male	17.9% (14)	33.3% (23)	6	8

	In patient mortality		Post-discharge mortality	
	TSCA: n %	NTSCA: n (%)	TSCA: n (%)	NTSCA: n (%)
Female	(4.8%) (1)	20.8% (11))	2	2
Aetiology				
RTA:	13 (72%) (73.3)		6	
Falls:	2 (11%)		2	
GSW:	17% (3)		1	
Malignancy:		14 (44.1%)		3
HIV:		3 (8.8%)		
TB:		10 (29.4%)		3
Vasc:		1 (2.9%)		
Other:		5 (14.9%)		
TOTAL	100%	100%		

* Differences in totals are due to missing values

Of all the patients that passed away, 18 had a malignancy of the spine and 19 were involved in a RTA.

Ten of the 19 patients who passed away following discharge had a NTSCA. The patients with TSCAs that passed away post-discharge were all male, and had an average age at injury of 43.4 years. Six of the patients that died were involved in a RTA. The majority had an affliction at C1-C5 level and none of them were functional walkers.

For patients with a NTSCA that passed away following discharge, the majority were males and came from Gauteng. However, the average age at initial admission to hospital was 60.6 years. Malignancy and TB accounted for three deaths each. Half of them had an affliction at T7-T12 levels and most were full-time wheelchair users.

4.2 Semi structured questionnaire: Follow-up post discharge

This section describes results from the semi structured review of the 19 PSCA that were followed up at home. Of the 19 that were obtained during the follow up visit, 13 patients had a TSCA and 6 patients had a NTSCA.

4.2.1 Demographics: Patients followed up

Table 4.10 presents the demographics of the 19 patients that were followed up. There were some missing values which account for the variations in denominators.

Table 4.10: Demographics of patients followed up

Characteristics	Total
Gender	
Male	15
Female	4
Marital status	
Married	5
Single	13
Province	
Gauteng	12
North West	2
Limpopo	1
Education level	
None	1
≤ Grade 5	3
≤ Grade 7	
≤ Grade 10	5
≤ Grade 12	2
> Grade 12	6
Age at injury	
Mean age, SD, Range	32; 11; 3-41
Male Mean age, SD	32, 11
Female Mean age, SD	21, 20
Years living with a SCA	5 y 6 months

4.2.2 Medical background information

Table 4.11: Medical information of patients followed up

Variable		Total n
Aetiology	RTA	9
	Fall	1
	Stab	1
	GSW	1
	Malignancy	1
	HIV	
	TB	4
	Arthritis	
	Vascular	
	Other /Unknown	2
Level of injury	C1-C5	2
	C6-C8	
	T1-T6	6
	T7-T12	8
	Lumbar	1
	Sacral	
	Not known	2
Mobility status	Full time wheelchair user	11
	Functional walker	5
	Wheelchair long distances.	2
	With walking frame	1

Nine of the patients were involved in a RTA and four of the patients had TB. Fourteen of the patients had a thoracic injury and 11 were fully dependent on a wheelchair. Six patients were re-admitted but the reasons for this were unclear.

4.2.3 Environmental factors

An analysis of the home environment is provided in Table 4.13

Table 4.12: Home Environment

Variable	Total
Type of house	n=19
Brick house	14
Room/flat in back yard or shared property	1
Informal dwelling	3
Shared property	1
Location of water source % (N)	
Percentage having access to running water	(n=19)
Inside dwelling	10
In yard	7
Percentage of patients that can access water	Yes 17 (n=19)
Source of water	(n= 19)
Municipal,	18
Other	1
Electricity	
Percentage of patients with access to electricity	Yes 19 N:19

Most of the patients indicated that they had remained in the house they were living in prior to the affliction and of those, 14 patients lived in a brick house. However, only three patients with NTSCA were living in a brick house.

All 19 patients had access to electricity. However, 17 of the 19 patients had access to running water with 10 having water access inside the dwelling and 7 having access to water in the yard.

In terms of accessibility most of the entrances were wheelchair accessible, however bathrooms and toilets were a challenge. Eleven of the 19 patients made use of a zinc bath for bathing purposes. More than half of the toilets were outside the dwelling. Most patients with TSCAs had access to flush toilets but six patients with NTSCAs were using pit toilets.

Most of the patients with NTSCAs reported that they can access public transport and all of them could do so independently. Only a third of the TSCA patients could access public transport.

4.2.4 Narratives of people living with a SCA

The majority of patients indicated that they spend most of their time at home with family and friends. Any assistance required is provided by family members except for two patients that were independent.

Six themes emerged from the narrative. These are around employment and income, social aspects, transport and mobility, health care, environmental factors and desire for justice.

Under employment and income patients expressed the desire to gain employment and to have access to money. As far as transport and mobility are concerned, patients expressed the wish to be able to walk and run whilst some wanted to have their own transport. Patients also stated the need to have an accessible home environment. Under social aspects patients expressed the longing to be able to provide for their family, to have somebody to live with and to be free of the limitations of their disability. One child expressed the wish to be able to do things like other children. Medical statements related to the need to see a doctor, to have pain relieved and having the bullet removed. The following sentiment was expressed by one participant regarding a desire for justice: *“To see my assaulters in jail – I see them walk past my house every day”* (male, respondent 4)

4.2.5 Detailed profile of patients followed up

Table 13 summarised the profile of each of the 19 patients visited at home with their unique number as identification. The full summary of the patients follow up visit is reflected under Appendix 9.

Table 4.13 Summary of patients followed up

Key FTWU= Full time wheelchair user. FW = Functional walker WLD- Wheelchair long distances.

Patient	Age @ follow up	Marital status	Education Level	Employed	Time living with SCA	Category	Aetiology	Level	Mobility	Re-admitted	Type house	Access running water		Accessibility			Independent to				Access electricity	Type toilet		Type bath
												In dwelling	In yard	Dwelling entrance	Bathroom	Toilet	To access water	wash	Use toilet	Use public transport		Flash	Pit	
11		S	G10	N	6y 4m	TSC A		T7-T12	FTW U	Y	Brick	Y		Y	N	Y	Y		Y	Y	Y		Y	Zinc
19	38	S	G 10	Y	4y 4m	NTS CA	TB	T7-T12	FW	N	Back yard	N	Y	N/A	N/A	N/A	Y	Y	Y	Y	Y	Y		Zinc
33	38	M	G 12	N	6y 3 m	TSC A	RT A	T1-T 6	FTW U	N	Brick	Y		Y	N	N	Y	Y	N	N	Y	Y		
37	44	M	G 10	N	4y 3 m	NTS CA	TB	T7-t12	FTW U	N	Brick	Y		Y	Y	Y	Y	Y	Y	Y	Y	Y		
43	39	M	G 12	N	4y 1 m	TSC A	GS W	L	FTW U	N	Brick	Y		N	Y	Y	Y	Y	Y	Y	Y	Y		Bath
44	44	S	-	Y	3y 7 m	TSC A	RT A	T1-T6	FTW U	N	Brick	Y		Y	N	Y	Y	Y	Y	N	Y	Y		Zinc
47	38	S	G 12	N	5y 6 m	TSC A	RT A	T1-T6	FTW U	N	Brick	Y		Y	Y	Y	N	Y	Y		Y			
48	25	S	G 12	N	5 y 6m	TSC A	RT A	T1-T6	FTW U	Y	Brick	Y		Y	N	N	Y	Y	N	N	Y	Y		Bath
76	24	S	G7	N	4y 7 m	TSC A	GS W	T1-T6	FTW U	Y	Brick		Y	N	N	N	N	N	N	N	Y		Y	Zinc
85	67	M	G10	Y	5 y 10 m	NTS CA	TB	T7-T12	FW	y	Brick		Y	N/A	N/A	N/A	Y	Y	Y	Y	Y		Y	Zinc

Patient	Age @ follow up	Marital status	Education Level	Employed	Time living with SCA	Category	Aetiology	Level	Mobility	Re-admitted	Type house	Access running water		Accessibility			Independent to				Access electricity	Type toilet		Type bath
												In dwelling	In yard	Dwelling entrance	Bathroom	Toilet	To access water	wash	Use toilet	Use public transport		Flash	Pit	
90	38	M	-	N	4y4m	TSC A	RT A	C1-C5	FW	N	Brick	Y		N/A	N/A	N/A	Y	Y	Y	Y	Y	Y		Bath
92	10		G 5	N/A	6y2m	TSC A	RT A	T7-T12	W-LD	N	Brick		Y	Y	N	N	Y	N	N	N	Y	Y		Bath
99	40	M	G10	N/A	-	TSC A	RT A	C1-C5	FW	N	Informal dwelling		Y	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Y	Y		Zinc
106	33	S	G 10	N	5y8m	TSC A	RT A	T7-T12	FTW U	Y	Brick	Y		Y	N	Y	Y	N	Y	N	Y	Y		Zinc
163	11	S	G5	N/A	5y	NTS CA	Ma lig		FW	N	Room back yard		Y	N/A	N/A	N/A	N/A	N/A	N/A	Y	Y	Y		Zinc
167	37	S	G12	N	6y4m	TSC A	Fall /ass ualt	T1-T6	FTW U	N	Informal dwelling		Y	Y	Y	Y	Y	Y	Y	N	Y	Y		Zinc
233	46	M		N	6y8m	TSC A	RT A	T7-T12	FTW U	N	Brick	Y		Y	Y	Y	Y	Y	Y	N	Y	Y		Bath
239	10	S	None	N	6y4m	NTS CA	TB	-	Walk frame	N	Informal dwelling		N	N/A	N/A	N/A	N	Y	Y	Y			Y	Zinc
250	44	S	-	N	8y 9m	NTS CA		T7-T12	W-LD	Y	Brick		Y	N/A	N/A	N/A	Y	Y	Y	N	Y		Y	Zinc

CHAPTER 5: DISCUSSION

5.1 Introduction

The 2015 UN sustainable development goals (SDGs) have re-emphasised both the importance of inclusive societies (irrespective of disability) and of high-quality, reliable data, which includes studies on disability (118). This study was conducted to determine the survival status of patients with spinal cord afflictions following discharge from a South African public sector academic hospital. The study was guided by an adaptation of the social adapted model, which consists of a consideration of epidemiological and health system factors, and the social determinants of health. A cross-sectional study design that used a combination of record review and follow-up visits of patients was used to answer the study questions.

The remainder of this chapter discusses the study findings in light of the study objectives, and the existing literature.

5.1 Key findings

Key findings of the study are shown in table 5.1 and discussed further below

Table 5.1 Key findings

• The record review found that 264 patients were admitted during the study period from 2008 until 2012.
• The majority of patients discharged were male (66.3 %). The mean age of all patients discharged during the review period was 37, with a standard deviation (SD) of 15.3. The mean age of patients discharged with traumatic spinal cord afflictions (TSCAs) was 32.2 years, and for patients discharged with non-traumatic spinal cord afflictions (NTSCAs) 42.3 years.
• In terms of medical profile, 45 % (94) had a TSCA and 48.3% (101) a NTSCA, with 6.7% (14) unknown. For patients discharged from hospital the leading cause of TSCA was road traffic accidents (RTAs) at 63.7%, while tuberculosis (TB) was the leading cause of NTSCA at 43.3%.
• A total of 55 patients died in hospital (55/264=20.8%) and an additional 19 patients are known to have died following discharge from hospital.
• There was very high non-response rate of 57.8 % (n: 152) for the second phase of the

study and only 19 patients were visited in their homes.

- The 19 patients followed up reported numerous challenges, environmental barriers, such as inaccessible dwellings and inability to use public transport.

5.2 Socio-demographic characteristics of PSCA

This is one of the first studies that examined the survival status of patients following discharge from a public sector academic hospital spinal unit. The study finding of a majority of male patients with TSCAs is consistent with the findings of other studies, both in South Africa and from other LMICs (86, 113, 119). Furthermore, this finding is consistent with the 2017 report from Statistics South Africa that indicated that the mortality rates for South Africans for non-natural causes of death are the highest amongst males in the age group 20 – 25 years of age (120).

In this study, the proportion of females with NTSCAs was lower at 35.7%. This finding contrasts with those from studies on NTSCAs in Australia and India, where females accounted for the majority of the NTSCA population (35, 119, 121). In terms of the burden of disease in South Africa, TB was the leading cause of death for both men and women during 2013-2014. The TB mortality has declined but TB remains the leading cause of death for males in 2015 (120).

Although the mean age of all patients was 37 years, the study found that the mean age of the patients with TSCAs was 32.2 years. This could be because RTAs caused the majority of TSCAs. The mean age is higher compared to earlier studies done in South Africa in the 2000s, but similar to a 2015 study in Cape Town and also a 2011 study in Canada and (34, 86, 92). The finding implies that these young men suffered a SCA in the prime of their lives, suggesting the need for appropriate prevention strategies.

In contrast, patients with NTSCAs were older than those with TSCAs. This is consistent with studies from Australia and Canada (34, 121). Rehabilitation services need to be tailored to meet the needs of an older population.

The relatively high percentage of single patients (38.1%) in this study, may pose challenges of long term support in the community because of the important role that family members play

in providing care and support. At the time of follow-up, the majority of patients were single (12 out of 18) and two of them were children. Apart from two that indicated that they were fully independent, the remainder relied on family assistance.

Although education levels may have a direct bearing on employment potential of disabled people, there was very little information on employment and education in the records.

The record review found that only 8.8% of individuals were non-South African citizens, and no information is available on their survival status.

The 25.4 % and 13% of patients discharged that were from the neighbouring North West and Limpopo province respectively suggest the need for spinal units in those provinces. As indicated, only three provinces have dedicated rehabilitation facilities in South Africa. Hence, improved access to acute care and rehabilitation services are important priorities as rehabilitation needs to take place as close to home as possible (1).

5.3 Medical profile

Although there was a small proportion of missing information on diagnosis, the study found that NTSCA were in the majority. The higher percentage of patients with NTSCAs in this study was in contrast with other studies done in South Africa (91). This could be because this study was done at an academic hospital, which serves as a referral centre for specialised oncology services (122). In contrast, Natalspruit Hospital is a regional hospital, where the patient profile was different. On the other hand, it could be an indication of the rising burden of non-communicable diseases in South Africa (123), which suggests that the profile of NTSCA is similar to that in HIC (43). For example in Canada the prevalence of TSCA and NTSCA is similar (3).

RTAs were the leading cause of TSCA followed by GSWs and stabs. This finding is similar to those of Mothabeng but contrast with the studies carried out in the Cape Metropole in 2015, which found that GSWs were the leading cause of TSCAs (86, 93). This study result is also different to studies previously conducted at Natalspruit hospital ((91, 92)

The reason for RTAs being the leading cause of TSCAs is not very clear but could be related to referrals to the DGMAH (124). It might also reflect the general increase in RTAs in South

Africa. South Africa recorded an increase of 17% in RTAs in December 2016, compared to the same period in 2015 (125). Nine of the patients followed up were involved in a RTA at the time of affliction. This study highlights the importance of prevention campaigns such as “Drive Alive” but also the need for further research in this area to establish appropriate prevention strategies.

In this study, TB and malignancies were the main causes of NTSCAs. In Australia malignancy was the highest cause of NTSCA (121), but in the USA it was the second highest cause after spinal stenosis (35). The study finding highlights the burden of TB in South Africa, and the rising burden of NCDs (123). Both conditions are amenable to a public health approach, with prevention at its core. The findings suggest that there should be closer collaboration between acute and rehabilitation services in terms of prevention, management and rehabilitation.

With regard to severity of the affliction, ISCoS has made the use of the ASIA scale mandatory in terms of publication in its journal, to ensure standardisation in the classification of the severity of the injury. A patient can only be classified as complete versus incomplete lesions if the ASIA scale was used (126). It is possible that if the ASIA scale was used consistently at DGMAH, more patients would have been classified as having a complete lesion. However, in spite of the data on severity of the affliction, being compromised due to the unit not utilising the ASIA scale, the percentage of TSCA patients with inability to move below the level is higher at 74.7%, than those classified as complete lesions in HIC and this might be a reflection of poor evacuation procedures. It is possible that poor evacuation processes lead to further damage to the cord and an incomplete lesion at injury site, turning into a complete lesion during evacuation (34, 54).

The higher percentage of NTSCA patients in this study with incomplete lesions is in line with global trends (121). However, in this case, the non-utilisation of the ASIA scale brings this statistic for NTSCA in serious jeopardy as it is possible that more of the patients with incomplete lesions were in fact complete lesions. Whilst in the TSCA category utilising the ASIA scale might have led to an even higher percentage of TSCA being categorised as having a complete affliction. The utilisation of the ASIA scale in the province should be promoted.

The majority of afflictions (32.8) in the RTAs group (32.8%) were at a T7 –T 12 level. NSCISC reported the highest incidence of RTAs at a cervical level (40). The possibility of tetraplegic patients not surviving evacuation procedures in South Africa could be an explanation for this but this requires further investigation.

Most patients that fell sustained a C1-C5 level of affliction, which was similar to the NSCISC (40). However the NSCISC indicated that most violence related afflictions led to paraplegia which was the case for GSWs in this study, but not for stab wounds. In this study, stab injuries most commonly occurred in the C6 – C8 level. It is difficult to speculate on the reason for this and it might be purely incidental.

As for data on a global level, the majority of patients with NTSCAs in this study were paraplegics. The most common level affected was T7- T12 (35, 121). This was the case for all four major causes of NTSCA and the level most affected was T7-T12 with the lumbar/sacral region was second most affected by malignancies and TB.

The higher percentage of RTAs in August and September was surprising as Easter and December are holiday periods in South Africa and these times are perceived as having a high incidence of RTAs. There was a slight increase in April but a reduction in December. This may possibly be a reflection of the start of the holiday period being more staggered over the first three weeks of December whereas the start of the new working year and school holidays are all around the second week of January. As mentioned before, there is an overall increase in RTAs in South Africa (125). Collecting data on location of accidents will provide more information, especially for prevention measures.

As in the Cape Town study (86), this study found a high incidence of violent related afflictions over the December period, but not in the mid-winter (July –August) period as found in Cape Town. The high incidence of violent related afflictions in the December summer holiday period in South Africa, suggests the probability of an increase in the use of substances and availability of more free time.

Most of the referrals (54%, 26/48) to the unit were from the hospital itself, which will positively contribute to a seamless service. However the information was only available for a small number of patients.

The length of stay of patients was considerably higher compared to HIC (127). Falls had the longest length of stay, followed by RTAs in the TSCA category and TB spine in the NTSCA category. The increase length of stay might be related, amongst others, to a delay in diagnostic and/or surgical procedures, the development of secondary complications or the lack of community support services. Patients that sustained a C1-C5 affliction stayed the longest at an average of 154 days which may be indicative of all the challenges this group of patients are faced with.

As stated before the limited OT and PT services in the community might be a further contributing fact to differences in LOS on a global level and in South Africa. The majority of OT and PT services are carried out post discharge in the USA (70). Patients are often unable to attend OPD services at a health facility due to challenges with transport (128). Community OT and PT services are limited and there were only 13 OTs and 9 PTs working in the Tshwane District in 2016 (129). However an increase in rehabilitation staff in the community and an expansion of community-based care might lead to a decrease in LOS, as some aspects of rehabilitation are carried out in the community.

The patient's ability to walk is a significant factor in reintegration into the community. Environmental factors such as uneven pavements or steps might be barriers in the patient's home environment. Mobile patients might cope better with environmental barriers than wheelchair dependent patients. In this study 17.6 % of TSCA and 34.4% of NTSCA were functional walkers on discharge from hospital. The medical intervention that patients with TB received may have improved their functional capability. The level of affliction may also have played a role as a higher percentage of the patients with TSCAs had a cervical affliction, 29.9% versus 16% of patients with NTSCAs. All the patients with NTSCAs that were followed up at home could walk but only 2 of the patients with TSCAs were followed up. This will also influence the ability of the patient to attend outpatient services at health facilities as the transport barrier will largely be neutralised in that the patients should be able to access public transport with more ease.

Access to wheelchairs and cushions are not a given in the LMIC, therefore the fact that all patients received the necessary wheelchairs and cushions and even in some cases power chairs is a good result in this context (130). The necessary walking devices were also issued.

However, this study did not venture into follow up services for wheelchairs and replacement of these wheelchairs.

It is encouraging that the therapists believed rehabilitation services were complete at time of discharge. It is a problem in South Africa as there is a demand for beds and patients are in some instances discharged without the rehabilitation process being completed or not available at all (128).

The majority of patients were discharged home which is in line with data from Australia (54). The hospital records reflected that attempts were made to establish contact with the main care giver and training of the care giver was done where ever possible. Very few alternative care facility options are available for patients hence the high rate of patients being discharged home, however this will undeniably place a burden on the close family as they will have to carry the brunt of care giving where required. Care giver training is an important part of the rehabilitation process, as well as the availability of community OT and PT services as pointed out above.

Several patients during the follow up mentioned pain as a challenge and this should be taken in consideration in future treatment. A few patients further reported not being treated well during follow up visits and this is of concern. Patients seem not to be aware of the existing complaints procedure at hospital level and pain management seems inadequate.

5.4 Environmental factors

Information on environmental factors was only available for the patients that were followed up. There seems to be a dearth of similar data from both HIC and LMIC, thus no comparisons could be made.

The White Paper on Rights of Person with Disability indicates the need for removal of all barriers to full integration of people with disability (131). Most patients followed up experienced environmental barriers. The inability of 7/10 of patients with TSCAs to access public transport, mainly due to mobility difficulties, is a major factor that will severely influence their ability to increase their skill level and enter the job market. Most patients indicated that they spent the majority of time at home with family and friends. They are in the economically active stage in their lives and the transport barrier renders them unable to

participate in all spheres of life (1). This does point to challenges in terms of full/complete integration of the patients into the community.

Part of the challenge being experienced with community integration, might be outside the realm of health services to address. Managing issues around disability requires collaboration between several government departments including social development, education, human settlement and transport (131).

Future wishes expressed by patients were dependent on their mobility level. Patients that were able to walk expressed the wish to gain employment. Patients that were unable to walk expressed the wish to walk again.

5.5 Survival status

In this study a total of 28% (74/264) patients passed away, 55 as inpatients and 19 following discharge. The mortality of patients with NTSCAs is linked to the primary disease (104). In this study 18 patients that had malignancies of the spine were known to have died. The progression of the malignancy did not form part of the study and additional information regarding the progression of the malignancies is needed to determine stage of malignancy at time of detection and referral to the unit.

The majority of TSCA patients that passed away were involved in a RTA with a T7- T12 lesion. This is in contrast to studies from Nigeria and Canada where cervical injuries accounted for the majority of deaths (41, 132). However, the fact that the majority of patients that died had a T7-T12 lesion is to be expected as the majority of patients in this study sustained an affliction of the lower thoracic spine.

5.6 Study limitations and strengths

The lack of a central SCA register in the hospital may have resulted in some patients not being captured in the study. Despite all attempts at using complementary records to fill in missing information, the patient records did not contain all the information required. A prospective study might have prevented the challenges with record keeping. Nonetheless, the study findings underscore the need for better records management at hospital level, and for improved follow-up of PSCA following discharge.

Patients could not be contacted telephonically for ethical reasons. Major limitations of the study were the non-response and the inability to follow-up the majority of patients, despite major efforts to reach all members of the study population.

The steps taken to reduce non-respondents are described in Chapter 3. The inability to trace patients and interview them in their homes meant that limited information was obtained on the environmental conditions and the status of PSCA post-discharge. It was not possible to determine the association between survival post-discharge and the demographic, medical background and/or environmental variables obtained.

However, there are a number of strengths of this study, both of methodology and the results obtained. The record review and follow-up questionnaire were tested in a large spinal unit, and elicited useful information. These tools could be used by researchers in South Africa, and in other LMICs. The study generated locally, context specific information on the: demographic profile of patients admitted to the unit; the medical background information of all PSCA treated in this period and a detailed profile of the 19 patients followed up.

The findings could be used for future studies at DGMAH to determine changes in these variables. The study findings could also be used to compare the findings of similar studies conducted in other spinal units in South Africa, and in other LMIC. The study findings point to recommendations at different levels, and these are discussed in the final chapter of the dissertation.

CHAPTER 6 CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

SCA is a complex condition that is caused by either TSCAs or NTSCAs. Using a retrospective record review and follow-up of patients at their homes, this study sought to determine the survival status of PSCA following discharge from a Gauteng Provincial Government Hospital spinal unit for the five year period from 1 January 2008 until 31 December 2012. The key results of the study were presented and discussed in the previous chapters.

But in conclusion, PSCA are mostly male. Patients with TSCAs are in their early 30ties whilst patients with NTSCAs are in their late 30ties. The majority had a high school education and was unemployed at time of affliction.

The majority of patients had sustained a NTSCA of which TB was the main cause. More patients were paraplegic with a complete lesion. All patients were discharged with the necessary mobility aids.

The main environmental obstacles experienced at home were related to transport and accessibility inside the house. Patients that need any form of assistance are heavily reliant on family members.

A considerable amount of patients died in hospital. However due non-respondents the relationship between survival status and the demographic, medical and environmental factors could not be established

South Africa has well formulated and broadly accepted strategic plans for NCDs, HIV, STIs and TB. Determined effort is needed to ensure adequate capacity and resources to deliver on the laudable outcomes of these plans (133, 134). However these plans do not include rehabilitation services for PSCAs. Furthermore, according to the WHO the demand for rehabilitation has increased and is largely unmet in Africa (128).

Hence, the recommendations in this final chapter derive from the study findings.

Recommendations

6.2.1. *Recommendations at National level*

- The researcher will present the findings, especially regarding TB and RTAs to managers and staff of the national department of health to raise awareness of issues pertaining to PSCA. This will be done in an effort to ensure inclusion of issues related to PSCA in future planning for NCDs, communicable diseases and injury.
- National Health should take the lead in establishing a database of SCA in the country and supporting surveys to determine information regarding, amongst others, aetiology.
- The custodians of the White Paper on the rights of people with disabilities, National Department of Social Development, should enforce the White Paper, especially regarding issues related to intersectoral collaboration. This should be done to improve issues related to access to transport and accessibility.

6.2.2. *Recommendation at provincial level*

- Clinical guidelines and protocols should reflect all aspects of care, with special emphasis on community integration and follow-up.
- District rehabilitation services need to be strengthened to ensure follow up and support in the community.
- GHD needs to investigate the feasibility of introducing the ASIA scale in clinical settings. Not only is this needed for further research but to improve patient management.
- A minimum standard for hospital record keeping for PSCA should be developed on a provincial level and the monitoring thereof.

6.2.3. *Recommendation at hospital level*

- Each spinal unit should have a patient register which should include the patients' hospital number along with other information. This will assist in tracking hospital files for research purposes and the register will assist with basic data collection.
- Rehabilitation guidelines and an implementation plan should be developed that includes community based integration of PSCA.
- A standard operating procedure for referral and follow up of patients with SCA in Gauteng and in the neighbouring provinces should be compiled.
- The use of the ASIA scale should be a minimum standard for record keeping.

6.3. Further research

Research is lacking in many areas of SCA care and collective efforts to increase appropriate research by clinicians, rehabilitation therapists and associations such as the Association for people with Quadriplegics and Paraplegics (Quadpara Association) and the Southern Africa Spinal Cord Association are needed.

- Detailed information regarding the nature of the affliction of TSCAs, especially RTAs needs to be established. For example to determine if the patient was a pedestrian or occupant of the vehicle and what was the exact cause of the RTA. This can possibly be based on the prevention data set from ISCoS.
- Research is required into evacuation processes for patients with TSCAs to determine the nature of it and if it is in compliance with evidence based practises.
- Comprehensive research on NTSCA, including incidence and referral procedures. The emphasis in research in South Africa is still mainly concentrating on TSCA.
- Data on the impact of HIV & AIDS was scant and needs further exploration, especially considering the possible impact of HIV&AIDS on incidence and secondary complication of PSCA. This needs to be explored in conjunction with disease patterns and the disease burden.
- Detailed data is required to establish the exact nature of barriers to community integration to provide direction for intersectoral collaboration.
- Care giver training is an important aspect of intervention – the nature and impact of it needs to be established.
- In-patients mortality needs to be further investigated to enable clinicians to take measures to reduce the mortality rate
- Additional resources are needed to ensure that the majority of patients admitted can be followed up. This study has found that significant financial and human resources are needed for follow-up, combined with a good hospital information system. Cohorts of PSCA could be established, and these individuals could then be followed up over a period of time.

6.4. Conclusion

This study focused on the survival status of PSCA following discharge from a spinal unit at a large, academic, central hospital. The study provided a comprehensive overview of the

demographic information of PSCA treated in a provincial hospital, the medical profile of patients admitted, and the environmental factors faced by a small group of surviving who were followed up in their homes. The study found that RTAs and TB were the leading causes of TSCAs and NTSCAs respectively, suggesting the need for a broader public health approach with prevention at its core.

The study generated new research questions, which have been outlined in the preceding section.

The high non-response rate requires improved hospital information systems to monitor patient outcomes after discharge, as well as larger prospective studies to determine the outcomes of PSCA following discharge from hospital.

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APPENDICES

Appendix 1 - Ethics certificate

M140485



HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140485

NAME: Ms Elma Burger
(Principal Investigator)

DEPARTMENT: School of Public Health
Dr George Mukhari hospital

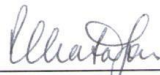
PROJECT TITLE: Factors Influencing the Survival of People with
Spinal Cord Afflictions (PSCA) Treated in a Gauteng
Provincial Government Hospital

DATE CONSIDERED: 25/04/2014

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Prof L Rispel and Prof M Lukhele

APPROVED BY: 
Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 30/05/2014

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 Secretary in Room 10004, 10th floor, Senate House University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit yearly progress report.**

Principal Investigator Signature

M140485 Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix 2 - Hospital permission



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Dr. George Mukhari Academic Hospital

Office of the Director Clinical Services

Enquiries : Dr. P. Shembe

Tel : (012) 529 3880

Fax : (012) 560 0099

Petunia.Shembe@gauteng.gov.za

To : Ms Elizabeth Burger
C/O Albertina Sizulu & Sauer Street
Private bag x 085
Marshall Town
: 2107

Date : 10 June 2014

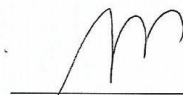
PERMISSION TO CONDUCT RESEARCH

The Dr. George Mukhari Hospital hereby grants you permission to conduct research on
"Factors that influence the survival of patients with Spinal Afflictions at Dr. George
Mukhari Academic Hospital."

This permission is granted subject to the following conditions:

- ☒ That you obtain Ethical Clearance from the Human Research Ethics Committee of the relevant University
- ☒ That the Hospital incurs no cost in the course of your research
- ☒ That access to the staff and patients at the Dr George Mukhari Hospital will not interrupt the daily provision of services.
- ☒ That prior to conducting the research you will liaise with the supervisors of the relevant sections to introduce yourself (with this letter) and to make arrangements with them in a manner that is convenient to the sections.

Yours sincerely


PP **DR. P SHEMBE**
DIRECTOR: CLINICAL SERVICES

Appendix 3 - Tshwane District Services Permission



Kuyasheshwa! Gauteng Working Better

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

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Enquiries: Mr. Peter Silwimba.

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TSHWANE RESEARCH COMMITTEE

CLEARANCE CERTIFICATE

Meeting: N/A

PROJECT NUMBER: 29/2014

Title: Factors influencing the survival of People with Spinal Cord Afflictions (PSCA) treated in a Gauteng Provincial Government Hospital

Researcher: EM Burger

Co-Researcher:

Supervisor: Professor Laetitia Rispel and Professor Mkhululi (Mac) Lukhele

Department: School of Public Health

DECISION OF THE COMMITTEE

Approved

NB: THIS OFFICE REQUESTED A FULL REPORT ON THE OUTCOME OF THE RESEARCH DONE

Date: 30/06/14

Mr. Peter Silwimba

Chairperson Tshwane Research Committee
Tshwane District

Mr. Pitsi Mothomone

Chief Director: Tshwane District Health

Tshwane District 2014.07.08

NOTE: Resubmission of the protocol by researcher(s) is required if there is departure from the protocol procedures as approved by the committee.

Appendix 4 - Record review

For official use only

1. Participant number		<table border="1"><tr><td></td><td></td><td></td><td></td></tr></table>						
2. Date of review:	DD/MM/YY	<table border="1"><tr><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>						
3. Date of injury	DD/MM/YY	<table border="1"><tr><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>						
4. Date of admission to hospital	DD/MM/YY	<table border="1"><tr><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>						
(In cases where pt not directly admitted to unit)								
5. Date of admission to unit	DD/MM/YY	<table border="1"><tr><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>						
6. Date of discharge	DD/MM/YY	<table border="1"><tr><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>						
7. Date of Birth	DD/MM/YY	<table border="1"><tr><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>						
8. Address								
9. Tel Number/cell number pts								
Tel Number next of kin								
10. Support structure								

SECTION 1: OUTCOME

For official use only

☐	R101	Did patient passed away during hospital stay	☐ Yes...1 ☐ No...0
☐	R102	Reason for passing away:	
☐	R201	Gender	☐ Male...1 ☐ Female...2
☐	R202	Age at time of record review (<i>in completed years</i>)	
☐	R203	Age at injury(<i>in completed years</i>)	
☐	R204	Population group ☐ Black...1 ☐ Coloured...2 ☐ Indian...3	☐ White...4 ☐ Other...5
☐	R205	Marital status at time of injury ☐ Married...1 ☐ Widow/...2 ☐ Single...3	☐ In relationship...4 ☐ Other...5
☐	R206	Foreign National	☐ Yes...1 ☐ No...0

☐	R207	Province of residence. ☐ KZN...1 ☐ Limpopo...2 ☐ WC...3 ☐ EC...4	☐ NC.....5 ☐ North West.....6 ☐ Free state.....7 ☐ Mpumalanga8 ☐ Gauteng9
☐	R208	Highest education level school ☐ None...1 ☐ ≤ Grade 5 ...2 ☐ ≤ Grade7 ...3	☐ ≤ Grade10 ...4 ☐ ≤ Grade12 ...5 ☐ ≥ Grade12...6
☐	R209	Employed at time of injury	☐ Yes...1 ☐ No...0
☐	R210	If no, reason not employed before ☐ Awaiting season ...1 ☐ Waiting recall ...2 ☐ Health reasons ...3 ☐ Pregnancy ...4 ☐ Training to find W5 ☐ No jobs6 ☐ No money transport.....7 ☐ Incorrect skills8 ☐ No transport9	☐ Scholar/student10 ☐ Retired11 ☐ Too old/young12 ☐ Lost hope13 ☐ Don't want14 ☐ Disabled/unable15 ☐ Housewife16 ☐ Don't need to17 ☐ Not indicated.....18

☐	R211	If Yes Employment categories before affliction ☐ Managers ...1 ☐ Professional ...2 ☐ Technicians & Trade worker ...3 ☐ Clerical & admin workers ...4	☐ Community & personal worker5 ☐ Sales Worker6 ☐ Machinery Operators & Driver7 ☐ Elementary occupation8 ☐ Other9
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SECTION 3: MEDICAL INFORMATION

For official use only			
☐	R301	Ever re-admitted	☐ Yes...1 ☐ No...0
☐	R302	Number of readmissions	_____
☐	R303	Diagnostic category ☐ C1 – C5...1 ☐ C6 – C8...2 ☐ T1 – T6 ...3	☐ T7- T12...4 ☐ Lumbar...5 ☐ Sacral ...6 ☐ Cervical/quad...7 ☐ Para/thoracic ...8 ☐ Not known....9
☐	R304	Is it a complete injury	☐ Yes...1 ☐ No...0

For official use only			
☐	R305	Type of injury	☐ Traumatic...1 ☐ Non Traumatic...2
☐	R306	Aetiology ☐ MVA...1 ☐ Fall...2 ☐ Stab...3 ☐ Gun Shot Wound...4	☐ Sport...5 ☐ Pre morbid...6 ☐ Other...7 Please specify _____ _____
☐	R307	If 6 was marked in 306 – indicate the Pre morbid conditions ☐ Malignancy ...1 ☐ HIV....2 ☐ TB ...3	☐ Peripheral vascular disease ...4 ☐ Arthritis all ...5 ☐ Other...6 Please specify _____ _____
☐	R308	If spinal # how treated	☐ Conservatively ...1 ☐ Surgical interventionl...2
☐	R309	Referral to Dr George Mukhari from ☐ Tertiary hosp ...1 ☐ Regional ...2 ☐ Dist Hosp ...3	☐ Dist service ...4 ☐ Self5 ☐ Private sector...6 ☐ From Dr G Mukhari...7
☐	R310	Associated injuries	☐ None1 ☐ Traumatic Brain Injury ...2 ☐ Limb fractures...3

For official use only			
☐	R311	If HIV + pt on ARV?	☐ Status not known ...2 ☐ Yes...1 ☐ No...0
☐	R312	Assistive devices issued?	☐ Yes...1 ☐ No...0 ☐ Pt has own3
	R313	Type Assistive devices issued	
☐	A	Wheelchair manual	☐ Yes...1 ☐ No...0
☐	B	Wheelchair - Motorised	☐ Yes...1 ☐ No...0
☐	C	Cushion	☐ Yes...1 ☐ No...0
☐	D	Back slabs	☐ Yes...1 ☐ No...0
☐	E	Frame with/without wheels	☐ Yes...1 ☐ No...0
☐	F	Elbow crutch or walking stick	☐ Yes...1 ☐ No...0
☐	G	Quadropod	☐ Yes...1 ☐ No...0
☐	H	Callipers and boots	☐ Yes...1 ☐ No...0
☐	i	Other	☐ Yes...1 ☐ No...0 Please specify:

For official use only			
☐	R314	Is patient a functional walker ☐ Yes...1 ☐ No...0	☐ Only use wheelchair for long distances...3 ☐ other ...4 Please specify: _____ _____
☐	R315	Is patient a full time wheelchair user	☐ Yes...1 ☐ No...0 ☐ other ...3 Please _____ specify: _____ _____
☐	R316	Was rehab completed	☐ Yes...1 ☐ No...0
☐	R317	Discharge to ☐ Home ...1 ☐ NGO ...2 ☐ Old age home ...3 ☐ Referring Hospital ...4 ☐ Hospice ...5	☐ Clinic...6 ☐ RHT...7 ☐ Not known...8 ☐ Other...9 Please specify _____
☐	R318	If passed away, reason. ☐ Pressure sore ...1 ☐ DVT ...2 ☐ Respiratory illnesses ...3	☐ Not known...10 ☐ Other ...4 Please specify _____

Appendix 5a - Patient information sheet: English

PARTICIPANT INFORMATION SHEET

TITLE: FACTORS INFLUENCING THE SURVIVAL OF PEOPLE WITH SPINAL CORD AFFLICTIONS (PSCA) TREATED IN A GAUTENG PROVINCIAL GOVERNMENT HOSPITAL

Introduction

Good morning. My name is I am assisting Elma Burger with a study to try to establish what things help people to live in the community with an injured spine. The study is being done for a postgraduate degree.

Why are we doing the study?

The purpose of the study is to learn from you, what things are helping you at home and in the community to manage as a person with an injured spine. We hope that the information obtained from the study will be used to assist us to improve our rehabilitation services in the province.

How we will do the study?

As part of this study we want to get the information from people that were treated at the Dr George Mukhari Spinal Unit between 2008 and 2012. We would like to ask you a few questions. It should take around 30 minutes for you to answer the questions.

We are going to ask question about your home and personal circumstances. Our role is to listen and to understand what you are saying. There is no right or wrong answer. How you answer the questions will not affect any future care that you yourself may require at Dr George Mukhari hospital and we will not tell any staff what *you* say to us. We will put your answers into an overall report and nobody will know who said these things.

We cannot help you with any complaints that you have with the spinal unit and we cannot tell the staff if you are really happy with their services.

How do I know that the information I give will be kept confidential?

The information that you provide to me will be kept confidential and will be used for the purpose of this study only. Everything that you say will be treated as private and confidential. I will complete the questionnaire with the answers that you give, but I will not tell people your name or any other information that could be used to identify you. This means that no other person apart from me and the researcher will know that you took part in the study, or know how you answered the questions.

The answers given by you and other participants will be looked at and the combined information will be written-up in a form of a report. Your name will not be used in any report.

Did you get permission to carry out the study?

Permission to carry out this project was obtained from the University of the Witwatersrand Research Ethics Committee. The health department has also approved the study.

Will there be any benefits from participating?

There will be no direct benefits to anyone who participates in the interviews as participation is voluntary. This means you have the right to refuse to answer the questionnaire or if you do agree to answer the questionnaire you can leave out the answers you are uncomfortable with and you can stop the interview at any time.

Will there be any harm from participating?

We don't foresee any risks to you taking part in the research apart from taking up your time. If you feel upset during the interview, we can stop the interview at any time.

It is no problem if you don't want to be interviewed. However, we would really appreciate it if you do share your thoughts and feelings about the questions we will be asking you. We hope that the information we will get from you, will be used to help us to improve health services for people with injured spines.

Who do I contact if I want to ask more questions?

We will be happy to answer any questions you have about this study. This research has been approved by the University of the Witwatersrand Research Ethics Committee. If you have any questions about your rights as a study participant, or questions or concerns about any aspect of the study, you may contact the ethics office on (011) 717 1234. If you have questions about the research, you may also contact the principal investigator: Elma Burger; Phone: 082 494 1138.

Thank you for your assistance with this study.

Appendix 5b - Patient information sheet: Tswana

(LETLAKALA LA KITSISO GO MOTSAJA-KAROLO)

(SETLHOGO (MABAKA A ETLEGETSANG GO PHELA GA BALWETSE BA BO GOBETSE MARAPO A MOKWATLA)

(Matseno)

(Madume). (Leina la me ke) (Ke thusa Elma Burger ka dipatlisiso tsa go leka go fitlhela gore ke dilo difeng tse di ka thusang go tshela ga batho ba ba gobetseng marapo a mokwatla mo setshabeng).

(Ke go reng re dira dipatlisiso tse)?

(lebaka la dipatlisiso ke go ithuta mo go lona, ke dilo difeng tse di go thusang kwa gae le mo setshabeng go tshela jaaka motho yo o gobetseng marapo a mokwatla). (Re tshepa gore thuto e re tla e bonang mo dipatlisisong tse e tla re thusa go matlafatsa / tokafatsa ditirelo tsa katiso ya balwetse mo porofenseng).

(Dipatlisiso di tlile go dirwa jang)?

(Jaaka karolo ya dipatlisiso tse re batla go fitlhela bopaki gotswa go batho ba ba okilweng kwa Dr George Mukhari Spinal Unit magareng ga 2008 le 2012). (Re kopa go go botsa dipotso di le mmalwa). (Go tla tsaya metsotso e ka nna 30 go araba dipotso tse).

(Re tlile go go botsa dipotso ka maemo a gago le mo gae). (Sa rona ke go utlwelela le go tlhaloganya se o se buang). (Ga go na karabo e e fosagetseng). Tsela e o arabang dipotso ka yona ga e kitla e go senyeletsa go fitlhela thuso ya kalafi kwa bookelong jwa Dr George Mukhari e bile ga re kitla re ba bolelela se o se buileng). (Dikarabo tse di tlile go akarediwa mo go tsa batho botlhe mme go go ope yo o tla boning gore mang a reng).

(Ga re kitla re kgona go go thusa ka go sa kgotsofaleng ga gago ka kalafi e o fitlhelang ko spinal unit e bile re ka se kgona go isa molaetsa wag ago ko go bona).

(Ke tla itse jang gore bopaki jwa me gab o kitla bo phatlaladiwa)?

(Bopaki jwa gago gabo kitla bo phatlaladiwa mme bo tla dirisediwa fela mabaka a dipatlisiso tse). Sengwe le sengwe se o se buang ga se kitla se phatlaladiwa le ka motlha ope). (ke tla tlatsa lenaane la dipotso ka dikarabo tsa gago), (Mme ga nkitla ke bolelela ope leina kampo bopaki bongwe le bongwe jo ba ka go itseng ka bona). (Se se raya gore ga go ope kwa ntle ga me le mmatlisisi yo o tla itseng gore o tsere karolo mo dipatlisisong tse), (kampo go itse ka mokgwa o o arabileng dipotso).

(Dikarabo tse o di neelang le batsaya-karolo ba bangwe di tla lebiwa mme kitsiso e e kopantsweng e tla dirwa ka mokgwa wa raporoto). (Leina la gago ga le ne le dirisiwa gope mo raporotong).

(Aa o neilwe tetla ya go dira dipatlisiso tse)?

(Tetla ya porojeke e e neilwe ke Komiti ya Dipatlisiso ya Unibesiti ya Witwatersrand). (Lefapha la tsa maphelo le lona le neile tetla).

(Aa go tla nna le dituelo tsa go tsaya karolo)?

Ga go kitla go nna le dituelo tse di tlang mo go motsaya-karolo mongwe le mongwe mo go arabeng dipotso gonne go tsaya karolo ke go ineela). (Se se raya gore o na le tshwenelo ya go gana go araba dipotso kampo ge o dumela go araba dipotso ebile o ka nna wa tlogela tse di sa go itumediseng).

(aa go ka nna le ditlamorago tse di bosula ka go tsaya karolo)?

Ga re bonele pele kgonagalo yo go tsaya karolo ga gago mo dipatlisisong go ka tlisa mathata kwa ntle ga go tsaya nako ya gago fela) . (fa o sa ikutlwe sentle ka nako ya go araba dipotso), (re tla emisa go go botsa dipotso).

(Ga go na bothata fa o sa battle go bodiwa dipotso) . (E fela), (re ka itumelela fa o ka re itsise se se mo tlhaloganyong le maikutlong a gago ka dipotso tse re tlileng go go botsa tsona). (Re na le tshepo ya gore bopaki jo re tla bo fitlhelang mo go wena), (bo tlile go dirisiwa go tokafatsa kalafi ya batho ba ba gobetseng marapo a mokwatla).

(Nka bua le mang fa ke na le dipotso)?

(Re tla itumelela go araba dipotso tse o ka nnang natso maelana le dipatlisiso tse). (Dipatlisiso tse di neilwe tetla ke Komiti ya Dipatlisiso ya Unibesiti ya Witwatersrand). (Fa o na le dipotso ka ditshwanelo tsa gago jaaka motsaya-karolo mo dipatlisisong), , (kampo dipotso le go sa iketle ka karolo ngwe le ngwe ya dipatlisiso, o ka nna wa bua le ba ofisi ya tsa dipatlisiso go) (011) 717 1234. (Fa o na le dipotso ka dipatlisiso tse, (o ka nna wa bua le mmatlisisi-mogolo): Elma Burger; Phone: 082 494 1138.

(Re leboga tirisano mmogo mo dipatlisisong).

Appendix 6a - Consent form: English

INFORMED CONSENT FORM

<u>Contact Details of Researcher:</u> Elma Burger, Occupational Therapist, Tel 011 355 3432 or 082 494 1138

I confirm that I have been informed about the details of the study entitled: Factors influencing the survival of 'People with Spinal Cord Afflictions (PSCA) treated in a Gauteng Provincial Government Hospital'. This study is being done by a post-graduate master's student, Elma Burger. I have read and understood the Information Sheet and all my questions have been answered satisfactorily.

I understand that it is up to me whether or not I would like to participate in the interview and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can stop the interview at any time.

I understand that the researcher involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports. I understand that comments that I make will not be reported back to anybody else. I consent voluntarily to participate in the interview for this study. I have been given telephone numbers that I may call if we have any questions or concerns about the research.

Participant's signature: _____

Date: _____

Fieldworker signature: _____

Date: _____

Appendix 6b - Consent form: Tswana

(foromo ya tumalano)

(Maina le dinomoro tsa mmatlisisi): Elma Burger, Occupational Therapist, Tel 011 3553432 or 082 494 1138

(nna ke dumela gore ke boeletse le go tlhalosediswa ka diteng tsa dipatlisiso tse di bitswang): (*mabaka a a etlegetsang go phela ga batho ba ba amogetseng kokelo ya go gobala marapo a mokwatla mo maakelong a puso ya Porofinsi ya Gauteng*). Dipatlisiso di diriwa ke moithuti wa dithuto tse di kwa godingwana tsa 'masters', Elma Burger). (ke buisitse le go tlhaloganya diteng tsa lekwalo le mme dipotso tsa me di arabegile sentle).

(Kea tlhaloganya gore gotswa mo go nna gore aa ke batla go nna karolo ya dipatlisiso tse le go bodiwa dipotso kgotsa nyaa, le gore ga go kitla go nna le ditlamorago tse dibosula fa ke tsaya tshwetso ya gore ga ke batle go tsaya karolo). (Ke tlhaloganya gape gore ga go tlhokege gore ke arabe dipotso dipe tse di ntlhakatlhakanyang maikutlo le gore nka nna ka ikgogela morago ka nako e nngwe le e nngwe).

(Ke tlhaloganya gore mmatlisisi yo o mo porojekeng ya dipatlisiso tse o tla leka ka bojotlhe jwa gagwe go sireletsa le go tlhompha botho le seriti sa me mme leina la me ga le kitla le tlhagelela mo go phatlhaladiweng ga dipatlisiso). Ke tlhaloganya gore ditshwaelo tse ke di umakang ga di kitla diphatlhaladiwa go motho ope). (Ke ineela go tsaya karolo le go bodiwa dipotso modipatlisisong tse). (Ke neilwe dinomoro tsa mogala tse nka di letsetsang fa kena le dipotso kampo go sa iketleng ka dipatlisiso tse).

(Tshaeno ya motsaya-
karolo: _____

Date
(Letlha): _____

(Tshaeno ya Modiri-
mmogo): _____

Date
(Letlha): _____

Procedure Manual

Patient survey Field work

Factors influencing survival of people with spinal cord affliction

July 2015

Contact information

Principal Investigator

Elma Burger

M.Sc Student, University of the Witwatersrand, Johannesburg

Tel: +27 11 3553432(office) or 083 449 1163

Email : elma.burger@gauteng.gov.za

Dear field worker:

This procedure manual was compiled to assist you in carrying out the fieldwork and to be a handy tool to keep with you at all times so that you can refer back to it when needed. All my contact details are on the front page. Please do not hesitate to contact me if you need any assistance or have any queries.

A bit more information on the study
--

What is the study about?

Factors influencing survival of people with spinal cord affliction.

What is a spinal cord affliction?

SCA is a devastating injury to the spinal cord. It does not only affect the ability to walk or use the upper limbs, it also has dire consequences for the functioning of the bladder and the bowel. Patients also have limited or no sensation and are at high risk of developing pressure sores and other complications. It can be caused by many things, amongst others, car accidents, gunshot wounds and even tuberculosis of the spine.

Why is the study being done?

There is limited information available on factors influencing the survival of patients with Spinal Cord Afflictions in South Africa. This study aims at gathering more data about this. If we do have this information, we would be able to make sure that we provide the patients with spinal cord afflictions, with appropriate treatment at hospital level.

Who is doing the study?

The study is being done as part of post-graduate studies at the University of the Witwatersrand, Johannesburg

Who will be the target population?

All patients that were treated in the Dr George Mukhari Hospital with spinal cord afflictions, from January 2008 to December 2012.

Where will the research study take place?

The fieldwork will be carried out all over South Africa where patients have been discharged to from the Dr George Mukhari Hospital. However you will be only be given a certain geographical area. The area you are going to cover will be discussed with you to make sure that you are happy with it. This area will be included in the list of names that you will be given – Form 1 A in your pack.

Introduction to the SCA study procedure manual

- This procedure manual sets out the steps for conducting the patients' surveys in the community.
- Please make sure that you are familiar with and understand all the aspects of the procedure manual.

Information on the forms in your pack

- You have received a pack of documents that includes the following:
 - Patients register: Form 1 A. The form has the following headings:
 1. Unique number – Will be provided to you.
 2. Patient name – Will be provided to you
 3. Contact numbers - Will be provided to you
 4. Address - Will be provided to you
 5. Patient traced: Yes - You need to complete this
 - a. Agree to participate
 - b. Refuse to participate
 6. Patients traced: No - You need to complete this
 7. Contact established but patient has passed away
 - a. Agree to participate
 - b. Refuse to participate
 8. Comment – For you to add if you wish to do so.

So you only need to complete the last 3 columns. Please refer to page 4 for an example of this form and more information on how it should be completed.
 - Outstanding information from record review form. Form number 1B
Please refer to page 5 for an example of this form and more information on how it should be completed.
 - Semi structured interview form in Tshwane and English. Form number 2.
The full form is in your pack. However certain sections might be problematic and is further explained on page 6
 - Participation information sheets in Tswana and English. Form number 3a.
This form is not included in the manual. You can give it to the patient to read or read it to the patient,
 - Informed consent forms in Tswana and English. Form number 3b. This form is also in the pack – after the patient has read the information sheet h/she needs to sign the form. Please make sure that you take this form from the patient and keep it with you. You need to hand this to the researcher with all the forms once the research is completed.
 - Verbal autopsy form. Form number 4. This form only needs to be completed if you have established that the patient has passed away and next of kin is prepared to answer questions. Please see comments on this form on page 7.

Form 1 A - Patient register.

1. Unique number	2. Patient name	3. Contact numbers	4. Address	5. Patient traced		6. Patients traced : No	7. Patient has passed away but contact established with next of kin		7. Comment
				5.a. Agree to participate	5.b. Refused to participate. Please provide reason in comment column.		Spoke to next of kin/care giver. Patient has passed on - NO information could be obtained regarding circumstances around death	Spoke to next of kin/care giver. Patient has passed on - information could be obtained regarding circumstances around death	
This number will be provided by the researcher.	The name will be provided by the researchers	You might be provided with several phone numbers, The researcher will indicate to whom the number belongs. You are required to phone all the numbers to try and trace the patient. Conversely if pt is traced with first call no other numbers needs to be phone	You will be provided with this – however it is critical to that you double check the address with the patient before embarking on the home visit.	Just tick	Just tick	Just tick	Just tick	Just tick and complete form 4.	
EXAMPLE 007	James Bond	083 596 8965 – Mother 089654 1234 – Patient	456 Zone 9, Diepsloot.		√				Says he never want contact with the hospital again,

PROCEDURES TO BE FOLLOWED TO CONTACT THE

Remember

- ✓ *In any study, preparation is very important to ensure that the data collection processes run smoothly.*

PATIENTS

1. Contact the patient telephonically

- In some cases more than one number are available.
- Please try all the numbers

≡ **If patients is traced and contact is established** with patient introduce yourself as follows:

Good day. Can I please speak to Mr Mrs Ms..... My name is I am currently assisting Elma Burger to do study of all patients that was treated at Dr George Mukhari hospital. Is this a good time to talk or should I phone back later? We would like to visit you at home and ask you a few questions on aspects related to your current circumstances and home environment. Please note that you can refuse to take part – that will be no problem
We will be in contact in the new year to set up a time for the visit.
Can you kindly confirm you address?
Thank you very much. I phone on the morning of the visit to confirm.

Note: Make a note of the address if different. – Possibly even ask for landmarks to assist you to find the dwelling.

≡ **If contact is established** with patient introduce yourself as above. If the patient indicated that he/she prepared to participate – thank them for their time and make a note on Form 1 A and tick column 5 a. Proceed to make an appointment to visit them

≡ **If contact is established** with patient introduce yourself as above. If the patient indicated that he/she does not want to participate – thank them for their time and make a note on Form 1 A and tick column 5 b.

≡ **If no contact is established** and all the contact numbers seems to be incorrect/out of order tick 6a on form 1 A

≡ **If contact is established** but only with the next of kin, friend, care giver and they indicate that the patient has passed away change the interview to the following:

Good day Can I please speak to Mr Mrs Ms..... I am sorry to hear about your loss. My name is I am currently assisting Elma Burger to do a study of all patients that was treated at Dr George Mukhari hospital. Can I please ask you a few questions about Mr., Mrs., Ms..... Please note that it will be no problem if you do not want to talk about it.

≡ **If contact is established** but only with the next of kin, friend, care giver and they indicate that the patient has passed away and that they are not willing to answer questions about it tick 7a on Form 1A

≡ **If contact is established** but only with the next of kin, friend, care giver and they indicate that the patient has passed away and that they are willing to answer questions about it tick 7b on Form 1A

:

Form 4 Verbal autopsy

Participant number: <i>Will be provided to you</i>			
When did s/he die (Day, Month, year)			
Where did s/he die (for e.g. at home, in the hospital)			
Could you tell me what you understood the cause of death to be?			

At the patients home

Introduce yourself to the patient and any other person present in the dwelling
Explain the reason for your visit

My name is _____. I am assisting Elma Burger to do a study on the factors influencing people with SCA. . We are doing a survey among patients that were treated in 2008 to 2012 at the Dr George Mukhari hospital

We have obtained permission to conduct this study. Ethical approval for this study has been obtained from the University of the Witwatersrand Ethics Committee for Research on Human Subjects.

The questions are not a test, so there is no right or wrong answers and it is your experiences that are important. Everything that you say will be treated as private and confidential. Your name will not be used when the results of the study are presented or written up.

Your participation is completely voluntary. There will be no negative consequences if you do not want to participate. There will be no direct benefit to you if you participate in this study but we hope that the information collected will be helpful in improving services for people with SCA in South Africa.

If you are willing to give your consent and take part, we will appreciate your participation and the information that you are willing to provide. This is an information sheet which explains the study in more detail. (Give the patient the information sheet 3a.).

If you are happy to continue can you please sign this form to confirm that you have agreed to this interview. (Give the patient the informed consent form sheet 3b.).

Are happy for us to start with completing the form?

Complete Form;

1A

1B

2

3B

Thank the patients and everybody present

REMEMBER

CHECK THAT THE QUESTIONNAIRE IS **COMPLETE**

PLEASE DO NOT FALSIFY INFORMATION OR COMPLETE THE QUESTIONNAIRE ON YOUR OWN.

Returning form to researcher

Please contact me as soon as you have completed all your forms. I will make arrangements to collect them from you.

Remember

- ✓ Please do not hesitate to contact me if there are any queries or any problems.

Maintaining confidentiality

DO YOU HAVE ANY QUESTIONS?

Remember

- ✓ Professional behaviour of the field workers are critical at all times
- ✓ Confidentiality, privacy and respect for individuals are not negotiable and must be adhered to
- ✓ The information sheet is critical to give to the client.

GENERAL TIPS

1. **Planning**-make sure there are sufficient number of questionnaires, consent forms and information sheets for participants.
2. MAKE SURE THAT ALL THE PAGES ARE THERE, INCLUDING THE TRANSLATION.
3. **Punctuality** is important-arrive early before the scheduled appointment with the client.
4. Make **appointments** with participants in the same **geographically area** on the same day. you may need to give a specific example
5. Make appointments but confirm visit on the morning of the visit.
6. Initial presentation to the participation is critical,
7. Checking questionnaires for completeness is critical – you will not have the opportunity to fill in missing details once you have left the client.

Appendix 8a - Semi structured questionnaire: English

For official use only

1. Participant number					
2. Date of interview:	DD/MM/YY				
3. Was the interview completed?	O No 0	☐			
	O Yes 1				
4. PSCA traced	O No 0	☐			
	O Yes 1				
5. If no, Reason for lost to follow up	☐ Incorrect telephone number1 ☐ Pt passed away2 ☐ Other3 Please specify _____				☐

SECTION 1: General information

Only complete items that were not completed in the record review form or if circumstances have changed.

For official
use only

☐

101 Your age

☐

102 Current marital status

☐ Married/ living together...1

☐ Widow...2

☐ Single...3

103

If question (209 in record review) was yes , did patient return to work

☐ Yes...1

☐ No...0

☐

104

Currently employed?

☐ Yes...1

☐ No...0

☐

105

If no why?

☐ Not skilled enough.....5

☐ Transport too difficult ...1

☐ Education level too low....6

☐ Function too limited ...2

☐ Other ...5

☐ Lack reasonable

Please specify

accommodation .3

☐ Perceived Attitudes of co

workers .4

SECTION 2: MEDICAL INFORMATION

For official
use only

☐

201

Was patient ever admitted again

☐ Yes...1

☐ No...0

☐

202

Was patient admitted in past
year?

☐ Yes...1

☐ No...0

☐

203

Reason for admission

☐ Other...4

☐ Pressure sores...1

☐ Pt is not sure...5

☐ Chest infections...2

Please specify:

☐ Urinary infections...3

☐

204

**Current Mobility state ito
walking**

Can you walk at all

☐ Yes ...1

☐ No ...

If so

how _____

☐

205

A

Wheelchair dexterity

☐ Yes...1

Push on flat

☐ No...0

B

Push on ramp

☐ Yes...1

☐ No...0

C

Negotiate Curb

☐ Yes...1

☐ No...0

SECTION 3: Environmental and COMMUNITY INFORMATION

For official
use only

☐

301

Are you still living in same
dwelling at time of discharge

☐ Yes...1

☐ No...0

☐

☐	302	Please indicate current dwelling info ☐ House or brick structure on a separate yard ...1 ☐ Traditional dwelling/hut ...2 ☐ Flat in block of flats ...3 ☐ Town/cluster house ...4 ☐ House/flat /room in back yard ...5	☐ Informal dwelling/ shack not in back yard ...6 ☐ Room/flatlet not in back yard - shared property...7 ☐ Caravan tent...7 ☐ None...7
☐	303	Can you access public transport	☐ Yes...1 ☐ No...0
☐	304	If yes, with or without assistance.	☐ With assistance 1 ☐ Without ...0
☐	305	Access to running water	☐ Yes...1 ☐ No...0
☐	306	If yes	☐ Inside dwelling ...1 ☐ In yard ...2 ☐ Outside yard
☐	307	Can pt access water independently	☐ Yes...1 ☐ No...0
☐	308	Source of water ☐ Municipal ...1 ☐ River ...2	☐ Borehole...3 ☐ Other...4 Please specify:
☐	309	Does dwelling have electricity	☐ Yes...1 ☐ No...0
☐	310	Is the dwelling wheelchair accessible	☐ Yes...1 ☐ No...0
☐	311	Is the bath room wheelchair accessible	☐ Yes...1 ☐ No...0

☐	312	Is the toilet wheelchair accessible	☐ Yes...1 ☐ No...0
☐	313	Can you use toilet independently	☐ Yes...1 ☐ No...0
☐	314	Type of toilet ☐ Flush sewerage ...1 ☐ Flush sept tank ...2 ☐ Chemical ...3 ☐ Pit w vent ...4	☐ Bucket...5 ☐ Pit no vent ...6 ☐ Nonet...7 ☐ Other...8
☐	315	Can pt access bathing facility	☐ Yes...1 ☐ No...0
☐	316	Toilet outside?	☐ Yes...1 ☐ No...0
☐	317	Type of bathing facility ☐ Bathroom in house ...1 ☐ Bathroom outside house ...2 ☐ Uses bucket...3	☐ Uses zinc bath...4 ☐ Other...5 Please specify
☐	318	Can u bath/wash independently	☐ Yes...1 ☐ No...0
☐	319	How do you spend an average day? 	
☐	320	Who is assisting you the most ☐ Nobody – can manage t...1 ☐ spouse...2 ☐ Parents...3 ☐ Siblings...4	☐ Friends...5 ☐ Other...6 Please specify
☐	321	Do you feel that rehabilitation services prepared you well to cope with things at home	☐ Yes...1 ☐ No...0

322	If not: What would you have liked to be included in rehabilitation services
323	What is THE most difficult thing for you to cope with now
324	Please tell us what will make you happier
324	Please tell us what will make your life easier?

Appendix 8b - Semi structured questionnaire: Tswana

(MABAKA A ETLEGETSANG GO PHELA GA BALWETSE BA BO GOBETSE MARAPO A MOKWATLA) (Dipotso ka go latelana)

(Tiriso ya ofisi fela)

1. Nomoro ya motsaya-karolo					
2. (letlha la dipotso):	DD(Letlha)/MM(kgwedi)/YY(ngwaga)				
3. (aadipotso di arabilwe tsotlhe)?	O No(Nyaa) 0 O Yes(Ee) 1				
4. PSCA traced?	O No(Nyaa) 0 O Yes(Ee) 1				
5. (fa go se jalo, lebaka la gore keeng go sa salwamorago)	☐ (nomoro ya mogala e e fosagetseng) ☐ (molwetse o tlhokofetse)2 ☐ (Lebaka lengwe)3 (Tlhalosa tlhe)				1

(KAROLO) 1: (KITSISO E E SA TLHAOLENG)

(tlatsafeladikarolo tse di neng di sa tladiwa moforomong yadipotso tsa rekoto kampofa go nnile le phetogo ya maemo).

(Tiriso ya ofisi fela)

101 (dijara tsa gago) _____

102 (maemo a jaanong a lenyalo)

- ☐ (nyetse / dula mmogo)...1
☐ (Motlholagadi)...2
☐ (gake a nyala)...3

(Tiriso ya ofisi fela)

103 (fa o arabile ka ee mo potsongya 2 (209), aa molwetse o ne a boela tirong?)

- ☐ Yes (Ee)...1
☐ No(Nyaa)...0

104 (Jaanong o a dira)?

- ☐ Yes (Ee)...1
☐ No (nyaa)...0

(Tiriso ya
ofisi fela)

☐

105

(Fa a sa dire, ke gore eng)?

- ☐ (Bothata ba dinamelwa)...1
 - ☐ (mmelega o kgone sepe)...2
 - ☐ (tlhokego ya thusa ko tirong maelana le go tlhofofatsa tiro go ya ka bogole jwa me)...3
 - ☐ (badiri-mogo ba inkgatolosa) ...4
 - ☐ (tlhokego ya bokgoni jwa tiro).....5
 - ☐ (Maemo a kwa tlase a thuto)...6
 - ☐ Lebaka lengwe)...5
- (Tlhalosa tlhe)
-

(KAROLO) 2: (KITSISO KA TSA BOLWETSE)

(Tiriso ya ofisi
fela)

☐

201

(Molwetse o kile a amogelwa
bookelong gape)

- ☐ Yes (Ee)...1
- ☐ No (Nyaa)...0

☐

202

Molwetse o amogetswe gape
bookelong mongwageng o o
fetileng)?

- ☐ Yes(Ee)...1
- ☐ No (Nyaa)...0

☐

203

(lebaka la go amogelwa)

- ☐ (dintho tsa kgatelelo ya letlalo)...1
 - ☐ (Tshwaetsego ya mafatlha)...2
 - ☐ (Tshwaetsego ya setlha sa moroto)...3
 - ☐ (Lebaka lengwe)...4
 - ☐ (molwetsega a na bonnete)...5
- (tlhalosa tlhe):
-

☐	204	(maemo a ga jaana a go tsamaya)	☐ (tirisoya 'wheelchair' nako tsotlhe) ...1 ☐ (se legae seseamogelang go ya go ile) ...2 ☐ (ntlu e eamogelang go ya go ile)...3 ☐ (thupelo/thuso mo ntlung)...4 ☐ (thupelo/thusoya se legae)...5 ☐ (se legae se se saamogelang)6 ☐ (ntlu e e sa amogelang)...7 ☐ (lebaka lengwe)...8
☐	205	(tsamaisoya 'wheelchair') (tsamisomo go senangdithaba) (tsamaiso mo go namelelang godimo) (tsamaiso mo go motsopodia)	☐ Yes (Ee)...1 ☐ No(Nyaa)...0 ☐ Yes(Ee)...1 ☐ No(Nyaa)...0 ☐ Yes(Ee)...1 ☐ No(Nyaa)...0

karolo) 3: (kitsiso ka tsa lefelo la bodulo le tlhaeletsano

(Tiriso ya
offisi fela)

☐

301	Aa o sa ntse o dula mo o neng o dula teng fa o tswa mo bookelong)	☐ Yes(Ee)...1 ☐ No(Nyaa)...0
-----	---	---

☐	302	Fa go se jalo, tlhalosa legae le lentshwa)	☐ (ntlw kampo moago wa ditene o o ikemetseng mo jarateng) ...1 ☐ (ntlw e nnye ya mmu) ...2 ☐ (mo foletseng) ...3 ☐ (mo ntlung e e sireletsegileng di le dintsi) ...4 ☐ (ntlw/foletse/kamore ko morago mo jarateng) ...5 ☐ (bodulo fela/mokhukhu ko morago mo jarateng) ...6 ☐ (kamore/foletse khiro e e seng mo jarateng kampo bodulo jwa botlhe)...7 ☐ (kharavane kampo tente)...7 ☐ (gago epe)...7
☐	302	(Aa o kgona go dirisa dipalangwa tsa botlhe)	☐ Yes(Ee)...1 ☐ No(Nyaa)...0
☐	303	(fa ele ee, go na le thuso kampo go se na thuso).	☐ (Ka thuso) 1 ☐ (Go se na thusa) ...0
☐	304	(Aa go na le metsi a pompo)	☐ YesEe)...1 ☐ No(Nyaa)...0
☐	305	(fa e le ee)	☐ (mo go dulang batho) ...1 ☐ I(mo jarateng) ...2 ☐ (kwa ntle ga jarata)
☐	306	((Aa molwetsi o kgona go fitlhela metsi ka bo ene)	☐ Yes(Ee)...1 ☐ No(Nyaa)...0

☐	307	(Motswedi wa metsi)	☐ (masepala) ...1 ☐ (noka) ...2 ☐ (mosima wa metsi)...3 ☐ lebaka lengwe)...4 (tlhalosa tlhe):
☐	308	(Aa bodulo bon a le motlakase)	☐ Yes(Ee)...1 ☐ No(Nyaa)...0
☐	309	(Aa bodulo bo dumelela di 'wheelchair')	☐ Yes(Ee)...1 ☐ No(Nyaa)...0
☐	310	(Aa kamore ya go tlhapela e dumelela 'wheelchair')	☐ Yes(Ee)...1 ☐ No(Nyaa)...0
☐	311	(Aa ntlwana ya boithusetso e dumelela 'wheelchair')	☐ Yes(Ee)...1 ☐ No(Nyaa)...0
☐	312	(Aa o kgona go dirisa ntlwana ya boithusetso ka bowena/kwa ntle ga thuso epe)	☐ Yes(Ee)...1 ☐ No(Nyaa)...0
☐	313	(Mofuta wa ntlwana boithusetso0)	☐ (E e dirisang metsi a soreje)...1 ☐ (E e dirisang metsi le mosima)...2 ☐ (E e dirisang dikhemikhale)...3 ☐ (Mosima wa vente)...4 ☐ (Emere)...5 ☐ (Mosima o o se nang vente) ...6 ☐ None(Ga go epe)...7 ☐ Other(E nngwe)...8
☐	314	(Aa molwetse o fitlhela di diriswa tsa go tlhapa)	☐ Yes(Ee)...1 ☐ No(Nyaa)...0
☐	315	(Mofuta wa sediriswa sa go tlhapa)	☐ (Kamore ya gotlhapela ka fag are ga ntlu) ...1 ☐ (Kamore ya go tlhapela ka fa ntle ga ntlu) ...2 ☐ (O dirisa emere)...3 ☐ (O dirisa bata ya lesenke)...4 ☐ Other(E nngwe)...5 Please specify(Tlhalosa tlhe)

<input style="width: 40px; height: 25px; border: 1px solid black;" type="checkbox"/>	316	(Aa o kgona go tlhapa kwa ntle ga thuso ya mongwe)	☐ Yes(Ee)...1 ☐ No(Nyaa)...0
<input style="width: 40px; height: 25px; border: 1px solid black;" type="checkbox"/>	317	O tlhola o dira eng ka gale mo letsatsing)	
<input style="width: 40px; height: 25px; border: 1px solid black;" type="checkbox"/>	318	(O thusiwa ke mang ka gale)	☐ (Ope – ke a itirela)...1 ☐ (mokaulengwe)...2 ☐ (batsadi)...3 ☐ (bo kgaitsemi)...4 ☐ (ditsala)...4 ☐ Other(O mongwe)...4 Please specify(Tlhalosa tlhe
<input style="width: 40px; height: 25px; border: 1px solid black;" type="checkbox"/>	319	(Aa ditirelo tsa pholo ka katiso di go thusitse go somagana le dilo tsa kwa gae)	☐ Yes(Ee)...1 ☐ No(Nyaa)...0
	320	If not:(Fa go se jalo) (Ke eng se o ne o ka rata se ka tsengwang mo katisong ya balwetse)	
	321	ke eng se se leng thata thata go somagana naso jaanong	

322	(Re kopa gore o re bolelele gore ke eng se se go itumedisang	
323	(Re kopa gore o re bolelele gore ke eng se se ka tlhofofatsang botshelo jwa gago	

Appendix 9- Summary Patients follow up

Patient 11

Demographics at follow up	
Age	29
Marital Status	Single
Education level	≤ Grade 10
Returned to previous employment if applicable	N/A
Employed at time of visit	No
Reason not	Looking for a job
Province	Gauteng
Time living with a SCA at time of field visit	6 years and 4 months
Medical History	
Category	TSCA
Aetiology	
Level	T7 – T12
Mobility at discharged	Full time wheelchair user
Medical status during field visit	
Was patient ever admitted again	Yes
Was patient admitted in past year?	Yes
Reason for readmission	Pressure sore
Current mobility status	
Able to walk	Full time wheelchair use
Wheelchair dexterity	Can manage flat service, ramp and curb
Environmental factors	
Type of house	Brick house
Water	
Access to running water	Yes
Location	Inside dwelling
Source of water	Municipal
Can Access water independently	Yes
Accessibility	
Dwelling entrance with wheelchair accessible	Yes
Bathroom wheelchair accessible	no
Use bath room independently	
Type of bath	Zinc Bath
Wash self independently	Yes
Is toilet wheelchair accessible	Yes
Is toilet outside	Yes
Can patient use toilet independently	Yes
Type of toilet	Pit with vent
Access to electricity	Yes
Public transport	
Can patient access	Yes
With or without assistance	Without
Qualitative questions	
How does patient spend average day	Home with wife / girlfriend
Who is assisting patient	Spouse
Does patient feel that rehabilitation services	Yes

prepared him/her well to cope with things at home	
What would patient have liked to be included in rehabilitation services	-
What is THE most difficult thing for patient to cope with now	Not working
Please tell us what will make you happier	Get a job
Please tell us what will make your life easier?	If I house fix my house to be more accessible wheelchair friendly

Patient 19

Demographics at follow up	
Age	38
Marital Status	Single
Education level	Grade 10
Returned to previous employment if applicable	
Employed at time of visit	Yes
Province	Gauteng
Time living with a SCA at time of field visit	4 years and 4 months
Medical History	
Category	NTSCA
Aetiology	TB
Level	T7 – T 12
Mobility at discharged	Functional walker
Medical status during field visit	
Was patient ever admitted again	No
Current mobility status	
Able to walk	Functional walker
Wheelchair dexterity	N/A
Environmental factors	
Type of house	Dwelling in back yard.
Water	
Access to running water	Yes
Location	In Yard
Source of water	Municipal
Can Access water independently	Yes
Accessibility	
	Functional walker accessibility not a barrier
Dwelling entrance with wheelchair accessible	N/A
Bathroom wheelchair accessible	N/A
Use bath room independently	Yes
Type of bath	Zinc
Wash self independently	Yes
Is toilet wheelchair accessible	N/A
Is toilet outside	Yes
Can patient use toilet independently	Yes
Type of toilet	Flush
Access to electricity	Yes

Public transport	
Can patient access	Yes
With or without assistance	Without
Qualitative questions	
How does patient spend average day	Work
Who is assisting patient	spouse
Does patient feel that rehabilitation services prepared him/her well to cope with things at home	Yes
What would patient have liked to be included in rehabilitation services	Feet sore in cold weather
What is THE most difficult thing for patient to cope with now	-
Please tell us what will make you happier	-
Please tell us what will make your life easier?	Getting a better job

Patient 33

Demographics at follow up	
Age	38
Marital Status	Married
Education level	≤ Grade 12
Returned to previous employment if applicable	No
Employed at time of visit	No
Reason not	Other
Province	Gauteng
Time living with a SCA at time of field visit	6 years and 3 months
Medical History	
Category	TSCA
Aetiology	MVA
Level	T1 –T6
Mobility at discharged	
Medical status during field visit	
Was patient ever admitted again	No
Was patient admitted in past year?	N/A
Reason for readmission	N/A
Current mobility status	
Able to walk	No
Wheelchair dexterity	Cannot negotiate flat services, ramps or curbs.
Environmental factors	
Type of house	Brick house
Water	
Access to running water	Yes
Location	Inside dwelling
Source of water	Municipal
Can Access water independently	Yes
Accessibility	
Dwelling entrance with wheelchair accessible	Yes

Bathroom wheelchair accessible	No
Use bath room independently	No
Type of bath	In dwelling
Wash self independently	Yes
Is toilet wheelchair accessible	No
Is toilet outside	Yes
Can patient use toilet independently	No
Type of toilet	Flush sewerage
Access to electricity	Yes
Public transport	
Can patient access	No
With or without assistance	N/A
Qualitative questions	
How does patient spend average day	Home with family
Who is assisting patient	Spouse.
Does patient feel that rehabilitation services prepared him/her well to cope with things at home	Yes
What would patient have liked to be included in rehabilitation services	They don't treat as well at hospital sometimes.
What is THE most difficult thing for patient to cope with now	Going to the toilet
Please tell us what will make you happier	If I can stand and walk
Please tell us what will make your life easier?	To do things by myself and not asked for help.

Patient 37

Demographics at follow up	
Age	44
Marital Status	Married
Education level	Grade 10
Returned to previous employment if applicable	N/A
Employed at time of visit	No
Reason not	Other
Province	Gauteng
Time living with a SCA at time of field visit	4 years and 3 months
Medical History	
Category	NTSCA
Aetiology	TB
Level	T7 – T12
Mobility at discharged	Full time wheelchair user
Medical status during field visit	
Was patient ever admitted again	No
Current mobility status	
Able to walk	With Crutches
Wheelchair dexterity	Able to push on flat services, and negotiate ramps and curbs.
Environmental factors	

Type of house	Brick house
Water	
Access to running water	Yes
Location	Inside dwelling
Source of water	Municipal
Can Access water independently	yes
Accessibility	
Dwelling entrance with wheelchair accessible	Yes
Bathroom wheelchair accessible	Yes
Use bath room independently	Yes
Type of bath	In house
Wash self independently	Yes
Is toilet wheelchair accessible	Yes
Is toilet outside	No
Can patient use toilet independently	Yes
Type of toilet	Flash sewerage
Access to electricity	Yes
Public transport	
Can patient access	Yes
With or without assistance	Without
Qualitative questions	
How does patient spend average day	Home with family
Who is assisting patient	Spouse
Does patient feel that rehabilitation services prepared him/her well to cope with things at home	Yes
What would patient have liked to be included in rehabilitation services	-
What is THE most difficult thing for patient to cope with now	=
Please tell us what will make you happier	To walk again
Please tell us what will make your life easier?	To get work

Patient 43

Demographics at follow up	
Age	39
Marital Status	Married
Education level	Grade 12
Returned to previous employment if applicable	
Employed at time of visit	No
Reason not	Other
Province	Gauteng
Time living with a SCA at time of field visit	4 years and 1 month
Medical History	
Category	TSCA
Aetiology	GSW
Level	Lumbar
Mobility at discharged	Full time wheelchair user

Medical status during field visit	
Was patient ever admitted again	No
Was patient admitted in past year?	No
Reason for readmission	
Current mobility status	
Able to walk	Full time wheelchair user
Wheelchair dexterity	Can push on flat an negotiate ramp but not curb
Environmental factors	
Type of house	Brick house
Water	
Access to running water	Yes
Location	Inside dwelling
Source of water	Municipal
Can Access water independently	Yes
Accessibility	
Dwelling entrance with wheelchair accessible	No
Bathroom wheelchair accessible	Yes
Use bath room independently	Yes
Type of bath	Bath in house
Wash self independently	Yes
Is toilet wheelchair accessible	Yes
Is toilet outside	-
Can patient use toilet independently	Yes
Type of toilet	Flush
Access to electricity	Yes
Public transport	
Can patient access	Yes
With or without assistance	Without
Qualitative questions	
How does patient spend average day	With Friends
Who is assisting patient	Spouse
Does patient feel that rehabilitation services prepared him/her well to cope with things at home	Yes
What would patient have liked to be included in rehabilitation services	Nobody is checking on his progress when he collects his medication
What is THE most difficult thing for patient to cope with now	No Problems
Please tell us what will make you happier	If they can check the bullet in his spine
Please tell us what will make your life easier?	If they can tell me when they will remove the bullet in the spine

Patient 44

Demographics at follow up	
Age	44
Marital Status	Single
Education level	
Returned to previous employment if	Yes

applicable	
Employed at time of visit	Yes
Reason not	-
Province	Gauteng
Time living with a SCA at time of field visit	3 years and 7 months
Medical History	
Category	TSCA
Aetiology	RTA
Level	T1 – T6
Mobility at discharged	Full time wheelchair user
Medical status during field visit	
Was patient ever admitted again	No
Was patient admitted in past year?	No
Reason for readmission	-
Current mobility status	
Able to walk	Full time wheelchair user
Wheelchair dexterity	Can negotiate flat and ramps but not curbs,
Environmental factors	
Type of house	Brick
Water	
Access to running water	Yes
Location	In dwelling
Source of water	Municipal
Can Access water independently	Yes
Accessibility	
Dwelling entrance with wheelchair accessible	Yes
Bathroom wheelchair accessible	No
Use bath room independently	-
Type of bath	Zinc bath
Wash self independently	Yes
Is toilet wheelchair accessible	Yes
Is toilet outside	No
Can patient use toilet independently	Yes
Type of toilet	Flush sewerage
Access to electricity	Yes
Public transport	
Can patient access	No
With or without assistance	With assistance
Qualitative questions	
How does patient spend average day	At work
Who is assisting patient	Siblings
Does patient feel that rehabilitation services prepared him/her well to cope with things at home	Yes
What would patient have liked to be included in rehabilitation services	
What is THE most difficult thing for patient to cope with now	Not being able to feel anything
Please tell us what will make you happier	I am happy because I am back at work, my colleagues treat me right

Please tell us what will make your life easier?	If I can be free it will make my life easier
---	--

Patient 47

Demographics at follow up	
Age	38
Marital Status	Single
Education level	Grade 12 and less
Returned to previous employment if applicable	N/A
Employed at time of visit	No
Reason not	Transport too difficult
Province	Mpumalanga
Time living with a SCA at time of field visit	5 years and 6 months
Medical History	
Category	TSCA
Aetiology	RTA
Level	T1 – T6
Mobility at discharged	Full time wheelchair user
Medical status during field visit	
Was patient ever admitted again	No
Current mobility status	
Able to walk	Full time wheelchair user
Wheelchair dexterity	Indicated that dexterity is poor on flat services, unable to negotiate ramps and curbs.
Environmental factors	
Type of house	Brick house
Water	
Access to running water	No
Location	-
Source of water	Municipal
Can Access water independently	No
Accessibility	
Dwelling entrance with wheelchair accessible	Yes
Bathroom wheelchair accessible	Yes
Use bath room independently	Yes
Type of bath	In house
Wash self independently	Yes
Is toilet wheelchair accessible	Yes
Is toilet outside	No
Can patient use toilet independently	Yes
Type of toilet	Flush sewerage
Access to electricity	Yes
Public transport	
Can patient access	No
With or without assistance	
Qualitative questions	
How does patient spend average day	Home and with friends
Who is assisting patient	Granny

Does patient feel that rehabilitation services prepared him/her well to cope with things at home	Yes
What would patient have liked to be included in rehabilitation services	-
What is THE most difficult thing for patient to cope with now	Transport and pain
Please tell us what will make you happier	To see myself walking again
Please tell us what will make your life easier?	To have my own transport

Patient 48

Demographics at follow up	
Age	25
Marital Status	Single
Education level	≥ Grade 12
Returned to previous employment if applicable	N/A
Employed at time of visit	No
Reason not	Other
Province	Gauteng
Time living with a SCA at time of field visit	5y 6 m
Medical History	
Category	TSCA
Aetiology	RTA
Level	T1-T6
Mobility at discharged	Full time wheelchair user
Medical status during field visit	
Was patient ever admitted again	Yes
Was patient admitted in past year?	No
Reason for readmission	Other
Current mobility status	
Able to walk	Full time wheelchair users
Wheelchair dexterity	Can push on flat and negotiate a ramp but not a curb
Environmental factors	
Type of house	Brick house
Water	
Access to running water	Yes
Location	Inside dwelling
Source of water	Municipal
Can Access water independently	Yes
Accessibility	
Dwelling entrance with wheelchair accessible	Yes
Bathroom wheelchair accessible	No
Use bath room independently	Yes
Type of bath	In house
Wash self independently	Yes
Is toilet wheelchair accessible	No

Is toilet outside	No
Can patient use toilet independently	No
Type of toilet	Flush sewerage
Access to electricity	Yes
Public transport	
Can patient access	No
With or without assistance	N/A
Qualitative questions	
How does patient spend average day	At home
Who is assisting patient	Parents
Does patient feel that rehabilitation services prepared him/her well to cope with things at home	Yes
What would patient have liked to be included in rehabilitation services	Should have provided information on quadpara association and on driving and modified cars.
What is THE most difficult thing for patient to cope with now	Left hand not working well
Please tell us what will make you happier	Working and 100% abled
Please tell us what will make your life easier?	When I can access things easier and an environment that is disabled friendly.

Patient 76

Demographics at follow up	
Age	24
Marital Status	Single
Education level	Grade 7
Returned to previous employment if applicable	
Employed at time of visit	No
Reason not	Other
Province	Gauteng
Time living with a SCA at time of field visit	4 years and 7 months
Medical History	
Category	TSCA
Aetiology	GSW
Level	T1 – T6
Mobility at discharged	Full time wheelchair user
Medical status during field visit	
Was patient ever admitted again	Yes
Was patient admitted in past year?	Yes
Reason for readmission	
Current mobility status	
Able to walk	No
Wheelchair dexterity	Unable to push on flat, negotiate ramps and curbs
Environmental factors	
Type of house	Brick building
Water	

Access to running water	Yes
Location	In yard
Source of water	Municipal
Can Access water independently	No
Accessibility	
Dwelling entrance with wheelchair accessible	No
Bathroom wheelchair accessible	No
Use bath room independently	No
Type of bath	Zinc
Wash self independently	No
Is toilet wheelchair accessible	No
Is toilet outside	No
Can patient use toilet independently	No
Type of toilet	Pit with vent
Access to electricity	yes
Public transport	
Can patient access	No
With or without assistance	
Qualitative questions	
How does patient spend average day	Home
Who is assisting patient	Parents
Does patient feel that rehabilitation services prepared him/her well to cope with things at home	No
What would patient have liked to be included in rehabilitation services	
What is THE most difficult thing for patient to cope with now	People that injured them pass by house every day.
Please tell us what will make you happier	To go to Physio and see people in jail
Please tell us what will make your life easier?	If I can walk again

Patient 85

Demographics at follow up	
Age	67
Marital Status	Married
Education level	Grade 10
Returned to previous employment if applicable	
Employed at time of visit	Yes
Province	
Time living with a SCA at time of field visit	5y 10 m
Medical History	
Category	NTSCA
Aetiology	TB
Level	T7 – T12
Mobility at discharged	Patient is a functional walker
Medical status during field visit	
Was patient ever admitted again	Yes
Was patient admitted in past year?	Yes

Reason for readmission	RTA
Current mobility status	
Able to walk	Pt is a functional walker
Wheelchair dexterity	N/A
Environmental factors	
Type of house	Brick house
Water	
Access to running water	Yes
Location	In Yard
Source of water	Municipal
Can Access water independently	Yes
Accessibility	Functional walker accessibility not a barrier
Dwelling entrance with wheelchair accessible	N/A
Bathroom wheelchair accessible	N/A
Use bath room independently	Yes
Type of bath	Zinc bath
Wash self independently	Yes
Is toilet wheelchair accessible	N/A
Is toilet outside	Yes
Can patient use toilet independently	Yes
Type of toilet	Pit no vent
Access to electricity	Yes
Public transport	
Can patient access	Yes
With or without assistance	Without
Qualitative questions	
How does patient spend average day	At home
Who is assisting patient	Independent
Does patient feel that rehabilitation services prepared him/her well to cope with things at home	Yes
What would patient have liked to be included in rehabilitation services	-
What is THE most difficult thing for patient to cope with now	Unable to run
Please tell us what will make you happier	To have money
Please tell us what will make your life easier?	Get myself busy and walk perfect

Patient 90

Demographics at follow up	
Age	38
Marital Status	Married
Education level	
Returned to previous employment if applicable	
Employed at time of visit	No
Reason not	Transport too difficult
Province	North West

Time living with a SCA at time of field visit	4 years and 8 months
Medical History	
Category	TSCA
Aetiology	Dislocation
Level	C1-C5
Mobility at discharged	Functional walker
Medical status during field visit	
Was patient ever admitted again	No
Was patient admitted in past year?	No
Reason for readmission	N/A
Current mobility status	
Able to walk	Functional walker
Wheelchair dexterity	N/A
Environmental factors	
Type of house	Brick house
Water	
Access to running water	Yes
Location	Inside dwelling
Source of water	Municipal
Can Access water independently	Yes
Accessibility	Functional walker accessibility not a barrier
Dwelling entrance with wheelchair accessible	N/A
Bathroom wheelchair accessible	N/A
Use bath room independently	Yes
Type of bath	In house
Wash self independently	Yes
Is toilet wheelchair accessible	N/A
Is toilet outside	No
Can patient use toilet independently	Yes
Type of toilet	Flush
Access to electricity	Yes
Public transport	
Can patient access	Yes
With or without assistance	Without
Qualitative questions	
How does patient spend average day	Home
Who is assisting patient	Nobody can manage
Does patient feel that rehabilitation services prepared him/her well to cope with things at home	Yes
What would patient have liked to be included in rehabilitation services	–
What is THE most difficult thing for patient to cope with now	I lose my mind sometime and sometimes my body is painful
Please tell us what will make you happier	I am alright
Please tell us what will make your life easier?	If I can have someone to live with me it will be easier as wife is not living with me

Patient 92

Demographics at follow up	
Age	10
Marital Status	N/A
Education level	Grade 5 or less : scholar
Returned to previous employment if applicable	N/A
Employed at time of visit	N/A
Reason not	Scholar
Province	Gauteng
Time living with a SCA at time of field visit	6 years and 2 months
Medical History	
Category	TSCA
Aetiology	RTA
Level	T7-T12
Mobility at discharged	Uses wheelchair for long distances
Medical status during field visit	
Was patient ever admitted again	No
Current mobility status	
Able to walk	No
Wheelchair dexterity	Can push on flat and negotiate ramp and curb
Environmental factors	
Type of house	Brick structure
Water	
Access to running water	yes
Location	Inside welling
Source of water	Municipal
Can Access water independently	Yes
Accessibility	
Dwelling entrance with wheelchair accessible	Yes
Bathroom in house	Yes
Bathroom wheelchair accessible	No
Type of bath	Bath
Wash self independently	No
Is toilet wheelchair accessible	No
Is toilet outside	Yes
Can patient use toilet independently	No
Type of toilet	Flush
Access to electricity	Yes
Public transport	
Can patient access	No
Qualitative questions	
How does patient spend average day	At school
Who is assisting patient	Parents
Does patient feel that rehabilitation services prepared him/her well to cope with things at home	Yes
What is THE most difficult thing for patient to cope with now	Pain in the body

Please tell us what will make you happier	If I can walk again
Please tell us what will make your life easier?	Do things like other kids

Patient 99

Demographics at follow up	
Age	40
Marital Status	Married
Education level	Grade 10 or less
Returned to previous employment if applicable	N/A
Employed at time of visit	No
Reason not	No Jobs
Province	North West
Medical History	
Category	TSCA
Aetiology	MVA
Level	C1-C5
Mobility at discharged	Functional walker
Medical status during field visit	
Was patient ever admitted again	No
Was patient admitted in past year?	N/A
Reason for readmission	N/A
Current mobility status	
Able to walk	Yes
Wheelchair dexterity	N/A
Environmental factors	
Type of house	Informal dwelling/shack not in back yard
Water	
Access to running water	Yes
Location	In Yard
Source of water	Municipal
Can Access water independently	Yes
Accessibility	
Dwelling entrance with wheelchair accessible	N/A
Bathroom wheelchair accessible	N/A
Use bath room independently	Yes
Type of bath	Zinc bath
Wash self independently	Yes
Is toilet wheelchair accessible	N/A
Is toilet outside	Yes
Can patient use toilet independently	Yes
Type of toilet	Flush
Access to electricity	Yes
Public transport	
Can patient access	Yes
With or without assistance	Without
Qualitative questions	
How does patient spend average day	At home
Who is assisting patient	Spouse if needed

Does patient feel that rehabilitation services prepared him/her well to cope with things at home	Yes
What would patient have liked to be included in rehabilitation services	Want to see dr more due to pain in body
What is THE most difficult thing for patient to cope with now	Cannot walk for long distances
Please tell us what will make you happier	To be checked by a doctor again,
Please tell us what will make your life easier?	If I can work for myself and earn a living wage

Patients 106

Demographics at follow up	
Age	33
Marital Status	Single
Education level	Grade 10
Returned to previous employment if applicable	No – was a domestic worker
Employed at time of visit	No
Reason not	Not skilled enough
Province	Gauteng
Time living with a SCA at time of field visit	5 years and 8 months
Medical History	
Category	TSCA
Aetiology	RTA
Level	T7-T12
Mobility at discharged	Full time wheelchair user,
Medical status during field visit	
Was patient ever admitted again	Yes
Was patient admitted in past year?	Yes
Reason for readmission	Swollen foot
Current mobility status	
Able to walk at ll	No , full time wheelchair user
Wheelchair dexterity	Can push on flat negotiate curbs and ramps
Environmental factors	
Type of house	Brick house
Water	
Access to running water	Yes
Location	Inside dwelling
Source of water	Municipal
Can Access water independently	
Accessibility	
Dwelling entrance with wheelchair accessible	Yes
Bathroom wheelchair accessible	No
Use bath room independently	No
Type of bath	Zinc bath
Wash self independently	Yes
Is toilet wheelchair accessible	Yes
Is toilet outside	Yes

Can patient use toilet independently	Yes
Type of toilet	Flush
Access to electricity	Yes
Public transport	
Can patient access	No
With or without assistance	
Qualitative questions	
How does patient spend average day	At home
Who is assisting patient	Parents
Does patient feel that rehabilitation services prepared him/her well to cope with things at home	Yes
What would patient have liked to be included in rehabilitation services	Satisfied with services
What is THE most difficult thing for patient to cope with now	Keep on forgetting things
Please tell us what will make you happier	
Please tell us what will make your life easier?	If I can walk

Patient 163

Demographics at follow up	
Age	11
Marital Status	Single
Education level	Grade 5
Returned to previous employment if applicable	Scholar
Employed at time of visit	Scholar
Province	Gauteng
Time living with a SCA at time of field visit	
Medical History	
Category	NTSCA
Aetiology	Malignance
Level	
Mobility at discharged	Functional walker
Time living with SCA at time of field visit	5 years
Medical status during field visit	
Was patient ever admitted again	No
Current mobility status	
Able to walk	Yes – functional walker
Environmental factors	
Type of house	Room/flatlet on shared property
Water	
Access to running water	Yes
Location	In yard
Source of water	Municipal
Can Access water independently	Yes
Accessibility	Accessibility not a factor as patient a functional walker
Use bath room independently	Yes

Type of bath	Zinc
Wash self independently	Yes
Is toilet outside	Yes
Can patient use toilet independently	Yes
Type of toilet	Flash
Access to electricity	Yes
Public transport	
Can patient access	Yes
With or without assistance	Without
Qualitative questions	
How does patient spend average day	With Family
Who is assisting patient	Parent
Does patient feel that rehabilitation services prepared him/her well to cope with things at home	No opinion expressed
What would patient have liked to be included in rehabilitation services	
What is THE most difficult thing for patient to cope with now	
Please tell us what will make you happier	
Please tell us what will make your life easier?	

Patient 167

Demographics at follow up	
Age	37
Marital Status	Single
Education level	Grade 12
Returned to previous employment if applicable	N/A
Employed at time of visit	No
Reason not	Function too limited
Province	Gauteng
Time living with a SCA at time of field visit	Six years and 4 months
Medical History	
Category	
Aetiology	Pushed from moving train
Level	T1-T6
Mobility at discharged	Full time wheelchair user
Medical status during field visit	
Was patient ever admitted again	No
Current mobility status	
Able to walk	No
Wheelchair dexterity	Able to push on flat and negotiate ramp, but unable to manage curb
Environmental factors	
Type of house	Informal dwelling
Water	
Access to running water	Yes
Location	In yard

Source of water	Municipal
Can Access water independently	Yes
Accessibility	
Dwelling entrance with wheelchair accessible	Yes
Bathroom wheelchair accessible	
Use bath room independently	
Type of bath	Uses zinc bath
Wash self independently	Yes
Is toilet wheelchair accessible	Yes
Is toilet outside	Yes
Can patient use toilet independently	Yes
Type of toilet	Flush
Access to electricity	Yes
Public transport	
Can patient access	No
With or without assistance	
Qualitative questions	
How does patient spend average day	At George Mukhari
Who is assisting patient	Sister-in-law
Does patient feel that rehabilitation services prepared him/her well to cope with things at home	Yes
What would patient have liked to be included in rehabilitation services	
What is THE most difficult thing for patient to cope with now	Using wheelchair for long time and will not be able to get a job,
Please tell us what will make you happier	To have own place where he can move freely
Please tell us what will make your life easier?	If I can get money for my condition

Patient 233

Demographics at follow up	
Age	46
Marital Status	Married
Education level	None
Returned to previous employment if applicable	No
Employed at time of visit	No
Reason not	Function too limited
Province	Gauteng
Time living with a SCA at time of field visit	6 years and 8 months
Medical History	
Category	TSCA
Aetiology	RTA
Level	T7-T12
Mobility at discharged	Full time wheelchair user
Medical status during field visit	
Was patient ever admitted again	No
Was patient admitted in past year?	No
Reason for readmission	N/A

Current mobility status	
Able to walk	No
Wheelchair dexterity	Push on flat and can negotiate a ramp but not a curb
Environmental factors	
Type of house	Brick
Water	
Access to running water	Yes
Location	In dwelling
Source of water	Municipal
Can Access water independently	Yes
Accessibility	
Dwelling entrance with wheelchair accessible	Yes
Bathroom wheelchair accessible	Yes
Use bath room independently	Yes
Type of bath	In dwelling
Wash self independently	Yes
Is toilet wheelchair accessible	Yes
Is toilet outside	No
Can patient use toilet independently	Yes
Type of toilet	Flash sewerage
Access to electricity	Yes
Public transport	
Can patient access	No
With or without assistance	N/A
Qualitative questions	
How does patient spend average day	At home
Who is assisting patient	Spouse
Does patient feel that rehabilitation services prepared him/her well to cope with things at home	No
What would patient have liked to be included in rehabilitation services	It took me some time to get use to my situation but now I am fine
What is THE most difficult thing for patient to cope with now	My wife – she wish I can be the same person I use to be
Please tell us what will make you happier	If anyone should not feel shame for me
Please tell us what will make your life easier?	If my family can get whatever they want as is use to be

Patient 239

Demographics at follow up	
Age	10
Marital Status	Single
Education level	
Returned to previous employment if applicable	N/A
Employed at time of visit	N/A
Reason not	Scholar
Province	North West

Time living with a SCA at time of field visit	6 years and 4 months
Medical History	
Category	NTSCA
Aetiology	TB
Level	Unknown
Mobility at discharged	Walking with frame
Medical status during field visit	
Was patient ever admitted again	No
Was patient admitted in past year?	N0
Reason for readmission	N/A
Current mobility status	
Able to walk	Able to walk
Wheelchair dexterity	N/A
Environmental factors	
Type of house	Informal dwelling
Water	
Access to running water	No
Location	
Source of water	Other
Can Access water independently	Yes
Accessibility	Pt is a functional walker – accessibility therefore not a challenge
Dwelling entrance with wheelchair accessible	
Bathroom wheelchair accessible	
Use bath room independently	
Type of bath	Zinc Bath
Wash self independently	
Is toilet wheelchair accessible	
Is toilet outside	Yes
Can patient use toilet independently	
Type of toilet	Pit no vent
Access to electricity	Yes
Public transport	
Can patient access	Yes
With or without assistance	
Qualitative questions	
How does patient spend average day	At school
Who is assisting patient	Parents
Does patient feel that rehabilitation services prepared him/her well to cope with things at home	Yes
What would patient have liked to be included in rehabilitation services	-
What is THE most difficult thing for patient to cope with now	-
Please tell us what will make you happier	-
Please tell us what will make your life easier?	-

Patient 250

Demographics at follow up	
Age	44
Marital Status	Single
Education level	
Returned to previous employment if applicable	
Employed at time of visit	No
Reason not	Other
Province	North West
Time living with a SCA at time of field visit	8 years 9 months
Medical History	
Category	NTSCA
Aetiology	
Level	T7- T12
Mobility at discharged	Part time wheelchair user
Medical status during field visit	
Was patient ever admitted again	Yes
Was patient admitted in past year?	Yes
Reason for readmission	Blood in urine
Current mobility status	
Able to walk	With walking stick
Wheelchair dexterity	N/A
Environmental factors	
Type of house	Brick house
Water	
Access to running water	Yes
Location	In yard
Source of water	Municipal
Can Access water independently	Yes
Accessibility	Patient is a functional walker accessibility to a challenge
Dwelling entrance with wheelchair accessible	
Bathroom wheelchair accessible	
Use bath room independently	Yes
Type of bath	Zinc
Wash self independently	Yes
Is toilet wheelchair accessible	
Is toilet outside	
Can patient use toilet independently	Yes
Type of toilet	Pit with vent
Access to electricity	Yes
Public transport	
Can patient access	No
With or without assistance	
Qualitative questions	
How does patient spend average day	At home
Who is assisting patient	Sibling
Does patient feel that rehabilitation services	Yes

prepared him/her well to cope with things at home	
What would patient have liked to be included in rehabilitation services	
What is THE most difficult thing for patient to cope with now	Not walking normal
Please tell us what will make you happier	If I can do things for myself without asking for help.
Please tell us what will make your life easier?	If my life can be back to normal so that I can work for my family