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ARTICLE

Mortality and secondary complications four years after traumatic spinal cord injury in Cape Town, South Africa

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Abstract

Study design A prospective, regional, population-based study.

Objectives (1) Determine the mortality rate and factors associated with it 4 years after a TSCI and (2) The point prevalence of secondary medical complications of survivors at 4 years.

Setting Communities of the Cape metropolitan area, South Africa.

Methods All persons ($n = 145$) sustaining a TSCI from 15 September 2013 to 14 September 2014 were eligible for follow-up at 4 years. Participants were contacted after 4 years. The next of kin, via verbal autopsy, was used to establish cause of death. Those who were alive at 4 years were asked to indicate any secondary medical complications. Logistic regression techniques were used to identify independently associated risk indicators for death and development of secondary complications, respectively.

Results Of the initial 145 persons, 87 were included and accounted for. Of these, 21 (24%) had died, 55 (63%) were alive and completed the survey, and 11 (13%) were classified as alive but did not submit the survey. The main cause of death reported was septicaemia ($n = 7$; 33%), followed by unknown natural causes ($n = 7$; 33%), then pressure injuries ($n = 5$; 24%). Out of the 55 persons alive, 89% had at least one medical complication at the time of enquiry, while more than 50% experienced 6 or more complications. The most common complications were pain (80%), muscle spasms (76%), sleeping problems (56%), and bladder dysfunction (44%).

Conclusions Almost one-quarter of persons with TSCI have died 4 years after injury. Also, secondary complications were found to be highly prevalent at 4 years. This information could be used to develop secondary complications prevention programmes to reduce premature deaths.

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Introduction

Spinal cord injury has been on the rise, and in South Africa, its incidence can be considered among the highest in the world at 76 per million persons, with the leading cause being assault [1]. Quite differently, the incidence of traumatic spinal cord injury (TSCI) in Botswana—a country neighbouring South Africa—was found to be 13 per million population, with the leading cause of injury reported to be motor vehicle accidents, accounting for 68%, and the acute in-hospital mortality rate was 20% [2].

In more developed countries, greater survival post-acute TSCI was found to be better aligned with specialised care processes. For example, an in-hospital mortality rate of 20% was found in Greece with a 0% rate in Sweden of those that survived the first week after SCI [3]. The difference could be due to the approaches followed towards TSCI management with Greece following a non-specialised approach for care, similar to that in South Africa [3].

Previous research has indicated that South Africa has a unique aetiologic profile. Due to this, a need exists to investigate the mortality rate and secondary medical complications

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that could lead to death in the acute and long term [1, 2]. A Theoretical Risk and Prevention Model was developed by Krause et al. [4] as a means of classifying risk and protective factors for mortality and secondary health conditions, as well as identifying points of intervention. This model categorised factors that may predict mortality and secondary health conditions into four groups (according to the type, and proximity to mortality), namely, (1) demographic and injury characteristics, (2) psychological and environmental factors, (3) health behaviours, and (4) health status [4].

Factors such as injury characteristics, socio-environmental status, psychological status and health behaviours are crucial predictors in determining early mortality of patients who have sustained a TSCI [4]. In developing countries, an increase in the mortality of patients with SCIs has been documented, due to the lack of specialised and coordinated systems for persons with SCIs. These factors may either be modifiable or non-modifiable, with secondary complications being the most notable factor that health care professionals could help mitigate. In the United States, the most frequently reported secondary medical complications 1 year post TSCI were urinary tract infections (62%), followed by autonomic dysreflexia (43%) and pressure ulcers (41%) [5]. In South Africa, the most common secondary medical complications during acute care were found to be pressure ulcers (30%), pulmonary complications (23%), and urinary tract infections (17%) [6]. However, the mortality risk in the spinal cord community remains higher when compared to the general population. Understanding the development of secondary complications in community life could therefore contribute to the development of interventions to promote survival [7, 8]. To date, the epidemiology with respect to mortality and its determinants of TSCI is poorly understood from the developing context.

In South Africa, very little is known about the long-term mortality rate and predictors that could predispose one to death. The aims for this study were (1) to determine the mortality rate, as well as reasons for death, 4 years after injury and (2) determine the point prevalence of secondary medical complications of those alive after 4 years, living in the City of Cape Town, South Africa.

Materials and methods

Research design

A prospective, population-based research design was employed, and all persons who sustained a TSCI during a defined period were included. This study was a follow-up of a prospective study, aimed at determining the incidence and aetiology of persons with TSCIs, for a 1-year period, from 15 September 2013 to 14 September 2014 [1]. Participants were followed up 4 years later for the investigation of survival and health status. In addition, a cross-sectional design was used to determine the point prevalence of secondary medical complications, using a standardised, valid, and reliable outcome measure [9].

The study population comprised all the respondents with TSCIs who were enroled for the incidence study [1]. The study population consisted of 145 consenting participants; 124 were male and 21 were female. For the current study, an inclusive sampling strategy was adopted, in which all those in the initial incidence study would be eligible to participate in this study. The inclusion criteria were: (1) the prospective respondent had to have a confirmed diagnosis of an acute traumatic spinal cord or cauda equina lesion; (2) be aged 18 or older at the time of injury; (3) be a resident of South Africa and of the catchment area; and (4) have provided informed consent. An additional criterion was added in case a person with TSCI was deceased by the follow-up time, whereby the immediate family member(s) was asked to provide verbal autopsy of cause of death. No specific exclusion criteria applied in the follow-up study. The University of the Western Cape's Biomedical Research Ethics Committee (Ethics reference number BM17/6/11) approved the study. We certify that all applicable institutional and governmental regulations concerning the ethical use of patient identifiable data were followed during the course of this research.

Research setting

This study was conducted in the City of Cape Town's metropolitan district in the Province of the Western Cape, which is situated in the southern western part of South Africa. According to the last census in 2011, the City of Cape Town's population was 3.74 million people, with a population density of 1530 people per square kilometre. The City of Cape Town's 2017 population is now estimated at 4,004,793 (City of Cape Town, 2017).

The metropolitan district consists of urban and peri-urban areas and has a single level 1 hospital with a specialised Spinal Cord Injury unit, Groote Schuur Hospital, working alongside Tygerberg Hospital, which is also a tertiary (level 1) hospital. Due to the limited resources at the specialised hospital, patients are seen on a referral basis, from the secondary hospitals, which is a major problem, as the quality of care is delayed [7]. In the City of Cape Town, there are 81 fixed clinics, 26 mobile/satellite clinics, 42 community day centres, and 9 district hospitals, with 0.26 ambulances available per 10,000 people.

Data collection procedure

All eligible respondents were initially contacted telephonically and provided with an option of selecting the mode

of data collection; either telephonically with a researcher-administered questionnaire, or in-person with a self-administered questionnaire. The respondents who chose to be surveyed via telephone were thoroughly informed about the study, after which verbal consent was sought from them.

Written consent was sought from those who opted for the in-person survey, prior to the start of the data collection. Close family members or former caretakers were asked to partake in the study, and upon consent were only requested to provide verbal disclosure of the cause of death, as stated on the death certificate of the deceased. The questionnaire for survivors captured a range of demographic, socio-economic, and functioning information, which took ~45 min to complete. Mortality data were gathered from a reliable source which included the deceased's primary caregivers.

In order to establish the generalisability of the findings in relation to the the initial study, the researcher accounted for every non-responder as cross-sectional studies are prone to non-responder bias, where only their gender, age, education, and level of lesion were considered, as available from the baseline data collected from 2013 to 2014.

Instrumentation and outcome measures

Information pertaining to (1) demographic and injury characteristics and (2) secondary medical conditions were collected using the International Spinal Cord Injury Core Data Set [9], with the inclusion of mortality items (date and cause of death), and Spinal Cord Injury Secondary Health Conditions Scale (SCI-SCS) [10], respectively. More specifically, the SCI Core Data Set covers aspects related to injury date and cause, presence of vertebral and associated injuries, length of hospital stay and neurological classification. Moreover, the SCI-SCS screens for 16 medical complications using a 4-point ordinal scale (0 = not experienced/insignificant problem never limiting activity) to 3 (significant/chronic problem). The scale presents with optimal reliability (test-retest reliability ranged from $p = 0.569$ to 0.805) and validity [11]. For the analysis and presentation in this current study, the Likert scale was collapsed into two categories, namely, "no problem" vs. "some problems".

Variables in the assessment of factors related to mortality

Death at the time of data collection (4 years after injury) was considered the main dependent outcome. The non-modifiable and modifiable independent variables selected for this study are described below.

Non-modifiable factors

Age, gender, level of injury, severity of injury using the International Standards for Neurological Classification of SCI, which include the Neurological Level of Injury and American Spinal Injury Association Impairment Scale (AIS) with the neurological categories A, B, C, D, E [12], aetiology, and acute secondary medical complications were classified as non-modifiable factors, as they are risk factors that cannot be changed. The presence of "acute" secondary medical complications was also analysed as a non-modifiable factor at 4 years after injury since these events had already occurred—the retroactive use of past secondary medical complications. These factors represent the following domains of the theoretical model used in the study: (1) demographic and injury characteristics and (2) health status.

Modifiable factors

Spinal surgery on admission, time to surgery, intermediate hospitalisation, education, current secondary medical complications, and length of hospital stay were classified as modifiable factors, as they are risk factors that could be changed. These factors represent the following domains of the theoretical model used in the study: (1) demographic factors, (2) environmental factors (health care services received), and (3) health status.

Data analysis

Data were captured on an Excel spreadsheet, summarised, visualised, and subsequently transferred to the statistical package for social sciences version 25 for analysis. Respondent and injury characteristics were displayed using descriptive statistics, while inferential statistics were used to determine the differences between the responders and non-responders. Mortality rate is presented as a percentage of those accounted for in the follow-up. Also, factors related to mortality and secondary medical conditions were determined using logistic regression analysis techniques. Results are displayed as an odds ratio (OR) and 95% confidence interval.

Results

Overview of included sample at 4 years

Of the initial 145 participants enroled in the earlier epidemiologic study, 87 (60%) were included in this follow-up study. This study had an attrition rate of 40% due to unique contextual factors. Of these, a total number of 55 persons (63%) were alive and completed the full survey, 21 persons (24%) had demised by the 4 years post injury enquiry, and 11 people (13%) were classified as alive but did not complete the survey/"missing" during the data collection period (see Fig. 1). There were no significant differences in the key

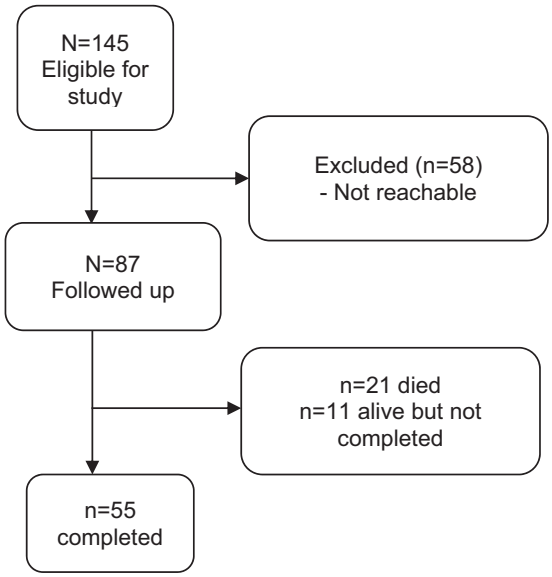

Fig. 1 Enrolment of study participants from inception study to follow up. Overview of included sample at 4 years.

variables found between responders and non-responders with respect to gender, age, injury level, injury completeness, and aetiology.

Participants' injury characteristics

As seen in Table 1, 87 participants were accounted for at the 4 years follow-up period. The majority of the participants were males ($n = 72$, 83%) and presented with incomplete spinal cord injuries of the cervical spine. The most common cause of injury was assault ($n = 53$; 61%), followed by transport injuries ($n = 24$; 28%). During the acute care episode, which was about 4 years prior, 48 persons (55%) had a secondary medical complication.

Mortality and related factors

The mortality rate was 24% (21 out of 87 included) 4 years post injury. The significant non-modifiable protective factors related to mortality were persons with incomplete injuries (OR: 0.2; 95% CI: 0.07–0.58) and those having transport-related injuries (OR: 0.11; 95% CI: 0.01–0.76). None of the modifiable risk indicators were found to be significantly related to mortality; however, presenting with a secondary complication during acute care was found to be close to significant (Table 2).

Secondary medical complications at 4 years

Of the 55 persons who were alive and completed the survey, 89% ($n = 48$) of persons had at least one medical complication, while the most common secondary medical complications at 4 years after injury were pain ($n = 44$, 80%), muscle spasms ($n = 42$, 76%), sleeping problems ($n = 31$, 56%), and autonomic dysreflexia ($n = 29$, 53%). Astonishingly, 73% ($n = 40$) of participants presented with 4 or more complications during the last 3 months of living with their spinal cord injury. Factors that were associated with the development of a medical complication 4 years

Table 1 Participants' characteristics ($n = 87$).

Gender (n; %)		
Male	72	83
Female	15	17
Age[a] (n, %)		
18–30	37	43
31–45	30	34
45–60	7	15
>60	13	8
Participants' status (n, %)		
Alive and completed survey	55	63
Dead	21	24
Missing (Alive but not reachable)	11	13
Level of injury (n, %)		
Cervical spine	45	52
Thoracic/lumbar/sacral	42	48
Completeness of injury (n, %)		
Complete (AIS A)	37	43
Incomplete (AIS B, C, D, E)	50	57
Aetiology (n, %)		
Sport/leisure	1	1
Assault	53	61
Transport	24	28
Falls	9	10
Spinal surgery (n, %)		
Yes	47	54
No	40	46
Medical complications on admission (n, %)		
Yes	48	55
No	39	45
Prevalence of pressure ulcers (n, %)		
Yes	25	29
No	62	71
Pulmonary complications (n, %)		
Yes	21	24
No	66	76
Associated injuries[b] (n, %)		
Yes	57	66
No	30	34

[a]Age as of 30 June 2017—for four year follow-up.

[b]Associated injuries included those operationalized in the International SCI Core Data Set.

Table 2 Univariate logistic regression analysis of non-modifiable and modifiable indicators for mortality 4 years after injury.

Variables	OR [95% CI]	*p* value
Non-modifiable factors		
Gender		
Male	1.00 (ref)	0.36
Female	1.75 [0.52–5.86]	
Aetiology		
Assault	0.49 [0.12–2.09]	0.34
Transport	0.11 [0.01–0.76]	**0.02**
Falls	1.00 (ref)	
Age		
18–30	1.00 (ref)	0.63
≥31	1.01 [0.97–1.04]	
Level of injury		
Tetraplegia	0.96 [0.36–2.58]	0.95
Paraplegia	1.00 (ref)	
Completeness of injury		
Complete (AIS A)	1.00 (ref)	**≤0.01**
Incomplete (AIS B, C, D, E)	0.2 [0.07–0.58]	
Modifiable factors		
Spinal surgery		
Yes	0.91 [0.34–2.45]	0.86
No	1.00 (ref)	
Acute medical complication (any)		
Yes	2.5 [0.86–7.23]	0.09
No	1.00 (ref)	
Pressure ulcers		
Yes	0.98 [0.33–2.93]	0.99
No	1.00 (ref)	
Pulmonary complication		
Yes	2.50 [0.86–7.31]	0.09
No	1.00 (ref)	
Education		
No schooling to <7 years	1.00 (ref)	0.52
Secondary and tertiary	0.68 [0.22–2.18]	
Length of hospital stay (continuous)	1.01 [0.98–1.02]	0.61

Bold values indicate a statistical significance.

post injury were completeness of injury, where those with an incomplete injury (AIS B, C, D, or E) had four times the likelihood (OR: 0.18; 95% CI: 0.05–0.61) of not developing a complication compared to their counterparts with complete injuries, and having a longer length of acute hospitalisation (OR: 1.04: 95% CI: 1.01–1.07) (Tables 3 and 4).

Discussion

The results of this study revealed a mortality rate of 24% 4 years after TSCI in South Africa, and significant non-modifiable risk indicators for mortality were completeness of injury and aetiology, specifically falls. Of those still alive at 4 years after injury, almost all presented with at least one secondary complication during the preceding three months, and the leading complications were pain, muscle spasms, sleeping problems, and bladder dysfunction. Similar to the prediction of risk indicators for mortality, those with complete injuries and those who had a longer acute hospitalisation were significantly more likely to develop a secondary complication at 4 years after injury. Collectively, this study suggests that those with complete injuries should be targeted in the management of their injuries both in terms of survival and recovery.

Table 3 Prevalence of medical complications 4 years after injury ($n = 55$).

Secondary medical complication	*n* (%)
Sleeping problems	31 (56)
Pain	44 (80)
Bowel dysfunction	23 (42)
Urinary tract infection	15 (27)
Bladder dysfunction	24 (44)
Sexual dysfunction	21 (38)
Contractures	22 (40)
Muscle spasms	42 (76)
Pressure sores	10 (18)
Respiratory problems	8 (15)
Injury due to loss of sensation	4 (7)
Any secondary complications	48 (89)
1 complication	3 (6)
2–3 complications	5 (9)
4–5 complication	11 (20)
≥6 complication	29 (53)

Mortality and related factors

About one-quarter of participants initially included in the study died within 4 years after injury. This figure is most likely an underestimation, since 58 participants were unaccounted for, yielding an attrition rate of 40%. Very few studies in the field have conducted similar investigations on mortality and secondary medical complications 4 years after injury, which limits our ability to directly compare our findings. A previous study conducted in Botswana found a mortality rate of 20% after 1 year, and this was after the introduction of a more specialised approach to the management of SCIs [2]. The high survival rates are in contexts where specialised systems exist. In certain first-world countries, ~80% of people with diagnosed SCI survive at least 10 years after injury [10].

In terms of factors related to mortality in our study sample, those with complete injuries and those who sustained their SCI's due to falls had a greater likelihood to die by 4 years after injury. This is in line with an Australia study where severity of injury, with a Standard Mortality Ratio of 2.4, was associated with premature death [13]. The difference observed in mortality based on the level and

Table 4 Factors related to developing a medical complication in the last 3 months.

Variables	OR [95% CI]	*p* value
Non-modifiable factors		
Gender		
Male	1.00 (ref)	0.55
Female	0.63 [0.13–2.92]	
Aetiology		
Assault	1.00 (ref)	0.25
Transport	0.51 [0.16–1.61]	0.16
Falls	0.19 [0.19–1.92]	
Age		
18–30	1.00 (ref)	0.37
≥31	0.98 [0.94–1.02]	
Level of injury		
Tetraplegia	0.93 [0.32–2.69]	0.54
Paraplegia	1.00 (ref)	
Completeness of injury		
Complete (AIS A)	1.00 (ref)	**≤0.01**
Incomplete (AIS B, C, D, E)	0.18 [0.05–0.61]	
Modifiable factors		
Spinal surgery		
Yes	0.45 [0.15–1.32]	0.14
No	1.00 (ref)	
Acute medical complication (any)		
Yes	2.5 [0.86–7.23]	0.09
No	1.00 (ref)	
Education		
No schooling to <7 years	1.00 (ref)	0.77
Secondary and tertiary	0.84 [0.27–2.62]	
Length of hospital stay (continuous)	1.04 [1.01–1.07]	**0.02**

Bold values indicate a statistical significance.

completeness of injury however seems to be at the greatest within the first years following an injury [14]. It is further suggested that these differences decrease significantly within 5–10 years after the injury.

Secondary medical conditions and related factors

It is well documented that secondary medical complications are common and at a high prevalence after spinal cord injuries [14–16]. These complications worsen the experience of disability as it has a negative effect on long-term health, quality of life and independence. This study furthermore confirmed that 89% of those that completed the survey indicated that they had at least one secondary medical complication. We further found that participants typically presented with more than one complication during a given period. In fact, more than 70% presented with four or more complications. There is therefore a dire need to implement self-management interventions in order to mitigate secondary complication development of community dwelling persons with TSCI.

The most common secondary medical complication in this study was pain (80%). Other studies similarly reported pain as the most common secondary medical complication. For example, Mashola and Mothabeng reported pain as a secondary medical complication in 47% of their sample, and muscle spasm in 36% [14, 17]. Poorer psychological functioning and diminished quality of life is associated with pain in those with a spinal cord injury [14] and pain after spinal cord injury has been deemed as one of the most complicated problems to manage in this group. It is therefore important to explore the origins of pain as well as current management plans for pain in persons with SCI, with the aim of developing targeted interventions. It is also worthwhile to explore other non-pharmacological treatments for pain management in SCI.

This study presented with a number of limitations which should be considered. First, the high loss to follow-up (40%) could have severely underestimated the mortality rate. The lack of follow-up was precipitated by the lack of safety, which was a major risk, as many of the areas the respondents emanated from were in the Cape Flats of the Western Cape, affected by high violence/crime-related activities. In addition, the changed/incorrect addresses and contact details received on acute admission made follow-up challenging. However, we have contacted eligible participants on numerous occasions and sent letters to their addresses. We have also tried to locate them by driving to their residences. A recent study conducted in North Macedonia experienced similar challenges to follow-up and thus proposed an improvement of health information systems in settings in order to conduct defensible epidemiological research [18]. Second, no physical assessment of functioning and deficits was performed at 4 years of injury; this information is necessary to identify the extent to which other outcomes are met. Despite these limitations, we recommend that the department of health invest in developing an information system specifically for SCI in order to track and observe trends, outcomes and ensure capacity of health care services, which could further lead to better coordinated and integrated care plans for persons with SCI.

In conclusion, almost one-quarter of persons with TSCI have died 4 years after injury. Also, secondary complications were found to be highly prevalent at 4 years after injury, with pain being the most problematic. In order to strengthen systems of SCI care in South Africa, particular focus should be placed on factors related to mortality and secondary medical complication development in order to address disparities in life expectancy, well-being and functioning.

Data availability

The datasets generated and/or analysed during the current study are available from the corresponding author on reasonable request.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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