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EPIDEMIOLOGY, OUTCOMES AND EXPERIENCES OF LIVING WITH TRAUMATIC SPINAL CORD INJURY IN BOTSWANA

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EPIDEMIOLOGY, OUTCOMES AND EXPERIENCES OF LIVING WITH TRAUMATIC SPINAL CORD INJURY IN BOTSWANA

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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BOTHO

The most important value held in Botswana is that of Botho (highest respect, honour, and esteem that one holds for another human life). Society expects and requires its members to have Botho, which is manifested through good manners, humility, compassion, kindness, respect, gentility and observance of traditional norms and behavioural code. Botho forms the fabric of the Botswana value-system and is one of the five national principles together with Democracy, Development, Self-reliance and Unity

ABSTRACT

When sustaining a traumatic spinal cord injury (TSCI) there will be substantial changes and challenges in a person's life no matter where they live. In many parts of the world, well-structured systems of care as well as governmental support assist the injured person to optimize his/her level of function and inclusion into society. In many resource-constrained settings those systems are often lacking which could lead to lower functional outcomes, as well as substantially higher morbidity and mortality rates. To work on prevention and to develop TSCI-specialized care, knowledge of the current situation is crucial; however the majority of studies in this field are conducted in resource-rich settings, even though the circumstances can be very different in the less resourced countries.

Therefore, the aims of these studies were to deepen the understanding of living with TSCI in Botswana and to explore the local epidemiology and outcomes of TSCI.

The studies were conducted at the Princess Marina Hospital (PMH) in the capital Gaborone, and primarily at the recently (2010) established SCI-rehabilitation centre. Both qualitative and quantitative methods were used. Study I explored the experiences of people living with a TSCI for at least 2 years. Study II-IV were mainly prospective studies on the same sample; namely all persons who were admitted with acute TSCI to PMH during a 2-year period; followed from admission (study II), throughout hospitalization to discharge (study III), and to the second yearly control (study IV).

The main findings were the importance of personal resources such as a strong sense of self and a positive attitude in order for the informants to feel more fully integrated into society. Family support and/or having a source of income were crucial for establishing and strengthening one's self. Spirituality and faith were seen as facilitators, while inaccessibility was a barrier from social inclusion (study I). The annual incidence of TSCI was 13 per million, with traffic-related injuries being the vast majority (68%), and of those almost 3/4 had been involved in single accidents. Stabilizing surgery was performed after a median of 12 days and mortality during the acute phase was 20% (study II). For the 39 persons who survived the acute phase, the median hospitalization was 5 months (including acute care and rehabilitation) with longer time for those with complete injuries and for those who developed pressure ulcers (n=16). Other common complications were pain (n=27) and urinary tract infections (n=11). All patients, except two, were discharged home and supplied with wheelchairs and other assistive devices as recommended by the therapists (study III). The follow-up rate with structured multi-professional yearly controls was 71%. The rates of pressure ulcers and urinary tract infections had increased in the home environment; however no one had died during the 2-year follow-up period. Finally 44% had resumed work or studies (study IV).

In conclusion, the outcomes for people with TSCI in Botswana were to some extent approaching the situation that is valid in some high-income countries. For example, the provision of technical aids, return-to-work, follow-up and survival rates 2 years post discharge are comparable. In other ways, the situation was closer to low-income countries, especially regarding the acute management, leading to long delays to surgery, high rates of complications and in-hospital mortality. As a middle-income country Botswana has financial power to persist to develop the management of people with TSCI in order to decrease secondary complications and acute mortality, which likely would contribute to continuous improvements of outcomes and survival after TSCI.

SAMMANFATTNING

En traumatisk ryggmärgsskada (TRMS) innebär stora förändringar och utmaningar i en persons liv oavsett var i världen man bor. Många länder har en väl utvecklad och strukturerad vårdkedja och social trygghet vilket möjliggör för personer med TRMS att optimera sin funktionsnivå och integreras i samhället. Dessvärre saknas de systemen ofta i låg- och medel-inkomstländer vilket kan leda till betydligt försämrad hälsa, lägre funktionsutfall och ökad mortalitet. För att underlätta skadeprevention och uppbyggandet av TRMS-specialiserad vård behövs kunskap om den aktuella situationen. De flesta studier inom TRMS-området är dock utförda i höginkomstländer, medan situationen ofta är väsentligt annorlunda i länder med begränsade resurser.

Med detta som bakgrund, var målet med denna avhandling att fördjupa förståelsen om hur det är att leva med TRMS i Botswana samt att studera epidemiologi och utfall efter TRMS.

Studierna genomfördes på Princess Marina Hospital (PMH), det största offentliga sjukhuset i Botswana, och primärt på det nyligen (2010) etablerade centret för TRMS-rehabilitering. Studie I var en kvalitativ studie med syfte att utforska erfarenheter av att leva med en TRMS; attityder, hinder och utmaningar. Studierna II-IV var huvudsakligen prospektiva studier och följde en och samma patient grupp, nämligen alla patienter som kom in till PMH med akut TRMS under en 2-års period; från inskrivning och det akuta omhändertagandet (studie II), under den inneliggande vårdtiden och rehabiliteringen till utskrivning (studie III), till och med den andra årliga uppföljningen (studie IV).

De huvudsakliga resultaten av dessa studier inkluderar hur essentiella personliga egenskaper som en stark självkänsla och en positiv attityd var för att känna sig inkluderad och integrerad i samhället. Familjestöd och/eller att ha en inkomst/försörjning hade en närmast avgörande betydelse för självkänslan. Spiritualitet och tro beskrevs befrämja integrering, medan otillgänglighet var ett betydande hinder (studie I). Den årliga incidensen av TRMS var 13 per miljon. Majoriteten skadades i trafikolyckor (68 %), av vilka nästan 3/4 i en singelolycka. Stabiliserande kirurgi utfördes efter 12 dagar (median) och mortaliteten under den akuta vårdtiden var 20 % (studie II). Inneliggande vårdtid för de 39 patienter som överlevt den akuta vårdtiden var 5 månader (median), vilket inkluderade både akut vårdtid och rehabilitering. Komplett skada och trycksår var de faktorer som signifikant förlängde vårdtiden. Förutom trycksår (n=16), var smärta (n=27) och urinvägsinfektioner (n=11) vanligt förekommande komplikationer. Alla, utom två patienter, skrevs ut till hemmet. Rullstolar och andra hjälpmedel förskrevs av avdelningens fysio- och arbetsterapeuter och tillhandahölls utan kostnad för patienterna (studie III). Av de 38 patienter som avslutat rehabilitering och var berättigade till multiprofessionella årskontroller, fullföljde 71 % uppföljningen. Frekvensen av trycksår och urinvägsinfektioner hade ökat något i hemmiljön, men ingen hade avlidit under den 2-åriga uppföljnings-perioden. Slutligen hade 44 % återgått till arbete eller studier (studie IV).

Sammanfattningsvis var situationen för personer med TRMS i Botswana nästan jämförbar med situationen i många höginkomstländer, i synnerhet när det gällde tillgång på hjälpmedel, återgång till arbete, uppföljningsfrekvens och överlevnad 2 år efter skadan. Dock var andra omständigheter jämförbara med situationen i många låginkomstländer, framförallt när det gällde akut omhänder-tagande och den basala vården vilket föranledde fördröjning av stabiliserande kirurgi samt höga frekvenser av komplikationer och mortalitet. Som ett medelinkomstland har Botswana finansiella möjligheter att vidareutveckla ryggmärgsskadevården, minska komplikationer och akut mortalitet, vilket sannolikt skulle kunna bidra till förbättrat utfall och ökad överlevnad efter TRMS.

LIST OF SCIENTIFIC PAPERS

I. Löfvenmark I, Norrbrink C, Nilsson Wikmar L, Löfgren M.
'The moment I leave my home – there will be massive challenges': experiences of living with a spinal cord injury in Botswana.
Disability and Rehabilitation 2016; 38: 1483-1492.

II. Löfvenmark I, Norrbrink C, Nilsson Wikmar L, Hultling C, Chakandinakira S, Hasselberg M. Traumatic spinal cord injury in Botswana: characteristics, aetiology, and mortality.
Spinal Cord 2014; 53: 150-154.

III. Löfvenmark I, Hasselberg M, Nilsson Wikmar L, Hultling C, Norrbrink C. Outcomes after acute traumatic spinal cord injury in Botswana – from admission to discharge.
On-line publication Spinal Cord 16 August 2016 doi:10.1038/sc.2016.122

IV. Löfvenmark I, Nilsson Wikmar L, Hasselberg M, Norrbrink C, Hultling C. Outcomes 2 years after traumatic spinal cord injury in Botswana: a follow-up study.
On-line publication Spinal Cord 19 July 2016 doi:10.1038/sc.2016.114

CONTENTS

LIST OF ABBREVIATIONS

AIS	ASIA Impairment Scale
ASIA	American Spinal Injury Association
FIM	Functional Independence Measure
ICU	Intensive Care Unit
IQR	Interquartile range
ISCoS	International Spinal Cord Society
LOS	Length of Stay
MVA-Fund	Motor Vehicle Accident Fund
NLL	Neurological Level of Lesion
Non-TSCI	Non Traumatic Spinal Cord Injury
PMH	Princess Marina Hospital
PU	Pressure Ulcer/s
RTC	Road Traffic Crashes
SCI	Spinal Cord Injury
SCIM	Spinal Cord Injury Measurement
Sida	Swedish International Development Cooperation Agency
SPSS	Statistical Package for the Social Sciences
TSCI	Traumatic Spinal Cord Injury
UTI	Urinary Tract Infection/s

FOREWORD

Little did I think about writing a thesis about spinal cord injuries (SCI) in Botswana until that day in 2008 when Claes Hultling asked me while passing in the Spinalis corridor, 'What would you think about working in Botswana?' Without any hesitation I said, 'Great, I'll go!' That the project would be realized and how that would lead to this point was not in my mind. While initiating the discussions about the Spinalis Botswana SCI-rehabilitation project, the lack of information regarding the current situation of traumatic SCI (TSCI) became obvious and partly challenged the planning of the specialized SCI-rehabilitation centre. This ignited the thought of conducting research, and I started to develop a deeper interest in research when realizing the practical implications the results could provide. The problems we were facing with the limited knowledge regarded, for example, capacity; how many people get injured, what type of injuries will they have, how many staff members do we need, how much technical aids do we need to provide are some examples of questions we had. I was, as the project coordinator, going to be the one spending most time in Botswana, which made performing both the clinical and research projects simultaneously seem feasible.

In April 2010 I and the Swedish team moved to Botswana. After the Memorandum of Agreement was signed, teaching and clinical work was initiated. We were at the time a full Swedish team staying there during different durations of time; Gunnel Lif (nurse), Göran Lagerström (project director), Katarzyna Trok (medical doctor), Per Vesterlund (rehabilitation coach), Lisa Bergmark (occupational therapist), and Tobias Holmlund and I were the physiotherapists. I lived in Gaborone for 2 years full-time and then commuted back and forth for 1.5 years before the project ended.

During these years there were many clashes of culture which at times led to funny realizations and comments and at other times less amusing experiences. The local team was initially three people; Maria Moopi (nurse), Beauty Kwadiba (occupational therapist), and Sharon Chakandinakira (physiotherapist), and increased one by one, and at the time we moved into our own unit, in July 2011, we got fully staffed with approximately 25 staff. We started inpatient TSCI-rehabilitation at the orthopaedic wards at the Princess Marina Hospital (PMH) and simultaneously established an outpatient clinic where people living with TSCI were scheduled, assessed, and assisted. We slowly adapted to the situation and the local team to us and today the unit is up and running and staffed with only local professionals.

During this time, we continued to construct and re-construct the research plan and writing funding applications on the side, with regular skype meetings and many e-mails with my supervisors in Sweden. Being on site facilitated the identification of the scientifically interesting areas and with setting realistic and useful goals for the studies. In retrospect, both the clinical work and the research studies have been great experiences. I have learned a lot of how to handle, and adapt to, different situations and I hope, and plan, to be a part of something like this again. With this in mind, I believe that being able to integrate my interest in different cultures with my clinical work and research is a good way to go forward.

1 INTRODUCTION

The current established SCI-system of care was initiated by Sir Ludwig Guttman during the 1940's; who at Stoke Mandeville in England started comprehensive SCI-management and rehabilitation. He also established the view of people with SCI as being healthy and independent individuals, but with a physical disability[1,2]. This concept has continued to spread; primarily in high-income countries but is also coming to be valid and benefit people in some less resourceful parts of the world. However, the differences in the health care systems, the availability of resources, and resource distribution are still huge between countries, and geographic areas, and affect the care of people with TSCI[3,4]. The situation also differs widely regarding knowledge and availability of specialized SCI-management, the provision of technical aids, governmental assistance, as well as the living environment that people have to endure[5].

Survival and life expectancy have increased substantially in more resource-rich countries over the last few decades, which have led to acute mortality rates close to zero in some settings, e.g. Sweden[6]. This success can be contributed to the well-developed specialized SCI-management, functioning systems of care, and structured medical follow-up. Additionally, the technological advances, access to assistance, and appropriate technical aids have increased the possibility for participation in society and improved quality of life for people living with SCI. In many resource-constrained countries, the limited availability of health care and rehabilitation personnel often lead to substantially poorer health outcomes for people who sustain SCI, or other injuries/diseases[7]. These constraints are the result of fewer systems and policies that facilitate a successful outcome and reintegration into society. There are also more environmental and technological barriers in countries with limited resources[8]. For those who survive hospitalization, the place of discharge is often to their rural home villages to be taken care of by their parents[9]. They have few means to access the community, and the burden on the family and the caregivers can be psychologically, socially, financially, and physically substantial, sometimes to the degree that families abandon their disabled family member[9,10].

In many parts of the Southern African region, challenges for people with SCI and their families are considerable, and can be aggravated because of poverty and unequal distribution of available resources. The rural, and even often the urban, environment is often harsh, with hilly and/or sandy terrain. Technical aids are, if available at all, usually supplied through charity donations and are not customized to the patients' needs[11].

The majority of studies on SCI are conducted in the resource-rich world, mainly North America, Europe and Australia. Many authors have addressed the issue of scarcity of epidemiological, clinical, and qualitative data from resource-constrained settings[12–14] which leaves a huge gap of SCI-knowledge to be filled.

1.1 SPINAL CORD INJURY

The spinal cord serves as a neurological link between the brain and the body and a lesion can result in total or partial loss of sensory and motor function below the level of injury, leading to a life-long impairment and disability. Other consequences of a SCI can include incontinence due to bladder and bowel dysfunctions, and sexual dysfunction. Neuropathic pain, autonomic dysfunctions (such as decreased function in temperature- and blood pressure regulation) and spasticity with muscle hyper-activity below the injury may also occur.

A TSCI is caused by external force from road traffic crashes (RTC), falls, violence or other causes, while a non-TSCI derives from internal causes such as bleedings, disc herniation, tumours, tuberculosis, or congenital diseases.

An injury in the cervical (neck) spine will result in tetraplegia, affecting all four limbs and the trunk. When the injury is located below the first thoracic vertebra, paraplegia will follow involving the lower limbs and, depending on the level of the lesion, the trunk. To determine the neurological level of lesion (NLL) and severity the standardized classification developed by the American Spinal Injury Association (ASIA) is used[15,16].

The neurological levels are:

Tetraplegia	Cervical level (C1-8)
Paraplegia	Thoracic (Th1-12)
	Lumbar (L1-5)
	Sacral (S1-5)

The severity of injury is defined by the sensory and motor function in the lower segments and the anal sphincter and categorized according to ASIA Impairment Scale (AIS) as:

AIS A: sensory and motor complete, i.e. no sensory or motor function in the anal sphincter

AIS B: sensory incomplete but motor complete; sensory function preserved in the sacral segments

AIS C: incomplete injury with some sensory and motor function in the sacral segments. The majority of key muscles below the NLL have muscle strength of grade ≤ 2

AIS D: incomplete injury with the majority of key muscles below the NLL of a muscle strength grade of ≥ 3

AIS E: full sensory and motor function (used to determine neurological recovery)

1.1.1 Complications

An SCI implicates increased vulnerability to secondary complications that occasionally can be fatal and likely to be aggravated for those patients that are cared for outside an SCI-system of care and specialized centres[6,17,18]. During the acute phase, pressure ulcers (PU), urinary tract infections (UTI), respiratory- and renal complications, and autonomic dysreflexia (i.e.

dysfunction of the autonomic nervous system seen with injuries above T6) are common as well as occasional cases of circulatory complications (e.g. deep vein thrombosis)[19,20] and heterotopic ossification (new bone growth). In addition, psychological considerations have to be taken into account. In the more chronic stage, pain, PU and UTI remain commonly prevalent which severely impact peoples' lives and decrease their life quality[6,21–23]. Cardiovascular disease, such as myocardial infarction, is also more prevalent after SCI compared with the general population[24].

Pressure ulcers

PU are one of the most common secondary complications and a major challenge after SCI.[25,26] Having a complete injury severely increases the risk of PU[27]. This risk seems to be universal even if the rates vary (21-54%)[27–31], with generally higher rates in resource-constrained settings compared with settings with more resources and where no specialized centres are available[32]. As Zakrasek et al. (2015)[33] state, the risk factors for PU are similar in resource-rich or poor settings, however some risk factors are more prevalent in resource-constrained settings, such as low income, low education, immobility, malnutrition, and long delays to admission[32,34]. When turning routines are not in place and pressure relief surfaces and adequate hygiene are lacking, PU are common. A pressure-reduction mattress is preferable, but not always available. However, regular skin checks, frequent turnings, keeping the patient clean and dry, and maintaining a good nutritious status are also important to prevent PU[1,5,35].

Urinary tract infections

Clean intermittent catheterization i.e. self-catheterization, is the preferred method to manage a neurogenic bladder and has shown to minimize the risks of UTI and other urinary complications, or suprapubic catheters for people with tetraplegia[23,36]. Nevertheless, urethral indwelling catheters are often used in resource-constrained settings due to lack of catheters and specialized SCI-units, limited knowledge, and a resistance among the patients to self-catheterize[23,25]. When self-catheterization is practiced in resourced-constrained settings, reuse of catheters is common due to economic issues, which also increases the risk of UTI compared with single use[37]. UTI are common among people with neurogenic bladder dysfunction and when frequent infections occur, sepsis or kidney complications might develop, which in the worst cases can be lethal. Rates of UTI range between 12-88%; usually with the higher rates in resource-constrained settings[20,29,36,38,39].

Pain

Pain is reported to be the most prevalent complication in the SCI-population (61-80%) in various settings and different phases after SCI[40,41]. Both neuropathic pain, which is a direct consequence of the injury, and nociceptive pain, due to overuse and shoulder instability for example, are common[35,40,42].

1.1.2 SCI - A life-changing event

When a person suffers an SCI, the patient and the family face numerous changes and challenges regardless of their socio-economic level. However, the physical and social circumstances that individuals experience vary substantially around the world, as well as coping mechanisms that might differ depending on their cultural backgrounds[43]. The impact of identity, self-worth, and a biographical disruption after an SCI has been described[44,45] along with the need to establish or re-evaluate a 'meaning', developing inner strength, autonomy and the ability to re-take control of one's life[45,46].

Loss of personal control and independence have been found to contribute to a change, or loss, of identity. Other people's behaviour toward persons with disabilities has also shown to affect identity[44], and might contribute to a lower self-esteem and self-worth. Biographical disruption has been described to include the body, conception of self, and time; such that an inability to perform an everyday task can lead to a loss of perception of our competence and self-worth[45]. Strong relationships with friends and family members, social support and peer support have been described to have a substantial impact on adapting to the new situation[47–49]. Spirituality and faith are also described as central for many people in the process of dealing with SCI, even though they are often of less importance in more secular societies[47,48,50,51].

Inaccessibility, financial constraints and stigma towards people with disabilities can limit integration into society in both resource-rich and poor settings[5,21,45,48,49,52,53]. In resource-constrained settings, the risks of poverty and dependency on the family might become barriers to participation in society and can be exacerbated by devaluing attitudes[3,25,48,54–56]. Stigma might also be aggravated by cultural beliefs that disabilities derive from a curse or as a punishment for sin, occasionally leading to families hiding their disabled family member out of shame[53].

The importance of return-to-work has been emphasized for several reasons; e.g. income, participation, contribution, and feeling useful and valuable[21,57]. Returning to work can though be hugely challenging, especially where the main form of labour is physically demanding, e.g. farming. From Southern Africa low return-to-work-rates have been reported. In Nigeria for example, none of the former patients had returned to work[26] and a similar situation was reported from Zimbabwe, where university studies also were terminated due to inaccessibility at the university and lack of transportation[11].

1.2 EPIDEMIOLOGY OF TSCI – SIZE AND DISTRIBUTION

The prevalence of TSCI (i.e. the number of people living with TSCI at a specific point of time) ranges from 280 to 1298 per million population[5]. Many high-income countries might present a high prevalence compared with resource-constrained settings due to the high survival rate; thus a high mortality rate can consequently decrease the prevalence.

The incidence rate (i.e. the annual number of new cases) often shows the reverse pattern; with generally lower incidence rates in high-income countries explained by successful

preventative measures. Incidence rates are oftentimes difficult to compare due to the lack of uniformed classifications and different inclusion criteria that are used such as: different ages (some do not include children or teens), retrospective versus prospective studies, pre-hospital mortality, and hospital-versus population-based rates[58,59]. The global estimates of annual incidences however range from 13 to 53 per million[5], with a mean of 23 per million[60], even though a wide dispersion, ranging from 3.6 (Canada) to 195 (Ireland) has been reported[12]. In the Southern Africa region rates range from 21 to 29 per million[60], although a recent study from Cape Town (South Africa) reported 76 new cases per million[61].

The main aetiologies (causes) of TSCI are RTC, falls, and violence, while sport related accidents account for less than 10%[5,26,62]. Although RTC have decreased in many high-income countries due to implemented traffic safety regulations, the United States still reports high rates compared with similar contexts[58,63]. Instead, the rate of TSCI due to falls, mainly low falls, have increased simultaneously with an aging, healthy, and active population[64]. Injuries due to falls from heights are frequent in Asia[65–67], while many African nations report low fall incidences[5,28]. In Sub-Saharan Africa, RTC account for approximately 70% of TSCI[5,54], followed by a variation of aetiologies dependent on the nature of the country such as high rates of assault[61,68,69], falls from trees[70], or collapsing tunnels[39]. In many resource-constrained settings, the growing middle-class population lead to increasing number of vehicles on the roads. Due to insufficient reinforcement of traffic safety legislation the transport-related injuries are expected to continue to increase in many of these countries. [23,54,71].

Historically, young men have had the highest risk of TSCI worldwide even if the ratios for both age and gender have been changing; especially in resource-rich countries[5]. With the increasing numbers of older people, and women, that sustain TSCI, the panorama of the "common" TSCI-victim has been revised, both concerning age and gender. In resource-constrained settings, the male dominance remains the norm, with commonly seen male:female ratios of 5-10:1[28,39,71].

1.2.1 Mortality

Mortality rates are often reported both as acute and long-term mortality. Comparing different studies are challenging as inclusion criteria often differ; e.g. acute mortality ranges from pre-admission, within 3 to 7 days post injury, and during the hospitalization period, while long-term mortality is often studied 1-2 years post injury or post discharge, or later. However, there is a consensus that especially people with tetraplegia and complete lesions have a higher risk of dying prematurely compared with the general population[5,58]. Additionally, mortality rates are reported to be higher in many resource-constrained settings which partly are explained by the existing health care system, the lack of specialized emergency management and inpatient care, and the lack of follow-up[5,63,72].

In-hospital mortality

Acute mortality has decreased to almost zero in some resource-strong settings with well-developed SCI-management even though variations still exist[6]. The main causes of death include respiratory issues, such as pneumonia or influenza, and cardiovascular disease[5]. In resource-constrained settings, in-hospital mortality rates are substantially higher (17.5-34%)[26,72–74], with sepsis due to PU and UTI being the main causes[5,11]. Respiratory failure has been reported to be a main cause of death also in these settings[75].

Post-discharge mortality

The first year post-injury involves the highest risk of premature death among people with SCI[5,11]. In some resource-rich settings, mortality 1-2 years post-injury can be zero e.g. Sweden[6], as compared to the high numbers (25-61%) in the Southern African region[74,76]. The causes of premature death after discharge among people with SCI are similar to those of inpatient mortality[5], with an additional cause due to cancer in high-income countries[30,77]. Chronic PU has also been reported to substantially decrease life expectancy in the United States[18].

1.3 MANAGEMENT

The provision for patients with TSCI varies from minimal available health care to highly specialized management according to international guidelines[35]. Optimal management should start at the site of the accident with proper stabilization and transport by professionals, followed by prompt emergency attention, 24-hour availability of x-ray, computerized tomography or Magnetic Resonance Imaging (MRI), and surgery, well-staffed acute care units, and specialized rehabilitation[32]. Added to that, provision of appropriate technical aids, home modifications, computerized aids, and access to personal assistance are crucial to optimize functional outcomes. However, these recommendations are often not incorporated in many resource-constrained settings, especially in rural areas, which most likely affect the long-term functional outcomes, participation in society, and the changes of survival.

1.3.1 Pre-hospital

The recommendations of pre-hospital management include stabilization of vital functions and the spine, with a combination of rigid cervical collar and supportive blocks on a backboard, from the site of injury and during transport to the appropriate level of hospital[35]. These recommendations are more likely to be followed in countries where the structure of health care is well-defined, developed, and resourced[14,23]. In resource-constrained settings, pre-hospital management such as ambulance transport and immobilization at the site of injury, are often lacking[25,78,79] and patients are transported by any available means (sometimes in sitting) e.g. in individual cars, on donkey carts, or on trucks, and often by lay-people; which involves a serious risk of further neurological damage[5,78]. Additionally, multiple hospital presentations prior to reaching an appropriate level of hospital are common, increasing the numbers of transfers and time to admission.

1.3.2 Acute care

Early transfer to a trauma or spinal center has shown to decrease secondary complications, improve outcomes, psychosocial adjustment, and survival[5,32,35]. An interdisciplinary approach is required from the early stage due to the multi-faceted medical issues that require attention after a TSCI; e.g. medical, physical, psychological, nutritional, and family support[35]. For bladder management, an indwelling catheter should be inserted acutely and a bowel programme initiated as soon as appropriate[35]. At the same time, proper care to prevent development of secondary complications is crucial. After admission to a tertiary-level hospital, stabilizing surgery, if appropriate, should ideally be performed as soon as possible to minimize the risk of further damage. In resource-constrained settings and where systematic SCI-care is lacking these interventions are often challenged by for example inconsistent availability or lack of neurosurgeons, which can lead to long delays. Meanwhile, spine immobilization needs to be maintained by using collars, braces and log-rolling i.e. maintaining the alignment of the spine while rolling the patient to the side; which is necessary to relieve pressure and maintain hygiene. Log-rolling is a staff demanding transfer and requires knowledge and training to be performed correctly, and can be challenged by limited knowledge, over-occupancy on the wards[34], and the fact that it is often family members who are assisting the patient with personal care.

1.3.3 Rehabilitation

After the acute phase, early transfers to specialized centres have shown to reduce cost, length of stay (LOS), secondary complications, and mortality[5,32]. Specialized SCI-rehabilitation by trained multi-professional teams, including physiatrists, nurses, physio- and occupational therapists, social workers, rehab coaches as well as often urologists, plastic surgeons, and dieticians are required to address the multitude of issues that arise after an injury[23]. One study that compared SCI-rehabilitation in four different countries concluded that the functional outcomes were affected by lesion severity, rehabilitation objectives, staff density per patient, LOS, and the condition of the community[80], while others have also identified hope as a facilitator for a positive outcome[57,81]. Additionally, appropriate technical aids are essential for the patient to optimize their level of function and independence[5].

Well-staffed and well-equipped SCI-units are established in many countries to serve this patient group. In resource-constrained settings these services are often lacking which results in substantially lower chances of returning to a productive and full life. The patients are often admitted to general wards with a low nurse-to-patient ratio and where special equipment such as pressure relief mattresses is none-existent. When no SCI-rehabilitation unit is in operation, the objectives for SCI-management are often not according to the recommendations, and the prognosis and expected functional outcomes are low. Limited knowledge among the staff might also contribute to poor functional outcomes, high rates of complications and high mortality rates[23]. The provision of technical aids is also often challenging and it has been estimated, that in resource-constrained settings 5-15% of the people who require technical aids has access to them; affecting the rural areas more compared with the urban[5,23].

1.3.4 Length of stay

LOS is one of the measures used to compare clinical effectiveness of care and rehabilitation[80]. It is, however, difficult to compare LOS between settings because of the different phases that can be included, e.g. acute care/rehabilitation, and whether it is pre-determined or based on the rehabilitation progress. Furthermore, LOS does not always correspond with the outcomes, e.g. teaching self-catheterization takes more time than using an indwelling catheter[80] and one study reported lower functional outcome scores due to reduced rehabilitation periods[82]. The places of discharge also vary depending on the conditions in the community, e.g. discharges to nursing homes might decrease LOS[80]. In places where specialized care is not available, the LOS can be short due to lack of rehabilitation. Likewise, high-level care and rehabilitation might lead to long LOS but can also result in higher functional outcomes.

Despite the shortcomings of this measure, LOS is often prolonged for patients with complete injuries and by the presence of secondary complications, mainly PU[28,33,34]. Delays in admission to rehabilitation have also shown to increase LOS[32,80]. Resource-rich settings report hospitalization periods of 2 to 3 months[19,83] compared with 3 to 5 months in resource-constrained settings[28,73].

1.3.5 Follow-up

Long-term specialized medical follow-up post-TSCI should be conducted in order to promote health, and to prevent, identify, and treat secondary complications[23,84]. In high-resource settings the follow-up is structured differently partly depending on the objectives of the centres; in some settings life-long follow-up includes multi-professional yearly controls with specialized staff, while in others the continuing care post-discharge is managed by local clinics.

In resource-constrained settings specialized TSCI follow-up is often limited or lacking. Patients are often discharged to rural home-villages with the local clinics or Home Base Care centres to turn to. Without patient registries and reliable ways of contacting patients (lack of addresses or valid phone numbers) there are few means of keeping track of the patients. Additionally, inaccessible transportation and financial constraints contribute to limit the access to TSCI-centres[23]. Scheduled follow-up visits are rare and lost-to-follow-up rates have been reported up to 97%[26]. The majority of studies on follow-up people with TSCI post-discharge in resource-constrained settings are done by home-visits, phone calls, or questionnaires[29,75].

1.5 BOTSWANA

Botswana, a land-bound country the size of France, is situated in the southern part of Africa. Around 80% of the country is covered by the sparsely populated Kalahari Desert and the population is just over 2 million inhabitants. The capital, Gaborone, has a population of 300 000 and is situated close to the South African border.

Map over the Southern African region.

1.5.1 History and culture

Botswana, then Bechuanaland, was a protectorate under the British Empire and gained independence in 1966. It was at that time one of the poorest countries in Africa. After the discovery of rich diamond resources and other minerals, the development of the country progressed and Botswana's economy changed rapidly. Today it is rated as a high middle-income country[85]. Still, poverty exists in almost one fifth of the population[85] and income differences are increasing.

Botswana's culture, along with the development of the country, has gone through big changes. As people tend to move towards the cities looking for job opportunities, their tribal societies and cultures change, however, the cultural value of the collective before the individual partly remain[86]. People used to divide their time between their three homes; "the lands" (for agriculture), the cattle post (for the livestock), and the home/village/city[86], a system still partly in place which leads to frequent long drives.

Religion is strongly embedded in Botswanan society with Christianity being the leading faith, often combined with a strong belief and respect for the ancestors[87]. The belief in the power of traditional healers is strong, especially in the older generations and in the rural parts of Botswana, and so are the beliefs that disabilities and diseases can be caused by a curse. With Western medicine gaining ground, being examined and treated by hospital medical staff is often combined with visits to traditional healers or healing ceremonies in churches[87].

The Swedish government (Swedish International Development Cooperation Agency, (Sida)) has supported Botswana for many years, with Partner Driven Cooperation's as the main form of collaborations during the last years, during a phase-out period. Sida ended their financial support in December 2013, in conjunction with several other middle-income countries, prioritizing less successful areas[88].

A typical village view.

1.5.2 Health care

The health care system in Botswana is centralized under the Ministry of Health and consists of a relatively well developed public health care system and two private hospitals in the capital. The three public referral hospitals are situated in the biggest cities, Princess Marina Hospital (PMH) in Gaborone, Nyangabgwe Hospital in Francistown, and a psychiatric hospital in Lobatse. Seven district hospitals are located in bigger villages and towns, and 16 primary hospitals in smaller villages[89]. In the rural areas, health clinics and Home Base Care clinics provide the health care services. Occasionally patients are referred to South Africa for treatment, mainly to Johannesburg, when additional resources are needed; an approximately 5 hours long travel by car.

The system of regular staff rotations is common throughout the public sector in Botswana. Once a year, a substantial number of the health care workers change departments, hospitals, or even cities/villages. This rotation system can facilitate supplying the rural and less attractive areas with educated professionals as well as promoting staff progression, which often is done by temporary transfers to rural areas. At the same time, this system might obstruct specialization and continuity.

The majority of the health care professionals (physicians, physiotherapists, occupational therapists, and partly nurses) are educated and trained outside the country on the government expenses. A medical school has been established in Gaborone and the first students have recently graduated. The education of specialized physicians has also been limited, thus, the majority of medically trained specialists are foreigners.

The Motor Vehicle Accident (MVA)-Fund is a parastatal insurance company covering all people injured in traffic-related accidents. This insurance is partly funded through the petrol sales and have offices situated in the major towns and villages in the country. The MVA-Fund can assist with the cost for treatment of body injuries, technical aids, consumables, house modifications, and occasionally payment for caregivers.

1.5.3 TSCI in Botswana

For people who sustained a TSCI the prognosis was often poor. One small study that was completed over 20 years ago described an in-hospital mortality rate of 25% and high rates of PU and UTI aggravated by depression[90]. Providing patients with wheelchairs was challenging and follow-up post-discharge was basically none-existent. The report acknowledged the challenges and shortcomings of the TSCI-care at the time and expressed requests for improvements of TSCI-management. To complement that report, local physicians estimated in 2010 that around 85% of the patients died within a year after discharge, especially those who were wheelchair bound; with PU and UTI being the main causes of death.

The knowledge regarding the basic care and rehabilitation of patients with TSCI was limited and specialized equipment, such as pressure relief surfaces, were lacking. Patients were mainly discharged to the rural home villages despite the fact that many had relocated to urban areas for work or studies pre-injury and in most of these cases their mothers became their designated caregivers. Due to the lack of specialized TSCI-rehabilitation in the country, some patients who were believed to have good rehabilitation potential could be referred abroad for training on the government or the MVA-Fund expense. However, this was usually not the case for people with tetraplegia, who were not considered to have potential for progress. Tetraplegia resulted instead in being discharged to home after having completed caregiver training.

Photographs that show variations of living standard among the patients.

Mud houses (top)

Simple brick buildings with or without electricity and water, and pit latrine (middle)

Higher standard house with electricity and bathroom inside (bottom)

The wheelchairs that were available, usually donated by charity organization or churches, were generally inappropriate for people with TSCI. Despite the size of the patient or the type of injury, wheelchair size depended on availability; and wheelchair cushions were rare. Commode and shower chairs were uncommon which lead to that personal hygiene and bowel management were oftentimes carried out in bed; a routine that is generally discouraged[23]. Colostomy was a common choice of method for bowel management, and indwelling catheters were used to manage a neurogenic bladder dysfunction.

Commonly seen wheelchair

Photographs of different toilet and bathroom facilities.

Pit latrine (above)

Traditional bath (basin) (middle right)

A higher standard bathroom. Toilet accessibility is still limited due to the narrow passage beside the basin (bottom)

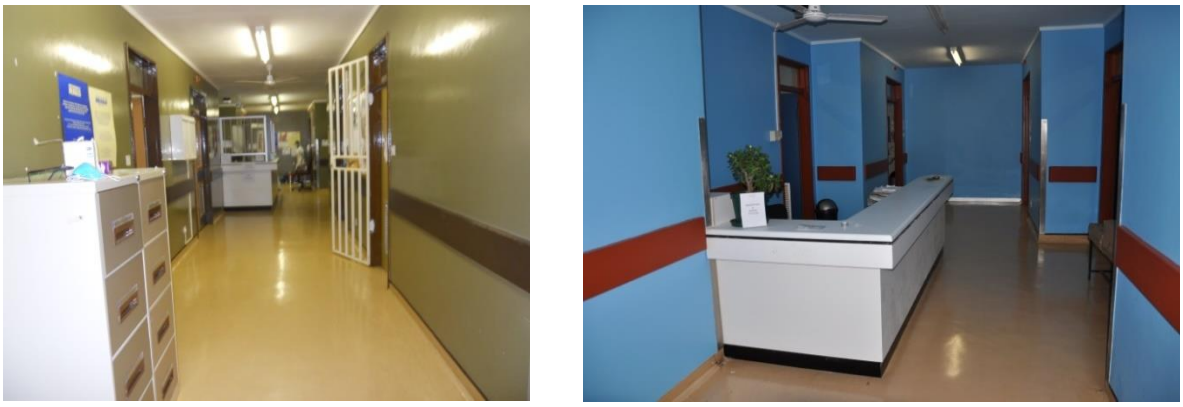
1.5.4 Spinalis Botswana SCI-Rehabilitation Project/Centre

The idea of the Spinalis Botswana SCI-rehabilitation project was sprung in 2008 when Claes Hultling, one of the founders of Spinalis in Sweden, was in Gaborone attending a conference. After some visits to explore the feasibility of such a project, the inception phase was initiated in 2009; establishing the project plan, negotiating agreements, and allocating resources. This resulted in a 3-year Partner Driven Cooperation project between the Ministry of Health in Botswana and the Spinalis Foundation in Sweden, partly funded by Sida, with the goal of establishing a SCI-rehabilitation centre within the public health sector run by local professionals.

The Spinalis concept includes both specialization and centralization with a focus on patient-centred empowering activities (using role models), rigorous skin and bladder regimes, health promotion, and psycho-pedagogical therapies. Three key components are optimizing body functions, building mind set, and re-integration into society. It also advocates for a "one-stop shopping" i.e. were all specialists involved with SCI-management are available under one roof and with pro-active follow-up with structured yearly controls. Finally, it acknowledges the importance of patient education and addresses the family member's needs, all with the overall vision to make possible "a good everyday life for people with SCI"

The transfer of specific SCI-knowledge from Sweden to Botswana in the form of clinical work and lecturing with the three allocated local staff members as well as the rotating doctors that currently covered the unit was initiated in 2010. The temporarily allocated premises were the orthopaedic wards at PMH with one cubicle in each of the male and the female wards. Lecturing was also done for the orthopaedic ward staff; mainly regarding the basic care, with the specific aim of preventing PU; a complication that affected almost all patients with TSCI at PMH at the time.

In July 2011, the SCI-rehabilitation centre transferred into a designated unit, which enabled the rehabilitation concept to be fully incorporated. For example, meals were served in the newly constructed day-room instead of in bed, training of self-care and transfers skills were incorporated in the daily care, weekly patient lectures was initiated, and patients were cared for by SCI-trained staff 24 hours a day.



Spinalis Botswana SCI-rehabilitation centre before and after renovation

Today, the Spinalis Botswana SCI-rehabilitation centre is well integrated into the public health care system and staffed with only local professionals. The structure of the TSCI-management has been altered, with PMH becoming the national TSCI-referral hospital and the SCI-rehabilitation centre mandatory for persons with TSCI. The services include inpatient rehabilitation, outpatient clinic (mainly wound care), and life-long follow-up with yearly controls (including assessment of persons living with TSCI and not previously registered at the centre). Additionally, out-reach clinics are conducted in rural communities to minimize travel for the patients and to facilitate follow-up and long-term supervision; and occasional training sessions with the staff at the rural hospitals. Today the TSCI-registry includes over 230 people with TSCI.

Despite similar needs for people with non-TSCI, the SCI-rehabilitation centre still admits mainly people with TSCI. This should be changed as soon as the major obstacles are solved; including a secured procurement chain for technical aids through the government and a double size unit with appropriate staff density to cover for the expected increasing demands.

A well rehabilitated patient changing room and playful wheelchair training.

1.6 RATIONAL

With the multiple impacts a TSCI has on a person's life, prevention, development of specialized care, and a desire to improve the situation for people with TSCI are essential, both for the individual and for society. However, this requires up to date information regarding the present situation. The majority of studies regarding TSCI are conducted in areas of the world with well-established systems of care and research resources; mainly North America, Europe, and Australia. However, the situation is often quite different in resource-constrained settings regarding health care systems, resource distributions, and environmental and living circumstances as some examples. The scarcity of studies from these regions, especially from Southern Africa, is well-documented, and based on our knowledge no such studies have been conducted in Botswana over the last 20 years. Conducting studies of these settings are often challenged by overwhelming workload for the medical staff, international guidelines and measures of outcome are often not followed, and the lack of research funding[14]. Botswana also differs from many other settings due to the economic and social changes that have occurred over the past decades, which have helped it move in status from a low-income to that of a middle-income country resulting in more financial power while at the same time the SCI-related knowledge and structure are still limited. The health care system, for example, is relatively well developed; even though specialized rehabilitation is rare and living circumstances are still challenging for many people. Therefore, the issue of research was raised at an early stage during the planning of the partnership project and constituted one important part of the development of specialized care for people with TSCI in Botswana. Furthermore, the findings from these studies can contribute to valuable insight and fill part of the knowledge-gap regarding TSCI in the Southern African region.

2 AIM

The overall aim of this thesis was to deepen the understanding of living with TSCI in Botswana, and to explore the epidemiology and outcomes of TSCI in this Southern African setting.

2.1 SPECIFIC AIMS

Study I: To explore the experiences of living with TSCI in Botswana, including how people manage their daily lives with regard to attitudes from their family and community, support systems, obstacles faced and environmental challenges.

Study II: To describe the epidemiology of TSCI, focusing specifically on transport-related injuries.

Study III: To increase the knowledge regarding clinical and functional outcomes after TSCI in Botswana. A special focus was placed on secondary complications such as PU.

Study IV: To identify indicators leading to compliance with yearly controls and to describe the clinical and functional outcomes 2 years after a TSCI.

3 METHODS AND MATERIALS

3.1 DESIGN

This thesis explores people with TSCI in Botswana from both a qualitative and quantitative approach. Study I was a qualitative study, which is appropriate when human experiences are in focus, and was conducted as an interview study analysed using a grounded theory approach[91,92], a suitable method when there is no previous knowledge in the field available. Grounded theory is an emergent design whereby new knowledge can be incorporated in the study and increase or alter the focus of the study; the interview guide can be altered according to emerging themes and saturation of themes when needed. Study II-IV were quantitative studies, with study II being a descriptive study with a cross-sectional design, including both prospective (incidence, characteristics) and retrospective (circumstances of RTC) data. Study III and IV were prospective follow-up studies. In all, studies II-IV create a longitudinal perspective on one patient group. See Table 1 and Figure 1.

3.2 SETTING

The setting for all studies was the national TSCI-referral hospital PMH in Gaborone, Botswana, and mainly the Spinalis Botswana SCI-rehabilitation centre.

PMH is a tertiary-level hospital and has a capacity of 500 beds but occupancy is usually much higher. Most specialities are available and patients are transferred from around the country, with distances up to 900 km. The nurse-to-patient ratio is sometimes low; occasionally 60-bed wards can be attended by 2 nurses, assisted by health care auxiliaries and nursing students. Due to the vast distances and transport limitations, patients are often kept for extended periods, even for minor injuries. Neuro- and orthopaedic surgeons are available here, and at the private hospitals. However, the availability of neurosurgeons is inconsistent and occasionally patient-transfers to Johannesburg (by hospital vehicles) are required for stabilizing surgery.

The SCI-rehabilitation centre is an 8 to12-bed unit, with rooms that can be used as single or double rooms depending on the patients; i.e. severity of injury and the current rehabilitation phase. The acute care, prior to spinal surgery and medical stability, remain at the intensive care unit (ICU) and the orthopaedic wards where the basic care is carried out by the regular staff; although, the patients are supervised and assessed by the SCI-specialized staff. Patients were occasionally also admitted to the surgical wards if their associated injuries so require, or to the paediatric ward for children.

Table 1. Schematic overview of the included studies; aims, design, study populations, data collection and analysis.

Study	Aims	Design	Study population	Data collection and analysis
I	Experiences of living with TSCI; attitudes, challenges and obstacles	Qualitative study with an emergent design according to grounded theory	13 persons with TSCI since at least 2 years, ≥16 years of age, English speaking, no secondary diagnose affecting the bodily functions (e.g. stroke or brain injury)	Semi-structured interviews recorded and verbatim transcribed. Analyzed using constant comparison according to a grounded theory approach
II	Incidence of TSCI, characteristics, aetiology, mortality (sample 1)	Quantitative, descriptive study with a cross-sectional design	All persons who sustained a TSCI during a 2-year period n=49	Data were collected from the medical charts after initial assessments. Descriptive statistics
	Circumstances of RTC leading to TSCI (sample 2)	Quantitative, retrospective part of study II	Persons injured in RTC from sample 1 (n=33) and an additional sample with people who sustained a TSCI before 2011 (n=50) n=83	Self-reported data by the participants were collected through informal interviews. Descriptive statistics
III	Outcomes after TSCI; clinical and functional outcomes, complications	Quantitative, prospective follow-up study	All persons in study II, sample 1, who were referred to the SCI-rehabilitation centre n=39	Data were collected from the medical charts after discharge assessments. Descriptive and inferential statistics
IV	Follow-up 2 years after TSCI; follow-up rate, clinical and functional outcomes	Quantitative, prospective follow-up study	All persons from study III who survived to be discharged n=38	Data were collected from the medical charts after yearly control assessments. Descriptive and inferential statistics

Abbreviations: RTC, road traffic crashes; SCI, spinal cord injury; TSCI, traumatic spinal cord injury

3.3 STUDY POPULATION

These studies include people with acute (newly sustained) or chronic (community-dwelling) TSCI. All participants were native to Botswana. The different samples are described below and illustrated in Figure 1.

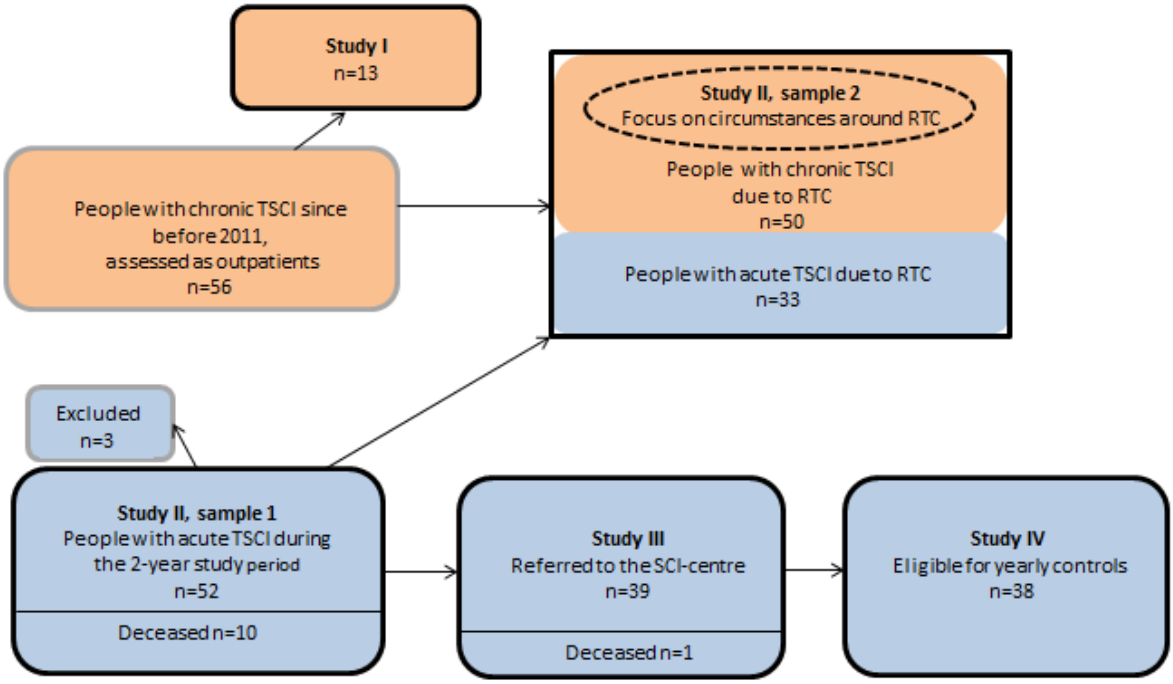


Figure 1. Flowchart over the inclusion process and the included samples. Blue represent acute TSCI, i.e. people admitted to PMH with a newly sustained TSCI during the 2-year inclusion period. Orange represents community-dwelling people with chronic TSCI who were assessed as outpatients at the SCI-rehabilitation center. Participants for study I was sampled from the group with chronic TSCI (orange). Study II consists of sample 1 and 2. Sample 1 in study II and study III and IV follow the same sample from admission to second yearly control. Sample 2 in study II consist of both people with acute and chronic TSCI. Among the people with chronic TSCI, 50/56 had traffic-related injuries. Black-framed squares represent conducted studies.

3.3.1 Study I

To ensure a multitude of experiences, participants were sampled out of the community-dwelling group of people with chronic TSCI and recruitment was conducted at their initial assessment (as outpatients) at the SCI-rehabilitation centre. They were at the time asked to sign a consent form to participate in a "base-line" study which ultimately did not materialize. On the consent form the participants were asked to check a box if they would be willing to be interviewed with regards to living with a TSCI. Positive responses were received from 28 persons of whom 25 met the inclusion criteria and thus constituted the sample from which informants were recruited (Table 2). Inclusion criteria were; ≥16 years of age, TSCI ≥2 years, and proficiency in the English language (the official language in Botswana). Persons with secondary diagnosis which could affect the bodily functions, i.e. brain injury or stroke, were excluded.

Table 2. Demographic and clinical characteristics of the community-dwelling people with chronic TSCI who were assessed as outpatients at the SCI-rehabilitation centre (column 1), agreed to be interviewed and met the inclusion criteria for study I (column 2), and the 13 informants included in study I (column 3).

		People with chronic TSCI assessed as outpatients n=56*	Met inclusion criteria study I n=25	Included study I n=13**
Age	16-30	12	4	2
	31-45	31	15	9
	46-60	13	6	2
Age at injury	<16	1	1	0
	16-30	34	16	9
	31-45	18	8	4
	>45	3	0	0
Gender	Male	35	13	8
	Female	21	12	5
Level of injury	Cervical 1-4	3	1	1
	Cervical 5-8	10	7	5
	Thoracic	41	15	5
	Lumbar***	2	2	2
Marital status	Married	18	9	5
	Single	32	13	7
	Relationship/cohabit	5/1	3	1
Living area	City	20	9	4
	Suburbs	8	3	3
	Village	28	13	6
Education	No school	2	0	0
	Primary school	8	1	1
	Secondary school	27	11	6
	Tertiary education	9	6	2
	University	9	7	4
	Missing data	1	0	0

Abbreviation: TSCI, traumatic spinal cord injury

*All, but one, had AIS-level A-C. Road traffic crash was the cause of injury for 50 out of the 56 persons

**All had AIS-level A or B

***Both were ambulating with bilateral crutches

3.3.2 Study II-IV

Study II-IV follows the same patient sample, namely all persons who were admitted to PMH with an acute TSCI during a 2-year period were included; from February 1st, 2011 to January 31st, 2013. The three studies describe different phases of TSCI-management from admission throughout the acute phase (study II), through hospitalization to discharge (study III), and at the yearly controls (study IV). Demographic and clinical characteristics are shown in Table 3. Fifty-two patients were admitted with acute TSCI during the 2 year inclusion phase. Three women were excluded from further analysis since they did not sign the consent form;

consequently, 49 persons were included in study II. However for incidence estimates the 52 patients were included.

Table 3. Demographic and clinical characteristics at admission, discharge, and yearly controls.

	Study II n=(52*) 49		Study III n=39		Study IV n=38/27**	
Age at injury						
median (IQR)	31	(23-39)	31	(23-40)	31	(23-38)
	n	%	n	%	N	%
*Gender****						
Male	36	(73)	27	(69)	27/18	(71/67)
Female	(16) 13	(27)	12	(31)	11/9	(29/33)
Type of injury						
C1-8 AIS A,B,C	15	(31)	10	(26)	9/7	(24/26)
T1-S5 AIS A,B,C	(20) 18	(37)	17	(44)	15/12	(39/44)
All AIS D	(9) 8	(16)	11	(28)	13/8	(34/30)
Tetraplegia unclear AIS	7	(14)	-	-	-	-
Paraplegia unclear AIS	1	(2)	1	(2)	1/0	(3/0)
Aetiology						
Traffic-related	(35) 33	(68)	24	(62)	23/20	(60/74)
Assault	(9) 8	(16)	8	(20)	8/4	(21/15)
Fall	5	(10)	4	(10)	4/1	(11/4)
Sport or struck by object	3	(6)	3	(8)	3/2	(8/7)
*Marital status*****						
Married /cohabiting	11	(28)	12	(31)	11/9	(29/33)
Single	26	(67)	25	(64)	25/17	(66/63)
Children (< 10 years of age)	2	(5)	2	(5)	2/1	(5/4)
Deceased	10	(20)	1	(2)	0	-

Abbreviations: AIS, American Spinal Injury Association (ASIA) Impairment Scale; C, Cervical; IQR, Interquartile range; S, Sacral; T, Thoracic

*Numbers in () represent incidence sample data (n=52) provided only for gender, aetiology, and type of injury.

**27 out of the 38 included in study IV attended yearly controls. For persons not attending yearly controls, discharge data were used when tabling for the total group of 38.

***Numbers differ from paper II due to an error in the data base; one male was indicated as female in study II. The correct numbers are presented in the table.

****Admission data excludes the deceased patients (n=10).

Due to the high incidence of traffic-related TSCI, a second aim in study II was focusing on the causes and circumstances of RTC leading to TSCI. For that purpose, a combined sample was used to increase statistical power; all patients with an acute TSCI caused by RTC from the above sample together with an additional sample of persons with a chronic TSCI caused by a RTC and who had been assessed as outpatients (out of the sample in Table 2, column 1), see Figure 1. Thus, the sample regarding RTC included 83 persons (acute TSCI=33 and chronic TSCI=50).

3.4 DATA COLLECTION

3.4.1 Study I

Demographic and clinical characteristics were collected from the patient files (Table 2, column 3). An interview guide was constructed based on the areas of interest that was raised during the Swedish team's initial period in Botswana: such as the role of the family, the variety of societal attitudes, and how people managed to handle the environmental challenges (Table 4). This guide was tested on two informants whose interviews were both included in the analysis due to the richness of information. Recruitment was then initiated with two informants being selected due to their broad experiences and willingness to share. After that, theoretical sampling was initiated in order to primarily attain a diversity regarding age, gender, time since injury, level of injury, level of education, and living area. Thereafter, the theoretical sampling was also focusing on emerging issues and expanding the properties and dimensions in order to develop theory. In total, 13 informants were included with the semi-structured interviews conducted in clusters of 2-5 and emerging issues were continuously incorporated in the interview guide.

Table 4. Included themes for the interviews

Introduction	Can you tell me about your life before the injury?
	In what ways has the injury had effect on your life? Consider negative and positive aspects.
Initial themes	How do you manage your daily life?
	Can you describe the role of your family in your daily life?
	Can you describe the challenges and obstacles that you face in your daily life?
	How do you experience attitudes from your family and society?
Ending questions	Do you have advice for those who are newly injured?
	Anything else you would like to add?
Emerging issues	What does acceptance mean for you?
	What is you view on relationships? Partner?
	Do you think it is different for women with disabilities?
	Does attitude differ between men and women?
	What is the male role in the families? Fathers?
	Have you visit a traditional healer or pastor? How was your experience?

The interviews lasted between 45 minutes to 1 hour and 45 minutes and were conducted in the informant's home or workplace, or in the private home of the interviewer. The interviews were recorded and transcribed verbatim and personal memos were written following each interview. Data collection was conducted from May 2013 to March 2014.

3.4.2 Study II-IV

Data gathering was done from the patient files after the completed assessments at admission (study II), discharge (study III), and yearly controls (study IV). The assessments were mainly

conducted by the staff; however, IL complemented collected file data with circumstances around living situations and RTC.

To determine the NLL and injury severity the International Standards of Neurological Classification was used[93]. The International data sets developed by the International Spinal Cord Society (ISCoS)[94] were used as shown in Table 5.

Table 5. ISCoS data sets used in Study II-IV.

	Study II	Study III	Study IV
Core data set	X	X	
Cardiovascular Function (2008-04-12)	X		
Lower Urinary Tract Function		X	X
Bowel Function (1.1)		X	X
Pain data set (1.1)		X	X
Male and Female sexual function (1.0)			X
Quality of life (1.0)			X

The variables included in the Core data set includes date of birth, date of injury, date of acute admission and final inpatient discharge, total days hospitalized, gender, aetiology, vertebral injury, spinal surgery, associated injury, ventilator assistance, place of discharge, and the NLL and severity of lesion at admission and discharge. The item aetiology is ranked in order of priority due to some overlap in these categories; with sport being the first, followed by assault, transport, and thereafter fall. Therefore, if an injury is caused by a fall from a horse while the person is engaged in sport activities, it should be classified as sport and not as fall[95]. Data were complemented with socio-demographics, complications, and mortality for all three studies. Spasticity was assessed using Modified Ashworth Scale 0-5[96]. Additionally, for study II information regarding the circumstances of RTC was self-reported. Study III and IV included also mode of mobility and functional performance using the Functional Independence Measure (FIM)[97]. FIM is rated on a 7-point scale (dependent to independent) and includes 13 motor tasks, grouped as self-care, sphincter control, mobility, and locomotion. The data set for bowel function was complemented with position for bowel care; bed, conventional toilet, toilet chair/commode, raised toilet seat, and other. In study IV data from the second yearly control were primarily used. If that was not available, the first yearly control was used. Finally, telephone follow-ups were done with participants who did not attend any yearly control.

3.5 DATA ANALYSIS

3.5.1 Study I

In grounded theory, data collection and analysis are ongoing simultaneously and the analysis was initiated after the second interview. The transcripts were transferred to the computer programme Open Code[98], used to facilitate the coding process which initially was done in an open, inductive process. Codes were then compared across the informants, axial coding, and clustered into sub-categories. Constant comparison was used throughout; comparing codes, properties, and sub-categories until no new information was added i.e saturation, incorporating emerging issues and ideas and, in the end, finalizing the theoretical model. Constant comparison is a data analysing method and the core in developing a theory that is grounded in the data and not derived from the investigators' pre-perception. Comparing the incident with incidents and then with the emerging properties and categories are done throughout in order to verify that the categories originate from the data, to generate properties, and to saturate the categories. The emerging design is also an important part of grounded theory, used throughout with incorporating themes that emerges from the interviews, selecting informants with relevance to emerging themes, and to allow the theory to emerge from the data. An example is that one informant was interviewed a second time due to that IL knew that the informant had experiences within the evolving theme of healing ceremonies. After conducting coding and analysis of seven of the interviews, preliminary categories were developed and the construction of a preliminary theoretical model was facilitated by exploring properties and dimensions and a constructed matrix. The analysing process constantly alters between an inductive process, originating from the data, and a deductive reasoning, where new data are tested towards the preliminary, emerging theory. After the remaining interviews, additional reviews of the transcripts, selective coding, and by using personal memos, the model was adjusted and the categories were confirmed to be grounded in the existing data. Coding was mainly done by IL but in close collaboration with ML who also read all transcripts. In the overall analysis additionally CN was involved, having read the four most representative transcripts. In the final stage, peer review was done with three people with various backgrounds and not previously engaged in the study who read and commented on the manuscript: one person with native knowledge about Botswana, one physiotherapist from South Africa, and one ethnologist from Sweden specialised in qualitative research.

3.5.2 Study II-IV

Study II includes mainly descriptive statistics of TSCI epidemiology, while study III and IV include both descriptive and inferential statistics with comparisons between groups and longitudinal comparisons. With regard to the small sample, elaborate statistics were not feasible. Descriptive data were presented as absolute numbers and proportions for categorical variables and continuous variables were presented as mean, standard deviation, median and interquartile range (IQR) or range, with the latter being more frequently used. To analyse differences between groups, mainly non-parametric analysis methods were used due to the

small samples, non-normal distributions, and for nominal and ordinal data: Mann Whitney U test for continuing data, Kruskal-Wallis test for continuing data between more than 2 groups, Chi-Square and Fisher's exact test for categorical data, Wilcoxon Signed Rank test to make longitudinal comparisons on the same group at different times, and finally, Spearman to analyse correlations. P-value was set to ≤0.05 throughout the analysis. For the statistical analysis SPSS statistics was used (Statistical Package for the Social Sciences version 21 and 22, IBM, New York, NY, USA).

3.6 ETHICAL CONSIDERATIONS

Ethical approvals were obtained from the Ethical committees at the Ministry of Health in Botswana and at the PMH (PPME: 13/18/1 Vol VIII (92) and PMH 5/79 (27a)) and were renewed yearly. An amendment was filed and approved for study IV in order to be able to contact persons that had not attended yearly controls since the data collection period had expired (HPDME-13/18/1 Vol IX (442) and PMH 5/79 (172)). Consent forms were signed by all participants.

Some ethical considerations, especially due to the participants' vulnerable situations and the lack of alternative choices of care were addressed. Explicit information regarding their right to withdrawal at any time, that participating or not would not in any way affect their present or future care at the SCI-rehabilitation centre, and our commitment to maintain anonymity were given. Additionally, for the patients who deceased prior to giving consent, only demographic and clinical information were used in study II; time and cause of injury, level and severity of injury, gender, and age. The cause of death was rarely available, but survival time was included.

4 FINDINGS

4.1 STUDY I

The main findings of this study were the importance of the informants' personal resources to facilitate experiences of societal inclusion. Having a source of income and family support were crucial facilitators to develop a strong *self*. Inaccessibility and devaluing attitudes were barriers to societal inclusion while spirituality was a facilitator. The findings led to the construction of a theoretical model (Figure 2) which illustrates the impact and interaction of the factors influencing the informants' current life situation.

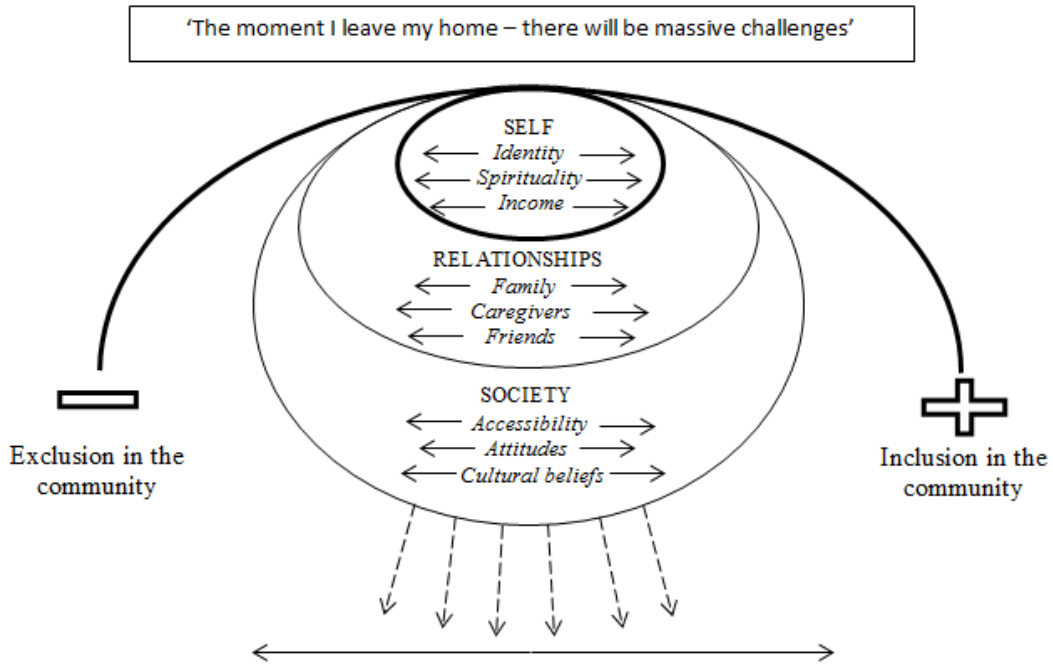


Figure 2. This theoretical model illustrates the relationships between the core category, *Self*, and the categories *Relationships* and *Society*, which can represent factors affecting whether to experience inclusion or exclusion in the community. (Published with permission from Disability and Rehabilitation, published 2016, Vol 38, No 15, 1483-1492. http://www.tandfonline.com)

The core category, *Self*, and two interrelated categories, *Relationships* and *Society*, in conjunction with the sub-categories, were identified to represent the facilitators and barriers described by the informants to have impact on their experiences of inclusion or exclusion in society after the injury. The informants described how central the personal resources, such as a strong *self* and a positive approach, were in order to achieve a satisfactory life situation. However, the development or re-capturing of the *self* was strongly affected by the presence of close family support and/or by having an income. Having a source of income affected all levels of life, such as living conditions and accessibility, but also the self-identity with being able to provide and contribute to the family and society. Having a disability also implies increased risk of poverty, especially when having been the breadwinner of the family. Spirituality and faith were strong facilitators for all, even though some had experienced humiliation when participating in pastoral sessions in hope for a curing miracle. Gratefulness of being chosen by God due to one's own capabilities was described as well as the

importance of keeping updated with scientific advances. Family support was essential for both practical and emotional reasons. Feelings of contentment was expressed from those living with close family members, however, those who had to rely extended family often expressed frustration and described feeling disregarded or rejected. Society's impact was mainly externalized as inaccessibility, even though some improvements over time were described mainly in new malls in the cities. Regarding attitudes towards people with disabilities in society, the dimensions were wide. Experiences of a respectful and positive reception by members of the community as well as devaluing and negative attitudes were described; "Church-going"-people were sometimes seen as being more supportive and having more positive attitudes. Despite the partly present view that a disability can be seen as a curse or a punishment, the general thought was that attitudes were improving. Even though experiences were few among the informants, some described that it is not uncommon to hide family members with disabilities out of shame.

4.2 STUDY II

Sample 1

During the 2-year inclusion period, 52 people sustained acute TSCI and were admitted to PMH. A consent form was signed by 49 people who were hence included in the study. Demographic and clinical characteristics are presented in Table 3.The annual estimated incidence of TSCI in Botswana was 13 per million with the majority being men (73%) and 80% younger or equal to 45 years of age. RTC was the most common cause of TSCI (68%), followed by violence-related injuries (mainly stabbings), and thereafter fall injuries (mainly work-related) (Table 3, Figure 3). Tetraplegia was present in 59% and 61% presented with an initially motor complete injury.

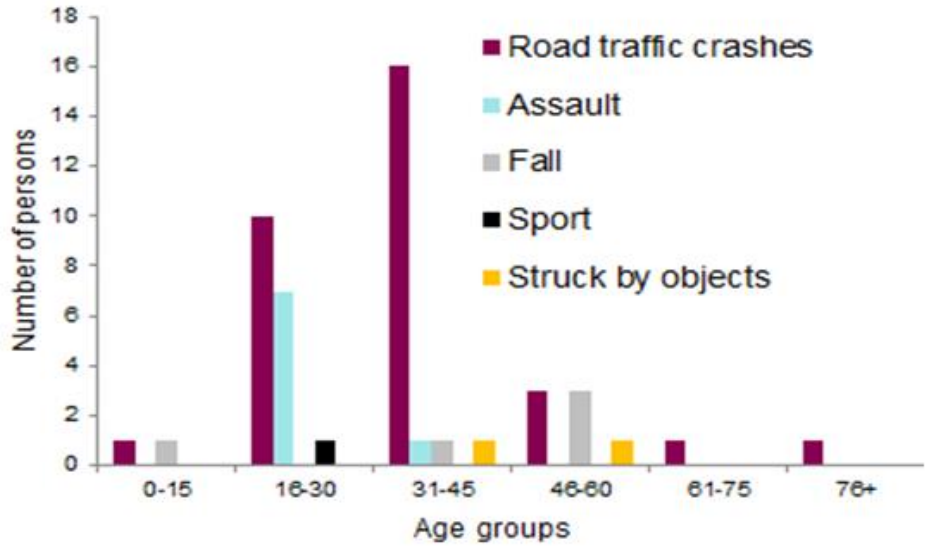


Figure 3. Cause of traumatic spinal cord injuries by age groups. (Published with permission from Spinal Cord)

Even though transport from the site of injury to an emergency unit or local clinic was mainly conducted by private cars, police cars, or by governmental vehicles, ambulance transport was used for the continuing transfers. Forty-one, out of the 49 patients, had additional hospital

presentations before reaching a tertiary-level hospital where spinal stabilization could be conducted; PMH or one of the private hospitals. There were no association between completeness of injury and mode or numbers of transport. Thirty patients underwent spinal surgery with a median time from injury to surgery of 12 days (IQR 5-21). The mortality rate was 20% (n=10) with a mean survival time of 28 days, ranging from 2 to 50 days from the onset of the TSCI. Nine of the deceased persons were male, nine had a tetraplegia, and nine were injured in RTC.

Sample 2, circumstances around RTC

The self-reported causes of RTC (by the combined sample 2 including people with acute and chronic TSCI, n=83) were primarily burst tires, followed by trying to avoid or hitting domestic animals, which resulted in a high rate of single accidents (72%). Collisions with other cars had occurred in 13% and 4% had been pedestrians. Seatbelts were significantly more used among the drivers compared with those who had been passengers; 70% and 35% respectively (p=0.013). Additionally, 10 persons had been transported on open pick-up trucks.

4.3 STUDY III

In total, 39 people were included in this study, i.e. had survived the acute phase after acute TSCI. Demographic and clinical characteristics are presented in Table 3.The median LOS at PMH was 20 weeks, with 13 weeks for patients with tetraplegia and 22 for those with paraplegia (p=0.140). Completeness of injury and the presence of PU significantly extended hospitalization, while age, gender, time to admission, and marital status did not. One ventilator dependent patient with a complete C3 injury deceased prior to the planned discharge. All remaining patients, except for one whom was transferred to South Africa for rehabilitation, were discharge home to live with their close or extended families.

Patients requiring mobility aids were supplied with electrical or custom-made active manual wheelchairs as recommended by the physio- and occupational therapists. For bladder management self-catheterization (34%) or suprapubic catheters (24%) were the main methods that the patients with neurogenic bladder dysfunction were trained with and digital ano-rectal stimulation (61%) to manage neurogenic bowel dysfunctions. The majority performed bowel management using a toilet or commode chair, while three carried it out in bed. The most prevalent complications were pain (69%), PU (41%), and UTI (28%). Additional complications observed were a few cases of surgical wound complications, burn injuries, heterotopic ossifications, deep vein thrombosis and respiratory complications.

Pressure ulcers

Three patients had developed PU at the SCI-rehabilitation centre while 13 patients developed PU during the acute phase prior to admission to, or at other wards, at PMH. The severity of injury significantly affected the rate of PU, while NLL did not; 13 out of the 16 with PU were diagnosed with AIS A.

4.4 STUDY IV

In this study, all patients who had been discharged from the SCI-rehabilitation centre and were eligible for yearly follow-ups were included, in total 38. Of them 19 had tetraplegia and 19 had a complete (AIS A) injury. Demographic and clinical characteristics are presented in Table 3. The compliance with attending yearly controls at the SCI-rehabilitation centre was 71% within the 2-year follow-up period (27 out of 38). Of those coming for yearly controls, 52% attended both the first and second yearly control. Complications during inpatient care (especially pain), having a complete injury, and aetiology of RTC were factors that indicated compliance with follow-up. Distance to SCI-rehabilitation centre, NLL, gender, age, or education did not impact the follow-up rate. Six out of the 11 people that did not attend yearly controls, were reached by phone for follow-up. Reasons for not attending were among them: not being scheduled, lack of transport, or not seeing the purpose of it.

Motor-FIM scores were significantly improved for the whole group and the paraplegic group at the yearly controls compared with assessments at discharge. Bladder and bowel management remained, to a large extent, similar to the situation at discharge, however only one out of the five persons who were discharged with an indwelling catheter remained with it (not attending yearly control=2). Out of the 27 people who attended yearly controls, had eight persons returned to work, four were students, and one had received early retirement. Two of the persons that were not working were housewives, just as before the injury. Of the six people followed-up by phone, four were working or students.

Complication rates, UTI and PU, were increased among those coming for follow-up compared with discharge rates; 41% and 48% respectively. All people who presented with PU were having a complete TSCI (AIS A) and all, but two, had been treated for PU during their inpatient stay. No deaths had occurred after discharge during the 2-year follow-up period; one person with incomplete tetraplegia (AIS D) had been lost to follow-up due to an invalid telephone number and thus had unknown status.

5 DISCUSSION

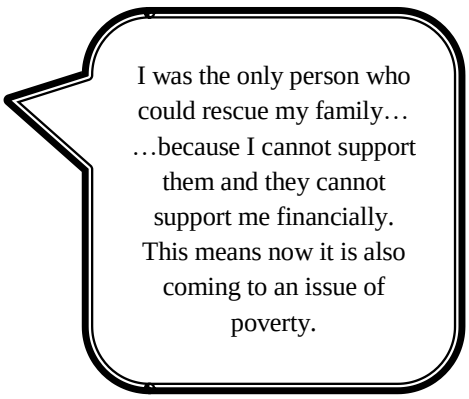
Access to specialized care is crucial for people with TSCI and beneficial for the society[99]. A specialized SCI-rehabilitation centre was recently established in Botswana, through cooperation between Botswana and Sweden, and constitutes the main setting for these studies. This thesis includes one interview study conducted with people with chronic TSCI and three consecutive quantitative studies following one patient sample from admission to PMH after acute TSCI, through discharge and to the second yearly follow-up.

5.1 EXPERIENCES OF LIVING WITH A TSCI

There is a need to address cultural differences from the insider's, i.e. people with TSCI, point of view of how to cope with an injury, meaning, beliefs, and experiences[43]. Study I explored experiences of people living with a TSCI in Botswana in regard to how they manage their daily lives, attitudes towards people with disabilities, obstacles and challenges in society. The core category *self*, and the categories *relationships* and *society* were developed during the analysis and together with the sub-categories they represent the identified factors that had an impact on whether the informants would experience inclusion or exclusion in the community.

The impact on the self with a lost or changed identity that was addressed by the informants has also been described previously[44]. The importance of close family support in order to re-build a strong self and the central role of the family might originate from the values of prioritizing the collective before the individual[86]. Similar findings have been seen when comparing Japan and the United States, where in Japan the family members are expected to make the important decisions, while in the United States, emphasis on independence is strong and patients are encouraged to make decisions and direct caregivers[100]. The strong role of the families, as addressed by the informants, was also observed during clinical work in Botswana, when for example during family meetings, mainly the family members were the active decision makers, while the patients often were quiet in the background.

The financial implications of a disability are well known [11,21,23,48,101]. Especially in resource-constrained settings and where governmental support is limited, the risk of poverty substantially increases for people with disabilities. Lack of financial resources impact many aspects of the informants' lives such as living circumstances, independence, transport and thereby community participation, but also the identity and self-worth by not being able to provide and contribute.



Devaluing attitudes towards persons with disabilities has been described from many settings[21,48,49,53] and were described by the informants, alongside with respectful, positive attitudes. The general experiences were though that societal attitudes, over time, were changing for the better.

Ingstad & Whyte (1995)[86] has pointed out that "by changing social circumstances, we might change "attitudes" more easily and lastingly than by awareness campaigns". In Botswana, awareness campaigns were believed to have positively impacted societal attitudes. The fact that people with disabilities were seen more frequently outside their home environment was also believed to have contributed to sensitise society. Improved environmental accessibility can facilitate independence and thereby reduce stigma, thus the extreme inaccessibility, especially in the rural areas, might on the other hand increase stigma and devaluing attitudes. Furthermore, that unrelated negative characteristics can be attributed, or spread, to the physical disabilities has been described previously and was also described by the informants[86].

[at the village clinic] they have to take my vitals outside, from under the tree, which is not good, it's humiliating and embarrassing

When you are disabled people think you are not normal, that you can't think straight

The importance of religion has also been described from different settings[47,48,50,102] and was also emphasized by the informants, for strength and encouragement or maintaining hope for a healing miracle. The conflicting roles between the traditional healers and the public health care system reported from Pakistan[53], were not described by the informants. Rather it seemed like many used both systems simultaneously; listening to and following the doctors' orders combined with occasional visits to traditional healers, or healing ceremonies in churches. On the other hand, witchcraft can sometimes be seen to cause accidents due to enviousness of success for example[86] which also made some informants stay away from traditional healers.

Miracles do happen, like if the doctors say you'll never walk, then we look at okay, God has created - God can still restore but …you do exercise, take medication while hoping that a miracle will come

Even though experiences were few among the informants, some addressed the issue with people with disabilities being hidden due to shame in the family, which has also been described previously[53]. However, Ingstad & Whyte (1995)[86] partly objected to this, stating that mistreatment, such as abuse and hiding, of people with disabilities does occur but is more of an exception. Instead, the "hiding" could often be from other causes than shame, such as that "unproductive" family members, which also can include grandparents and children, often stay on "the land" or the cattle post. Others can be kept in confinement to protect others and themselves from aggressive behaviour as an example[86].

I don't go to traditional healers myself ... they will tell you 'your aunty bewitched you that's why you are in a wheelchair'

5.2 EPIDEMIOLOGY OF TSCI

Botswana is a middle-income country and the results of these studies partly correspond with low-income countries, while other parts correspond more with high-income countries. The incidence rate of 13 per million was surprisingly low when compared to the global rates (13-53 per million population)[5] and especially compared to Southern African rates of 21-76 per million[60,61]. Due to the low number of patients with acute TSCI that were admitted during the first year of study II, the initially 1-year inclusion period was extended to 2 years; even so the number of new cases remained the low. Some studies have shown large fluctuations of incidence over time, such as a study from Iceland, also a country with a small population, with incidence rates going from 30 to 12.5 to 33.5 per million[59]. The number of new TSCI cases in Botswana has remained low, with approximately 30 new patients being admitted yearly. The incidence rate might though be underestimated and some possible explanations for unrecorded cases are the lack of standardized classification at rural hospitals that can lead to missed TSCI-diagnosis, especially for patients with incomplete SCI (i.e. AIS D); an uncertainty of the new referral system with PMH being the only referral hospital for TSCI; and the fact that neither data regarding pre-hospital mortality or acute mortality at other hospitals were available. There are also mine and private hospitals that previously admitted patients with TSCI and referred them to South Africa for rehabilitation. Lastly, there were only a few patients admitted from the north of the country, however the majority of RTC occur around Gaborone and along the major highway that connects the two biggest cities, which is also the area best equipped for emergency assistance (see map below). The MVA-Fund also confirmed that they had no additional information of people who sustained TSCI in traffic-related events. With all this said, some underestimation of incidence is likely, but we do believe that we captured the vast majority of newly acquired TSCI.

That RTC is the major cause of TSCI in many areas is well known[5], nevertheless have the circumstances of RTC leading to TSCI has not been widely explored. One study[103] though, presented a higher risk for TSCI compared with other serious injuries when travelling in a non-sedan vehicle compared with a sedan. Single crashes and roll over crashes also increased the likelihood of TSCI[103]. Almost 3/4 of the participants in the sample regarding RTC (study II, sample 2) had been involved in single accidents (primarily caused by burst tires or animals on the road); whether the car had rolled over was unknown by many of the participants. One reason for the overwhelming rate of TSCI that were caused by single crashes, might be explained by the high mortality rates in traffic in Botswana[104]; that high impact crashes result in mortality rather than TSCI, or other types of injuries[103]. Burst tires were the self-reported main cause of RTC and might be caused by the hot climate, long distances, a lack of maintenance, and low quality tires. One participant suggested that "people haven't learnt that they have to decrease the air pressure in the tires before long drives" since the expansion of air during heat can cause explosions. This was not confirmed by the MVA-Fund or the Road traffic safety department but is supported by previous research[105]. The amount of domestic animals on the roads is a safety issue in many countries[105] and also in Botswana; even though

many highways are fenced to separate domestic animals from the traffic area. Finally, the use of seatbelts was significantly higher among the drivers compared with the passengers, and 10 passengers were transported on pick-up trucks, a common form of transportation in many countries which imply a substantial risk in the case of accident. Seatbelts are mandatory only in the front seats and are often not available in the backseats. These results indicate that improved traffic safety awareness and re-enforced legislations are required to decrease the number of TSCI cases. The circumstances around RTC need though to be further investigated.

Road map over Botswana. The red dots are marking the accident sites of road traffic crashes (from MVA-Fund yearly report (December 2010))[104]

5.3 MANAGEMENT AND OUTCOMES AFTER TSCI

Parent et al. (2011)[32] have shown that early referral to specialized units can decrease LOS after TSCI and decrease secondary complications, especially PU. Minimizing transports and maintaining proper stabilization during transport are also crucial factors in order to decrease the risks of further deterioration of the injuries. Challenges with transports from the site of accidents and multiple hospital presentations are common in resource-constrained settings[25,78] and were also identified in study II, with the majority being transferred from the site of accident by private or police cars, sometimes in sitting, or donkey-carts. The acute management at the site of accident might be difficult to change in rural areas where lay-people do what they can to assist the patient to the nearest clinic. However, for further transports, the referral system needs to be explicit to make the transfers as swift as possible.

The first year post-TSCI constitutes the highest risk of premature death[11] and in the Southern African region mortality rates are reported to be 25-61%[23,74,76] due to the strained health care resources and limited knowledge that often fail to accommodate for these severely injured people. The 20% in-hospital mortality rates in Botswana might be explained by several reasons: the pre-hospital transport, insufficient access to the ICU, premature discharges from the ICU, and limited TSCI-knowledge might be part of the causes. Additionally, the number of patients with high cervical lesions was high which most likely contribute to the in-hospital mortality rate; nine out of the ten deceased had cervical injuries. The lack of portable ventilators profoundly affected patients with injuries above C4 who ultimately could not be discharged from the ICU. The one patient that died at the rehabilitation was, as far as we know, the first patient in Botswana who had been provided with a portable ventilator (provided from South Africa) and was scheduled to be discharged home after completed caregiver training. Except for the above mentioned ventilator dependent patient who demised during rehabilitation, mortality 2 years post-injury (among those who survived the acute phase) was zero. These low mortality rates might be explained by the mandatory and almost free rehabilitation services available, patient and family education programmes, provision of proper technical aids and consumables, the outpatient wound-care clinic at the SCI-rehabilitation centre, as well as the high follow-up rate.

Follow-up after TSCI has, as discussed, proven to be challenging in many resource-constrained settings[5,26]. It has though, been shown that structured and regular follow-up can positively impact survival after TSCI even in these settings[106]. The high follow-up rate in study IV can likely be contributed to the establishment of a specialized SCI-rehabilitation centre with clear objectives, a dedicated staff being responsible for scheduling, and the available lodging possibilities for the long-distant travellers (up to 900 km). Given that hospital transport was available, even though unreliable, it has certainly contributed to the high compliance rate. Patient education and an increasing trust in the staffs' knowledge might also have contributed to that people thought it worthwhile. While patients with high level lesions and more complete injuries had been prioritized, with sometimes more frequent scheduled follow-ups than yearly; some ambulating patients had not been scheduled. The challenge forward will be to maintain and further improve the follow-up visits, taking into account the annually increasing number of people eligible for structured yearly follow-ups.

Measure of functional outcomes was not conducted at admission, whereby functional gains during rehabilitation could not be evaluated. The motor function items on FIM were though assessed at discharge and at the yearly controls and showed an improvement for the total and the paraplegic group. However, due to the small sample, sub-group analysis might be unreliable. Measure of outcomes also included data regarding technical aids, return-to-work and complications. Despite the challenges reported from resource-constrained settings with providing proper wheelchairs and other technical aids[5,25,90], the absolute majority of patients were, prior to discharge, provided with appropriate technical aids, at no cost for the patient or family; but through the MVA-Fund or through the government. This may be contributed to

the financial power of a middle-income country, even though facilitating structures need to be implemented, and that the importance of technical aids has been emphasized and prioritized.

Bladder and bowel dysfunctions and secondary complications have been described as the main factors to decrease quality of life, and not primarily the loss of mobility[22,44]. These are areas that clinically have shown substantial progress for people with TSCI in Botswana. Due to the scarcity of published material from Botswana, analysis of unpublished data (Löfvenmark et al.) that had been collected for a "base-line" study was therefore conducted. The study was not materialized due to that the sample were not considered representative for the country, e.g. the vast majority were injured in RTC, 77% had paraplegia, and almost half of the participants were working or studying, suggesting that this sample might be showing the "best" outcomes. Nevertheless, this sample can still provide valuable base-line data regarding the situation prior to the introduction of specialized SCI-care. At the time (2012), 56 people living with a chronic TSCI had been assessed as outpatients and constituted the sample for the planned study (Figure 1). Demographic and clinical characteristics are presented in Table 2, column 1. Among the 56 persons with chronic TSCI assessed as outpatients, 25% used indwelling catheters, 21% supra-pubic catheters, and 29% performed self-catheterization (two by assistance). In comparison with the data collected at the yearly controls (study IV) the bladder management was 7%, 22%, and 30% respectively; i.e. a substantial decrease in the use of indwelling catheters. At the SCI-rehabilitation centre the patients have practiced single use of catheters for self-catheterization during hospitalization; while in the home environment catheters were reused due to limited supply, which is not uncommon in low- and middle-income countries[37]. This might be one factor explaining the increased rate of UTI post discharge[37]. After the study period, contributed to an improved availability of catheters, the SCI-rehabilitation centre had changed their recommendations to single use of catheters even in the home environment.

The bowel management methods that were used among the 56 persons with chronic TSCI at the time of their initial visit to the SCI-rehabilitation centre were digital stimulation by 23% and colostomy by 20%, as compared to the sample in study IV, with 48% and 0% respectively at the yearly control assessments (one person had colostomy but did not attend yearly controls). This recent numbers are in line with the reported 35-50% of people with SCI that are conducting digital stimulation[23]. An important difference was also that 39% of the 56 persons with chronic TSCI performed bowel management in bed compared with 15% among the 27 at yearly controls, which is a positive development.

One risk factor for PU is previous PU[107]. Therefore, prevention of PU during the acute hospitalization period is crucial in order to decrease the risk of PU long-term, as well as to decrease LOS[28,33,34]. PU are, as mentioned, common in many settings[5,71,101], both during in-hospital stay and in the home environment, and is one of the leading causes of premature death in low-and middle-income countries[5,11]. In Botswana, PU were mainly developed during the acute phase of hospitalization which lead to prolonged LOS. Even though the prevalence of PU was high, a positive development could clinically be seen when rates were

compared to the situation at the time when the clinical work was initiated in 2010; the absolute majority of the inpatients with TSCI were at the time having PU. This indicates that the changed routines in basic care have improved at the general wards; although more so at the SCI-rehabilitation centre where PU were healing after specialized wound-care management had been implemented. Despite the fact that half of the persons attending yearly controls had developed PU in the home environment, this did not cause any deaths. The high follow-up rate and the medical/wound care outpatient clinic are likely some of the factors that have impacted survival. Still, further improvements in PU prevention are required especially with the impact on life quality and participation that PU have been shown to have[44]. To completely avoid PU in the home environment might not be a realistic goal, nevertheless, during hospitalization there should be zero tolerance.

All findings, positive and negative, and limitations in these studies have been discussed with the staff in order to facilitate further development of the SCI-rehabilitation centre. Filling out protocols has improved with time, as have scheduling for follow-up appointments and contacting those who are not attending. Protocols have been adjusted to fit the specific setting to facilitate that progress get detected and documented, as for example the improvements of performing bowel management on toilet or commode chair instead of in bed. The findings have also been discussed at the hospital administration level and at the Ministry of Health in order to pin point successes and challenges, and to stimulate continuing development of the management of people with TSCI. The findings might further, encourage initiatives and facilitate the development of specialized chains of care and centres for other diagnostic groups.

5.4 METHODOLOGICAL CONSIDERATIONS

These studies were strengthened by the national approach with the PMH/Spinalis SCI-rehabilitation centre having a catchment area covering the whole country. This system, of PMH being the only TSCI-referral hospital, was implemented simultaneously with the establishment of the SCI-rehabilitation centre and might not have been fully incorporated at all sites, which could have led to an underestimation of the incidence rate as discussed earlier. As mentioned, inclusion time was doubled in order to increase the patient sample; although power remained weak. The small samples also limit more advanced statistical analysis and further categorizing into sub-groups would water-down the already low power. Comparisons with the previous situation were complicated by the limitation of studies that were available[90]. Therefore, comparisons mainly refer to information gathered from health care professionals that for a long time worked with TSCI in Botswana and possess deep knowledge in the area, and by analysing unpublished data collected for a base-line study at the first outpatient visit/assessment for people living with chronic TSCI.

Another strength was the limited number of staff members involved in data collection (compiling data for clinical use) which increases consistency. Collecting data was occasionally challenged by the fact that some staff members were not experienced in this kind of documentation. New staff members were also allocated to the SCI-rehabilitation

centre during the study period with occasional delays to introduction regarding protocols and TSCI-rehabilitation. Study I contained a relatively high amount of missing data which mainly depend on the high mortality rate; i.e. complementary and follow-up questions were not possible. Additionally, data collection was initiated approximately one year after the clinical work had been started, even though the centre was still at the orthopaedic wards. In the middle of the study-period, the SCI-rehabilitation centre transferred to the designated site within the hospital. This move complicated the LOS analysis; i.e. to separate the acute care phase from the rehabilitation phase.

Conducting studies in resource-constrained settings can be challenged by the lack of specialized units, structured chains of care, and of standardized protocols being used. In these studies, the ISCoS data sets and the International classification of neurological level of lesion were used. A limitation, however, was the use of FIM for functional outcomes, which has been debated for the SCI-population; not being diagnose specific and too indiscreet to capture progress (especially in people with tetraplegia). The Spinal Cord Independence Measure (SCIM) was constructed for the SCI-population and is recommended for quantitative functional performance evaluation, both for clinical and research purpose[23,108,109]. FIM had, however, been implemented at the unit and changing protocols at the time was not feasible which may have resulted in occasional lack of detected or documented progress. Within some time, SCIM will probably be implemented at the SCI-rehabilitation centre since several staff members are engaged in master studies and therefore have become increasingly involved in the discussion, along with their supervisors.

Finally, my mixed role as a researcher and clinician can be both positive and problematic. Positive aspects include that the majority of participants were more or less familiar with me, which can build comfort and trust. But this familiarity can also be seen as a limitation if the participants in any way should have felt obliged to participate or give answers in order to please me or answer in an expected way. To minimize this risk, clear instructions were given that their future care at the SCI-rehabilitation centre would not be affected regardless of whether they participated or not. At the time of interviews, I had a more administrative position and was only minimally involved in the clinical work. Data collection for the quantitative studies was mainly done by the local staff for clinical use while performing the assessments. However, completion of missing data and data collection regarding RTC and telephone follow-ups were done by me or by co-author Sharon Chakandinakira when I was not at site or when knowledge in the local language was needed.

5.4.1 Trustworthiness

To ensure trustworthiness in the qualitative study, the following considerations were addressed; credibility, transferability, dependability, and confirmability [92,110]. Credibility is to ensure that credible findings are produced (internal validity). The 3 years I spent in Botswana ensured prolonged engagement, which is important to understand and become familiar with the culture and setting. It also enables building trust, detect distortions in the data, and ask appropriate follow-up questions. Peer debriefing was conducted with three previously not engaged persons as well as investigator triangulation was created by the cooperation of three co-authors being involved in the analyses, each with different experience, fields of expertise, and relation to the subjects. Monthly to second monthly debriefing sessions were held in which the co-authors where giving feedback and took part of the analysis. Discussions regarding data were also ongoing in order to involve different perspectives to prevent a one-sided decipherment.

To enable the reader to decide if the results can be applied in other settings, i.e. transferability (external validity), a thorough description of the setting and the environment was given as well as detailed information regarding the materials and methods. Dependability (reliability) and confirmability (objectivity) were addressed by a detailed description of the study process (audit trail), from recruiting informants and collecting data; maintaining openness to emerging issues and changes of focus. Coding was performed in three stages; open, axial, and selective, and constant comparison was used throughout to ensure that the findings were grounded in the data. Finally, a diary was kept for writing reflective notes and memos.

5.6 POSSIBLE IMPLICATIONS

While some of these results are relatively specific to Botswana, other aspects of the studies could most likely be transferred to other settings. For the TSCI-management and rehabilitation in Botswana, these studies can be used to pinpoint some successes and challenges of the TSCI-management in order to make continuing improvements.

- Cultural backgrounds, with respect to the informants' perspective on personal resources, the role of the family, and spirituality, can be taken into consideration by maintaining an open attitude, especially when assisting patients from other cultures.
- Vocational rehabilitation is an important part of rehabilitation and need to be stressed, especially in resource-constrained settings where return-to-work can be even more challenging and governmental benefits are fewer.
- The high rates of RTC leading to TSCI indicates that improvements in road safety may reduce the incidence of TSCI; improvements and maintenance of road and tire quality, re-enforce the use of seatbelts and decrease the common use of pick-up trucks for transport as some examples.
- To reduce secondary complications, improved education and awareness among the staff responsible for the basic care of people with TSCI is required; prioritizing prevention of PU and UTI with interventions such as regular turnings, maintaining hygiene, dietician consultations, and proper bladder management.
- To allow the patients to maintain their achieved skills after discharge, home modifications are paramount; especially toilets need to be built and/or adapted or commode chairs provided to improve continence and thereby quality of life.
- Long-term follow-up of people with TSCI by trained specialized staff is challenging but might be possible with clearly stated objectives, dedicated staff, transport, and educated patients. Creative solutions for specific setting need to be developed; hospital visits, telephone contacts, home visits, mobile teams, outreach programmes, or telemedicine as some examples.
- Rehabilitation cultures and concepts might be transferred to different settings; with appropriate adjustments, responsiveness and perseverance.

5.8 FUTURE RESEARCH

There are still many unanswered questions on TSCI to address in Botswana and in many other countries in Southern Africa. Preventive measures need to be addressed, implemented and evaluated. Continuing epidemiological research is important to focus the attention of policy-makers; a renewed incidence study in Botswana might give a truer estimate when the chain of care system has been fully adopted. Furthermore, this study did not have sufficient data to ensure what caused the high mortality in the acute phase, which is crucial information in order to be able to take appropriate measures; with for example circumstances around the delays to surgery and the availability of ICU-beds. Additionally, functional gains during the rehabilitation phase would need further attention as well as increased knowledge of the long-term outcome could provide valuable information for the continuing development of the TSCI-management and rehabilitation; such as a 5-year follow-up study.

Middle-income countries are in a research context often combined with low-income countries even though there can be substantial differences; a more detailed separation might provide a clearer picture of the situation. Additionally, the distribution of resources and the health care systems can profoundly impact people with disabilities, in both the acute phase and long-term, as well as the social security system. Several of the staff members at Spinalis SCI-rehabilitation centre in Botswana have initiated their master degree studies and are pursuing their research, which is a positive development.

6 CONCLUSION

To conclude the findings of this thesis on TSCI in Botswana, the importance of strong personal resources and a positive approach were essential to facilitate inclusion into society after the injury. Having family support and/or a source of income were crucial facilitators to develop a strong self and for societal inclusion. The experienced societal attitudes towards people with disabilities ranged from being met in a good and respectful manner by most people to mainly experiencing devaluing attitudes and rejection. Spirituality and faith were described as strong facilitators towards societal inclusion, while inaccessibility was a barrier. The environmental inaccessibility was also described to increase stigmatization as a result of that independence becomes severely restricted. Additionally, having a disability seriously increased the risk of poverty. The informants were requesting legislation that advocates for the rights of people with disabilities to be respected; regarding improvements in accessibility, education and job opportunities.

The epidemiology in Botswana included a low annual incidence of TSCI of 13 per million. RTC, mainly single accidents caused by burst tires or animals on the road, was the main aetiology (68%), followed by assault and falls. The acute mortality was high, 20%, and waiting time for stabilizing surgery was long. Pain, PU, and UTI were common secondary complications, both during inpatient care and at the second yearly follow-up. Despite the high rates of PU and UTI, no one died after discharge during the 2-years follow-up period. Self-catheterization and digital stimulation were the main methods for management of neurogenic bladder dysfunction, and bowel dysfunction. Finally, the follow-up rate at the yearly controls was over 70%; with factors such as having a complete injury or complications during hospitalization (mainly pain) increasing compliance; however, distance to the clinic did not impact on compliance with follow-up.

These four studies on TSCI in Botswana, a middle-income country, provide results that correspond with settings of wide variation with regard to financial power, health care systems, welfare and infrastructure. Aspects of the outcomes have to some extent become more like the situation in high-income countries with developed and well-resourced TSCI-specialized units; provision of technical aids, techniques used to manage neurogenic bladder and bowel dysfunctions, return-to-work rate, and 2-years survival. On the other hand, aetiology, pre-hospital transports and parts of the acute care remain similar to many low-income countries; such as the delays to surgery, high rates of secondary complications and the high in-hospital mortality rate.

Even though there is a lack of published studies conducted in Botswana, these results suggest that substantial improvements in TSCI-management have occurred during and after the rehabilitation phase, which was the primary focus for knowledge transfer and support during the SCI-rehabilitation centre project. Meanwhile, areas that show poorer outcomes, such as acute management and the basic care prior to medical and spinal stability would need renewed attention. Structural changes have also been developed and implemented, such as a centralized defined chain of care for TSCI-management, rehabilitation concept and specific

rehabilitation objectives. That the centre is under the public health system, which is highly subsidised, is an important factor for the availability of care, especially considering that the cost of health care has been shown to be one of the major reasons for people with disabilities not to approach health care facilities[111]. Taking all of this into consideration this study supports that specialized SCI-centers are needed and beneficial[5,99], both for the individual and for society. Especially in resource-constrained settings, where 80% of people with disability lives[7,112], the need for proper health care, rehabilitation, technical aids, and specialized units are highly required.

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8 REFERENCES

1. Guttmann L. New hope for spinal cord sufferers. *Paraplegia* **17,** 6–15 (1979).

2. Dick TB. Traumatic paraplegia Pre-Guttmann. *Paraplegia* **7,** 173–178 (1969).

3. Weerts E, Wyndaele JJ. Accessibility to spinal cord injury care worldwide: the need for poverty reduction. *Spinal Cord* **49,** 767 (2011).

4. Rathore FA. Spinal Cord Injuries in the Developing World. *Int. Encycl. Rehabil.* (2013). Available from http://cirrie.buffalo.edu/encyclopedia/en/article/141/. Accessed 20 August 2016.

5. World Health Organization & International Spinal Cord Society. *International perspectives on Spinal Cord Injury*. Geneva, Switzerland (2013).

6. Divanoglou A, Westgren N, Seiger A, Hulting C, Levi R. Late mortality during the first year after acute traumatic spinal cord injury: a prospective, population-based study. *J. Spinal Cord Med.* **33,** 117–127 (2010).

7. Gupta N, Castillo-Laborde C, Landry MD. Health-related rehabilitation services: assessing the global supply of and need for human resources. *BMC Health Serv. Res.* **11,** 276 (2011).

8. Reinhardt JD, Mansmann U, Fellinghaur BG, Strobl R, Grill E, von Elm E et al. Functioning and disability in people living with spinal cord injury in high- and low-resourced countries: a comparative analysis of 14 countries. *Int. J. Public Health* **56,** 341–352 (2011).

9. Thrush A, Hyder A. The neglected burden of caregiving in low- and middle-income countries. *Disabil. Health J.* **7,** 262–272 (2014).

10. Rathore FA, Mansoor SN, Qureshi SB. Re: Burns & O'Connell. The challenge of spinal cord injury care in the developing world. *J. Spinal Cord Med.* **35,** 195–196 (2012).

11. Oderud T. Surviving spinal cord injury in low income countries. *African J. Disabil.* **3,** Art #80. (2014). Available from http://dx.doi.org/10.4102/ajod.v3i2.80. Accessed 20 August 2016

12. Jazayeri SB, Beygi S, Shokraneh F, Hagen EM, Rahimi-Movaghar V. Incidence of traumatic spinal cord injury worldwide: a systematic review. *Eur. spine J* **24,** 905–918 (2015).

13. Hagen EM. Still a need for data from developing countries on traumatic spinal cord injury. *Neuroepidemiology* **41,** 86–87 (2013).

14. Hofman K, Primack A, Keusch G, Hrynkow S. Addressing the growing burden of trauma and injury in low- and middle-income countries. *Am. J. Public Health* **95,** 13–17 (2005).

15. Waring WP, Biering-Sorensen F, Burns S, Donovan W, Graves D, Jha A *et al.* 2009 Review and Revisions of the International Standards for the Neurological Classification of Spinal Cord Injury. *J. Spinal Cord Med.* **33,** 346–352 (2010).

16. Maynard FM, Bracken MB, Creasey G, Ditunno JF, Donovan WH, Ducker TB *et al.* International Standards for Neurological and Functional Classification of Spinal Cord Injury. *Spinal Cord* **35,** 266–274 (1997).

17. Donovan W, Carter E, Bedbrook G, Young J, Griffiths E. Incidence of medical complications in spinal cord injury: patients in specialised, compared with non-specialised centres. *Paraplegia* **22,** 282–290 (1984).

18. Krause JS, Saunders LL. Health, secondary conditions, and life expectancy after spinal cord injury. *Arch. Phys. Med. Rehabil.* **92,** 1770–1775 (2011).

19. Chen D, Apple DF, Hudson LM, Bode R. Medical complications during acute rehabiltition following spinal cord injury - current experience of the Model Systems. *Arch Phys Med Rehabil* **80,** 1397–1401 (1999).

20. Joseph C, Nilsson Wikmar L. Prevalence of secondary medical complications and risk factors for pressure ulcers after traumatic spinal cord injury during acute care in South Africa. *Spinal Cord* **54,** 535-539 (2016).

21. Manns P, Chad K. Components of Quality of Life for Persons with Quadriplegic and Paraplegic Spinal Cord Injury. *Qual Heal. Res* **11**, 795-811 (2001).

22. Hammell KW. Spinal cord injury rehabilitation research: patient priorities, current deficiencies and potential directions. *Disabil. Rehabil.* **32,** 1209–1218 (2010).

23. Chhabra HS. *ISCoS textbook on comprehensive management of spinal cord injuries*. Lippincott Williams and Wilkins (2015). pp 428, 446, 888, 925, 985-992, 1068.

24. Wahman K, Nash MS, Lewis JE, Seiger A, Levi R. Increased cardiovascular disease risk in Swedish persons with paraplegia: The Stockholm spinal cord injury study. *J. Rehabil. Med.* **42,** 489–492 (2010).

25. Burns AS, O'Connell C. The challenge of spinal cord injury care in the developing world. *J. Spinal Cord Med.* **35,** 3–8 (2012).

26. Nwadinigwe C, Iloabuchi T, Nwabuda I. Traumatic spinal cord injuries (SCI): a study of 104 cases. *Niger J Med* **13,** 161–165 (2004).

27. Scheel-Sailer A, Wyss A, Boldt C, Post MW, Lay V. Prevalence, location, grade of pressure ulcers and association with specific patient characteristics in adult spinal cord injury patients during the hospital stay: a prospective cohort study. *Spinal Cord* **51,** 828–833 (2013).

28. Hoque MF, Grangeon C, Reed K. Spinal cord lesions in Bangladesh: an epidemiological study 1994 - 1995. *Spinal Cord* **37,** 858–861 (1999).

29. Scovil CY, Ranabhat MK, Craighead IB, Wee J. Follow-up study of spinal cord injured patients after discharge from inpatient rehabilitation in Nepal in 2007. *Spinal Cord* **50,** 232–237 (2012).

30. Lidal IB, Snekkevik H, Aamodt G, Hjeltnes N, Kvalvik Stanghelle J, Biering-Sorensen F. Mortality after spinal cord injury in Norway. *J. Rehabil. Med.* **39,** 145–151 (2007).

31. Ikechukwu EC, Ayodiipo IO, Emeka AD, Kayode AJ, Michael NI, Deborah OT. Prevalence and factors associated with healing outcomes of hospital-acquired pressure ulcers among patients with spinal cord injury. *J. Public Heal. Epidemiol.* **4,** 44–47 (2012).

32. Parent S, Barchi S, LeBreton M, Casha S, Fehlings MG. The impact of specialized centers of care for spinal cord injury on length of stay, complications, and mortality: a systematic review of the literature. *J. Neurotrauma* **28,** 1363–1370 (2011).

33. Zakrasek EC, Creasey G, Crew JD. Pressure ulcers in people with spinal cord injury in developing nations. *Spinal Cord* **53,** 7–13 (2015).

34. Idowu OK, Yinusa W, Gbadegesin SA, Adebule GT. Risk factors for pressure ulceration in a resource constrained spinal injury service. *Spinal Cord* **49,** 643–647 (2011).

35. Consortium for Spinal Cord Medicine. Early acute management in adults with spinal cord injury : a clinical practice guideline for health-care professionals. *J. Spinal Cord Med.* **31,** 403–479 (2008).

36. Benedetto PDI. Clean intermittent self-catheterization in neuro-urology. *Eur J Phys Rehabil Med* **47,** 651–659 (2011).

37. Krassioukov A, Cragg JJ, West C, Voss C, Krassioukov-Enns D. The good, the bad and the ugly of catheterization practices among elite athletes with spinal cord injury: a global perspective. *Spinal Cord* **53,** 78-82 (2015).

38. Ackery A, Tator C, Krassioukov A. A global perspective on spinal cord injury epidemiology. *J. Neurotrauma* **21,** 1355–1370 (2004).

39. Igun GO, Obekpa OP, Ugwu BT, Nwadiaro HC. Spinal injuries in the plateau state, Nigeria. *East Afr. Med. J.* **76,** 75–79 (1999).

40. Finnerup NB, Norrbrink C, Trok K, Piehl F, Johannesen IL, Sorensen JC *et al.* Phenotypes and predictors of pain following traumatic spinal cord injury: a prospective study. *J. Pain* **15,** 40–48 (2014).

41. van Gorp S, Kessels AG, Joosten EA, van Kleef M, Patijn J. Pain prevalence and its determinants after spinal cord injury: A systematic review. *Eur. J. Pain* **19,** 5–14 (2015).

42. Divanoglou A, Westgren N, Bjelak S, Levi R. Medical conditions and outcomes at 1 year after acute traumatic spinal cord injury in a Greek and a Swedish region: a prospective, population-based study. *Spinal Cord* **48,** 470–476 (2010).

43. Saravanan B, Manigandan C, Macaden A, Tharion G, Bhattacharji S. Re-examining the psychology of spinal cord injury: a meaning centered approach from a cultural perspective. *Spinal Cord* **39,** 323–326 (2001).

44. Dickson A, Allan D, O'carroll R. Biographical disruption and the experience of loss following a spinal cord injury: an interpretative phenomenological analysis. *Psychol. Health* **23,** 407–425 (2008).

45. Hammell KW. Quality of life after spinal cord injury: a meta-synthesis of qualitative findings. *Spinal Cord* **45,** 124–139 (2007).

46. Suarez NC, Levi R, Bullington J. Regaining health and wellbeing after traumatic spinal cord injury. *J. Rehabil. Med.* **45,** 1023–1027 (2013).

47. Monden KR, Trost Z, Catalano D, Garner AN, Symcox J, Driver S *et al.* Resilience following spinal cord injury: a phenomenological view. *Spinal Cord* **52,** 197–201 (2014).

48. Babamohamadi H, Negarandeh R, Dehghan-Nayeri N. Barriers to and facilitators of coping with spinal cord injury for Iranian patients: a qualitative study. *Nurs. Health Sci.* **13,** 207–215 (2011).

49. Joseph C, Wahman K, Phillips J, Nilsson Wikmar L. Client Perspectives on Reclaiming Participation After a Traumatic Spinal Cord Injury in South Africa. *Phys. Ther.* Epub 2016 Apr 14. Doi:10.2522/ptj.20150258.

50. McColl MA, Bickenbach J, Johnston J, Nishihama S, Shumaker M, Smith K *et al.* Spiritual issues associated with traumatic-onset disability. *Disabil. Rehabil.* **22,** 555–564 (2000).

51. Augutis M, Anderson CJ. Coping strategies recalled by young adults who sustained a spinal cord injury during adolescence. *Spinal Cord* **50,** 213–219 (2012).

52. Dionne CD, Gainforth HL, O'Malley DA, Latimer-Cheung AE. Examining implicit attitudes towards exercisers with a physical disability. *ScientificWorldJournal.* (2013). doi:10.1155/2013/621596

53. Rathore FA, New PW, Iftikhar A. A report on disability and rehabilitation medicine in Pakistan: past, present, and future directions. *Arch. Phys. Med. Rehabil.* **92,** 161–166 (2011).

54. Draulans N, Kiekens C, Roels E, Peers K. Etiology of spinal cord injuries in Sub-Saharan Africa. *Spinal Cord* **49,** 1148–1154 (2011).

55. Crabb J, Stewart RC, Kokota D, Masson N, Chabunya S, Krishnadas R. Attitudes towards mental illness in Malawi: a cross-sectional survey. *BMC Public Health* **12,** 541 (2012).

56. Hampton NZ, Qin-Hilliard DB. Dimensions of quality of life for Chinese adults with spinal cord injury: A qualitative study. *Disabil. Rehabil.* **26,** 203–212 (2004).

57. Hammell KW. Experience of rehabilitation following spinal cord injury: a meta-synthesis of qualitative findings. *Spinal Cord* **45,** 260–274 (2007).

58. Devivo MJ. Epidemiology of traumatic spinal cord injury: trends and future implications. *Spinal Cord* **50,** 365–372 (2012).

59. Knútsdóttir S, Thorisdottir H, Sigvaldason K, Jonsson Jr H, Björnsson A, Ingvarsson P. Epidemiology of traumatic spinal cord injuries in Iceland from 1975 to 2009. *Spinal Cord* **50,** 123–126 (2012).

60. Lee BB, Cripps RA, Fitzharris M, Wing PC. The global map for traumatic spinal cord injury epidemiology: update 2011, global incidence rate. *Spinal Cord* **52,** 110–116 (2013).

61. Joseph C, Delcarme A, Vlok I, Wahman K, Phillips J, Nilsson Wikmar L. Incidence and aetiology of traumatic spinal cord injury in Cape Town, South Africa: a prospective, population-based study. *Spinal Cord* **53,** 692–696 (2015).

62. Ibrahim A, Lee KY, Kanoo LL, Tan CH, Hamid MA, Hamedon NM et al. Epidemiology of Spinal Cord Injury in Hospital Kuala Lumpur. *Spine* **38,** 419–424 (2013).

63. Cripps RA, Lee BB, Wing P, Weerts E, Mackay J, Brown D. A global map for traumatic spinal cord injury epidemiology: towards a living data repository for injury prevention. *Spinal Cord* **49,** 493–501 (2011).

64. van den Berg MEL, Castellote JM, Mahillo-Fernandez I, de Pedro-Cuesta J. Incidence of spinal cord injury worldwide: a systematic review. *Neuroepidemiology* **34,** 184–192 (2010).

65. Ning G-Z, Yu T-Q, Feng S-Q, Zhou X-H, Ban D-X, Liu Y *et al.* Epidemiology of traumatic spinal cord injury in Tianjin, China. *Spinal Cord* **49,** 386–390 (2011).

66. Mathur N, Jain S, Kumar N, Srivastava A, Purohit N, Patni A. Spinal Cord Injury: Scenario in an Indian State. *Spinal Cord* **53,** 349-352 (2015).

67. Chiu W-T, Lin H-C, Lam C, Chu S-F, Chiang Y-H, Tsai S-H. Review paper: epidemiology of traumatic spinal cord injury: comparisons between developed and developing countries. *Asia. Pac. J. Public Health* **22,** 9–18 (2010).

68. Hart C, Williams E. Epidemiology of spinal cord injuries: a reflection of changes in South African society. *Paraplegia* **32,** 709–714 (1994).

69. Velmahos G, Degiannis E, Hart K, Souter I, Saadia R. Changing profile in sci and risk factors influencing recovery after penetrating injuries. *J. Trauma* **38,** 334–337 (1995).

70. Seye SIL, Sow CM, Bassene N, Gueye M, Pouye I. Traumatismes recents du rachis a propos de 496 cas, 30 necropsies. *Med Trop.* **53,** 471–477 (1993).

71. Rahimi-Movaghar V, Sayyah MK, Akbari H, Khorramirouz R, Rasouli MR, Moradi-Lakeh M *et al.* Epidemiology of traumatic spinal cord injury in developing countries: A systematic review. *Neuroepidemiology* **41,** 65–85 (2013).

72. Chamberlain JD, Meier S, Mader L, Von Groote PM, Brinkhof MWG. Mortality and longevity after a spinal cord injury: Systematic review and meta-analysis. *Neuroepidemiology* **44,** 182–198 (2015).

73. Obalum DC, Giwa SO, Adekoya-Cole TO, Enweluzo GO. Profile of spinal injuries in Lagos, Nigeria. *Spinal Cord* **47,** 134–137 (2009).

74. Gosselin RA, Coppotelli C. A follow-up study of patients with spinal cord injury in Sierra Leone. *Int. Orthop.* **29,** 330–332 (2005).

75. Hossain MS, Rahman MA, Herbert RD, Quadir MM, Bowden JL, Harvey LA. Two-year survival following discharge from hospital after spinal cord injury in Bangladesh. *Spinal Cord* **54,** 132–136 (2016).

76. Levy LF, Makarawo S, Madzivire D, Bhebhe E, Verbeek N, Parry O. Problems, struggles and some success with spinal cord injury in Zimbabwe. *Spinal Cord* **36,** 213–218 (1998).

77. Middleton JW, Dayton A, Walsh J, Rutkowsi SB, Leong G, Duong S. Life expectancy after spinal cord injury: a 50-year study. *Spinal Cord* **50,** 803–811 (2012).

78. Ahidjo KA, Olayinka SA, Ayokunle O, Mustapha AF, Sulaiman GAA, Gbolahan AT. Prehospital transport of patients with spinal cord injury in Nigeria. *J. Spinal Cord Med.* **34,** 308–311 (2011).

79. Rathore FA, Hanif S, Farooq F, Ahmad N, Mansoor SN. Original Article Traumatic Spinal Cord Injuries at a Tertiary Care Rehabilitation Institute In Pakistan. *J Pak Med Assoc* **58,** 53–57 (2008).

80. Fromovich-Amit Y, Biering-Sorensen F, Baskov V, Juocevicius A, Hansen HV, Gelernter I *et al.* Properties and outcomes of spinal rehabilitation units in four countries. *Spinal Cord* **47,** 597–603 (2009).

81. Kortte KB, Stevenson JE, Hosey MM, Castillo R, Wegener ST. Hope predicts positive functional role outcomes in acute rehabilitation populations. *Rehabil. Psychol.* **57,** 248–255 (2012).

82. DeVivo MJ. Sir Ludwig Guttmann Lecture Trends in spinal cord injury rehabilitation outcomes from model systems in the United States : 1973 – 2006. *Spinal Cord* **45,** 713–721 (2007).

83. Eastwood EA, Hagglund KJ, Ragnarsson KT, Gordon WA, Marino RJ. Medical Rehabilitation Length of Stay and Outcomes for Persons With Traumatic Spinal Cord Injury 1990-1997. *Arch Phys Med Rehabil* **80,** 1457–1463 (1999).

84. Holtz A, Levi R. *Ryggmärgsskador - behandling och rehabilitering*. Studentlitteratur (2006). p 275.

85. The World Bank. Available from http://data.worldbank.org/country/botswana. Accessed 20 August 2016.

86. Ingstad B, Reynolds Whyte S. *Disability and Culture*. The Regents of the Univercity of California (1995). pp 139-143.

87. Embassy. Botswana Embassy. doi:2014-11-27. Available from http://www.botswanaembassy.or.jp/tourist.php?La=E&Show=2#beliefs. Accessed 20 August 2016.

88. Sida. Swedish International Developmental Cooperation Agency. Available from http://www.sida.se/Svenska/Har-arbetar-vi/utfasade-samarbetslander/Botswana/Vart-arbete-i-Botswana/. Accessed 20 August 2016.

89. Seitio-Kgokgwe O, Gauld RD, Hill PC, Barnett P. Assessing performance of Botswana's public hospital system: the use of the World Health Organization Health System Performance Assessment Framework. *Int. J. Heal. Policy Manag.* **3,** 179–189 (2014).

90. Gureja Y, Opiyo W, Campbell E. Experiences with traumatic quadripleiga and paraplegia at Princess Marina Hospital Gaborone. *J Med. Dent. Assoc Botswana* **23,** 19–20 (1993).

91. Strauss A, Corbin J. *Basics of qualitative research. Techniques and procedures for developing grounded theory. 2nd ed.* London, Sage Publications (1998).

92. Dahlgren L, Emmeling M, Winkvist A. *Qualitative Methodology for International Public Health*. *2nd ed.* (2007).

93. Kirshblum SC, Burns SP, Biering-Sorensen F, Donovan W, Graves D, Jha A *et al.* Reference for the 2011 revision of the International Standards for Neurological Classification of Spinal Cord Injury. *J. Spinal Cord Med.* **34,** 547–554 (2011).

94. The International Spinal Cord Society. Available from http://www.iscos.org.uk/international-sci-data-sets. Accessed 20 August 2016.

95. DeVivo M, Bierieng-Sorensen F, Charlifue S, Noonan V, Post M, Stripling T *et al.* International Spinal Cord Injury Core Data Set. *Spinal Cord* **44,** 535–540 (2006).

96. Bohannon RW, Smith MB. Interrater reliability of a Modified Ashworth Scale of muscle spasticity. *Phys Ther* **67,** 206–207 (1987).

97. Functional Independence Measure. Available from http://www.rehabmeasures.org/Lists/RehabMeasures/DispForm.aspx?ID=889. Accessed 20 August 2016.

98. Umeå University. Open Code 4.0. Available from www.phmed.umu.se/enheter/epidemiologi/forskning/open-code/. Accessed 20 August 2016

99. Illis LS. The case for specialist units. *Spinal Cord* **42,** 443–446 (2004).

100. Munce SEP, Perrier L, Tricco AC, Straus SE, Fehlings MG, Kastner M *et al.* Meaning of self-management from the perspective of individuals with traumatic spinal cord injury, their caregivers, and acute care and rehabilitation managers: an opportunity for improved care delivery. *BMC Neurol.* **16,** 11 (2016).

101. Hossain MS, Rahman MA, Bowden JL, Quadir MM, Herbert RD, Harvey LA. Psychological and socioeconomic status , complications and quality of life in people with spinal cord injuries after discharge from hospital in Bangladesh : a cohort study. *Spinal Cord* **54,** 483–487 (2016).

102. Chun S, Lee Y. 'I am just thankful': the experience of gratitude following traumatic spinal cord injury. *Disabil. Rehabil.* **35,** 11–19 (2013).

103. O'Connor PJ, Brown D. Relative risk of spinal cord injury in road crashes involving seriously injured occupants of light passenger vehicles. *Accid Anal Prev.* **38,** 1081-1086 (2006).

104. Motor Vehicle Accident Fund. Road crash and claims annual report. MVA Fund House: Gaborone, Botswana. (2010).

105. Jungu-Omara I, Vanderschuren M. Ways of reducing accidents on South African roads. *25th SATC, Pretoria, South Africa* 454–464 (2006).

106. Barman A, Shanmugasundaram D, Bhide R, Viswanathan A, Magimairaj HP, Nagarajan G *et al.* Survival in persons with traumatic spinal cord injury receiving structured follow-up in South India. *Arch. Phys. Med. Rehabil.* **95,** 642–648 (2014).

107. Chen Y, DeVivo MJ, Jackson AB. Pressure ulcer prevalence in people with spinal cord injury: age-period-duration effects. *Arch. Phys. Med. Rehabil.* **86,** 1208–1213 (2005).

108. Catz A, Itzkovich M. Spinal Cord Independence Measure: Comprehensive ability rating scale for the spinal cord lesion patient. *J. Rehabil. Res. Dev.* **44,** 65–68 (2007).

109. Itzkovich M, Gelernter I, Biering-Sorensen F, Weeks C, Laramee MT, Craven BC *et al.* The Spinal Cord Independence Measure (SCIM) version III: reliability and validity in a multi-center international study. *Disabil. Rehabil.* **29,** 1926–1933 (2007).

110. Lincoln YS, Guba EG. *Naturalistic Inquiry*. Sage Publications, (1985).

111. Shah N, Shrestha B, Subba K. Spinal cord injury rehabilitation in Nepal. *Jnma, J. Nepal Med. Assoc.* **52,** 427–431 (2013).

112. World Health Organization. Available from http://www.who.int/nmh/a5817/en/. Accessed 20 August 2016.

10. ERRATA IN PUBLISHED PAPERS

Paper II, an error in the data base regarding gender was detected; one male was indicated as female. When this was corrected no significant gender differences were found (gender difference regarding delayed spinal surgery P=0.09)