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# TRAUMATIC SPINAL CORD INJURY IN SOUTH AFRICA AND SWEDEN: EPIDEMIOLOGIC FEATURES AND FUNCTIONING

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### TRAUMATIC SPINAL CORD INJURY IN SOUTH AFRICA AND SWEDEN: EPIDEMIOLOGIC FEATURES AND FUNCTIONING

THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

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To my parents

#### ABSTRACT

**Background:** Trauma to the human spinal cord typically strikes out of the blue, leaving those surviving the initial ordeal with permanent or temporary deficits in health and functioning. Because of this, traumatic spinal cord injuries (TSCI) impose a significant burden on society. While these facts are well known for certain countries, the International Perspectives on Spinal Cord Injury Report highlights the need for the remaining countries to establish a foundation upon which injuries could be prevented and functioning problems addressed. In South Africa, the foundation for primary prevention and knowledge of the unmet needs of persons with TSCI are not yet established.

**Aim:** To develop an evidence-based foundation for TSCI in South Africa that addresses prevention both in terms of injury occurrence and problems with functioning.

**Methods:** This thesis utilised a mixed-method approach to answer epidemiologic and functioning questions. A prospective, population-based design was used in Study I and II to determine the incidence, aetiology and injury profiles of newly-injured adults with TSCI in Cape Town, South Africa and Stockholm, Sweden. In the Functioning section of the thesis (Study III), a comparative content validity design was used to define the nature of functioning categories in a generic outcome measure currently used in the South African SCI rehabilitation field, and a standardised measure not yet adopted in the local context, against the International Classification of Functioning, Disability and Health and the brief ICF core sets for SCI in the post-acute context. In Study IV, qualitative description was used to explore the experiences of reclaiming *participation* in 17 chronic survivors of TSCI by emphasising their met and unmet needs as well as the conditions influencing them.

**Findings**: One-hundred and forty-seven and 49 incident cases, resulting in an annual crude incidence rate of 75.6 and 19.0 per million population, were registered for the region of South Africa (study I) and Sweden (study II), respectively. The leading cause of injury in South Africa was assault, accounting for approximately 60% of all incident cases, compared with the leading cause in Sweden, where falls was responsible for 58% of all cases. The two cohorts differed significantly with respect to demographic and aetiologic characteristics. Concerning functioning, Study III found that the generic rehabilitation outcome measure was not fully conceptualised within the ICF and did not cover all the essential functioning aspects as contained in the brief core set. In contrast, the standardised outcome measure was fully conceptualised within the ICF and covered, in its entirety, the activity and participation categories contained in the brief core set. In Study IV, clients' perspectives confirmed *'participation'* as a desirable and possible goal by effectively dealing with the new self, negotiating obstacles, identifying facilitators of participation, and becoming an agent. These critical aspects – also categories – were essential for reconstructing meaning and prioritising important life situations.

**Conclusions:** The incidence of TSCI in South Africa is among the highest in the world and is mainly caused by assault, while the incidence in Sweden appeared consistent to what is proposed for Western Europe. Furthermore, there is a need to raise awareness and facilitate the use of standardised outcome measures in TSCI rehabilitation, since the current operational measure in the South African SCI rehabilitation field presented some shortcomings. It is remarkable to conclude that while participation is indeed a reality after injury, the dimensionality of challenges remains an issue for further discourse. The insights gained from these studies provide an evidence-based foundation for impacting primary prevention action plans and the alignment of rehabilitation practices towards addressing the unmet needs of survivors.

#### ABSTRAK

**Agtergrond en doelstelling:** Besering aan die menslike spinale koord slaan gewoonlik toe sonder enige waarskuwing en laat die oorlewendes van die traumatiese gebeurtenis met permanente of tydelike nadelige gevolge in hul gesondheid en funksionering. Die gevolge van hierdie beserings sorg vir 'n beduidende las op die samelewing. Waar hierdie feite welbekend aan sekere lande is, aksentueer " the International Perspectives on Spinal Cord Injury Report" die noodsaaklikheid dat die oorblywende lande 'n grondslag daarstel, waarvolgens beserings voorkom kan word en probleme met funksionering aangespreek kan word. Die grondslag vir primêre voorkoming en kennis van die onvervulde behoeftes van persone met spinale koordbeserings, is nog nie in Suid-Afrika gevestig nie. Die doel is om 'n grondslag, gebaseer op bewyse vir persone met spinale koordbeserings, te ontwikkel betreffende die voorkoming van sowel die voorkoms van beserings as probleme met funksionering.

**Metodes:** Hierdie tesis maak gebruik van 'n gemengde-metodebenadering, ten einde epidemiologiese en funksionele vrae te beantwoord. 'n Vooruitwerkende, populasie- gebaseerde ontwerp was in Studies I en II gebruik om die invloedsfeer, etiologie (oorsaaksleer) en beseringsprofiele van nuut- beseerde volwassenes met traumatiese spinale koordbeserings in Kaapstad, Suid- Afrika en Stockholm, Swede vas te stel. In die funksionele afdeling van die tesis (Studie III) word 'n vergelykende inhoudsgevalideerde ontwerp gebruik om die aard van funksionerende kategorieë van 'n generiese uitkomsmaatstaf, wat tans in rehabilitasie in Suid-Afrika gebruik word en 'n gestandaardiseerde maatstaf, wat nie in rehabilitasie gebruik word nie, te definieër en teenoor die "International Classification of Functioning, Disability and Health en die "brief ICF core sets" vir spinale koordbeserings in die na-akute konteks te plaas. In Studie IV was gebruik gemaak van kwalitatiewe beskrywing deur te fokus op die ervaringe van 17 oorlewendes van traumatiese spinale koordbeserings om deelname te herwin deur hul vervulde en onvervulde behoeftes en die beïnvloedende kondisies, te eksploreer.

**Bevindinge**: Een honderd sewe- en veertig en 49 gevalle was geregistreer, wat herlei word na 'n jaarlikse algemene voorkomstempo van 75,6 en19,0 vir 'n gebied in Suid-Afrika (Studie I) en 'n gebied in Swede (Studie II) respektiewelik. Die hoofoorsaak van beserings in Suid-Afrika was aanranding, wat vir 60% van die gevalle gegeld het, vergeleke met Swede waar die hoofoorsaak valle was, wat verantwoordelik vir 58% van die gevalle was. Die twee kohorte het merkbaar verskil wat hul demografiese en etiologiese karakter betref. Wat funksionering betref, het Studie III bevind dat die generiese rehabilitasie uitkomsmaatstaf nie ten volle binne die "ICF" gekonseptualiseer was nie en dat dit nie al die belangrike funksionele aspekte soos vervat in die "brief core sets" gedek nie. Daarteenoor was die gestandaardiseerde uitkomsmaatstaf ten volle binne die "ICF" gekonseptualiseer en in volledigheid al die aktiwiteit- en deelname kategorieë vervat in die "brief core sets" gedek. In Studie IV het die kliënteperspektiewe bevestig dat deelname wenslik en moontlik was deur effektief met die nuwe self te handel, struikelblokke te hanteer, fasiliteerders vir deelname te identifiseer en 'n agent te word. Hierdie kritieke aspekteok kategorieë- was belangrik om betekenis te rekonstrueer en belangrike lewenssituasies te prioritiseer.

**Gevolgtrekkings:** Die omvangsfeer van traumatiese spinale koordbeserings in Suid- Afrika is van die hoogste in die wêreld en die hoofoorsaak is aanranding, waarteenoor dit voorkom of die omvangsfeer in Swede stabiel laag gebly het. Daar bestaan daarom die behoefte aan bewusmaking en die fasilitering van die gebruik van gestandaardiseerde uitkomsmaatstawwe in rehabilitasie, omdat die huidige operasionele maatstaf in die Suid- Afrikaanse opset sommige tekortkominge toon. Dit is merkwaardig om te kan afsluit met die opmerking dat deelname na die besering moontlik is, hoewel die verskillende dimensies van die uitdagings wat nog voorlê, verdere ondersoeke regverdig. Die insigte wat uit hierdie studie opgedoen was, het 'n grondslag, wat op bewyse berus, gelê, wat 'n impak op primêre voorsorgmaatreëls sal hê en die regskikking van rehabilitasiepraktyke om die onvervulde behoeftes van oorlewendes aan te spreek.

## LIST OF SCIENTIFIC PAPERS

- I. **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 population-based study. *Spinal Cord* 2015;53:692-696.
- II. Joseph C, Andersson N, Bjelak S, Giesecke K, Hultling C, Nilsson Wikmar L, Phillips J, Seiger Å, Stenimahitis V, Trok K, Åkesson E, Wahman K. Incidence, aetiology and injury characteristics of traumatic spinal cord injury in Stockholm, Sweden: a prospective, population-based update. *Submitted*
- III. Joseph C, Phillips J, Wahman K, Nilsson Wikmar L. Mapping two measures to the International Classification of Functioning, Disability and Health and the brief ICF core set for spinal cord injury in the post-acute context. *Disability and Rehabilitation* 2016. [Epub ahead of print] <u>http://dx.doi.org/10.3109/09638288.2015.1107762</u>
- IV. Joseph C, Wahman K, Phillips J, Nilsson Wikmar L. Client perspectives on reclaiming participation after a traumatic spinal cord injury in South Africa. *Physical Therapy* 2016; [Epub ahead of print] doi.10.2522/ptj.20150258

Additional analyses were performed when combining *Study I* and *II* results in the thesis frame.

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## LIST OF ABBREVIATIONS

AIS	American Spinal Injury Association Impairment Scale	
ASCI	Acute spinal cord injury	
ASIA	American Spinal Injury Association	
CI	Confidence interval	
ICF	International Classification of Functioning, Disability and Health	
ISCoS	International Spinal Cord Society	
PABAK	Prevalence-Adjusted Bias-Adjusted Kappa	
ROL	Rehabilitation Outcome Levels measure	
SCI	Spinal cord injury	
SCIM III	Spinal Cord Independence Measure version III	
SD	Standard deviation	
TSCI	Traumatic spinal cord injury	
WHO	World Health Organisation	

### **Operational definitions**

Developing country:	South Africa was termed a developing country due to the status of health indicators (and not economic), such as life expectancy at birth and the HIV/AIDS and Tuberculosis epidemics.
Epidemiology:	Is the study of the distribution and determinants of disease/injury in a specific population.
Functioning:	Is a multi-dimensional concept that includes all body functions, activities and participation, according to the International Classification of Functioning, Disability and Health (ICF).
ICF:	The International Classification of Functioning, Disability and Health is a conceptual model for evaluating activity limitations and participation restrictions in persons with impairments.
ICF core sets:	These are summaries of functioning categories according to a particular health condition or health care context.
Public Health Approach:	This model addresses primary prevention by investigating influencing factors, developing targeted interventions and facilitating the adoption of successful campaigns.
Spinal cord injury:	Damage to the spinal cord, including cauda equina and conus medullaris, leading to motor and/or sensory deficits, and/or autonomic dysfunction lasting more than three days post-injury.
South Africa:	Is considered a middle-income country with large discrepancies in health and wealth. The collection of data in this thesis was from one region, the City of Cape Town metropolitan area.
Sweden:	Is considered a high-income country. The collection of data in this thesis was from one region, the Greater Stockholm area.
Traumatic spinal cord injury:	A spinal cord injury caused by external trauma, typically both high and low velocity mechanisms like sport or transport related, or falls.

#### Foreword

One day in 2009 I sat opposite a young man who was about my age at the time, who had recently sustained a traumatic spinal cord injury (TSCI). He was ready to start his rehabilitation and had entrusted me with the task of accompanying him on his journey of finding and building a life worth living. As his physiotherapist I was responsible for ensuring this young man's entry back into society. Before I began working on the 'plan of action' I could not help the feeling of powerlessness I experienced by briefly imagining myself in his situation. I suppose this feeling was fueled by my understanding that his progress towards full and effective participation in society would be slow.

From the very beginning I had been fixated on the visibility of persons with disabilities, especially those with SCI and their role in their communities. This was most likely the outward expression of the role that our profession plays in facilitating this goal. As I grew in the profession I looked to the ability of the healthcare system to deliver essential services and support. I was struck with the high number of persons experiencing complications, the missed rehabilitation appointments, the lack of appropriate assistive devices, and people who were 'getting lost' in the system without knowing their survival status. These observations made me ask if this was the optimal system for the rehabilitation of people with SCI in South Africa?"

In 2012 I moved to Stockholm, Sweden where I was inspired by the high quality of care available to people living with SCI. I wanted to know the 'active ingredients' responsible for good health and wellbeing, and was then that I first learned about life-long follow-up and rehabilitation. This was so far removed from my experiences in the South African health care system where rehabilitation is known to be neglected. This was evident in the lack of quality assurance practices as well as an iterative approach to rehabilitation, including life-long follow-up, that highlighted the unmet needs of living with injury. By weighing up what I knew of the two healthcare systems, the Swedish story started to look more like the gold standard.

Admittedly, I had trouble separating my life-long ambition of strengthening the South African health systems for people with SCI from what is possible to achieve in four years of doctoral research. By keeping the goal in mind, I constrained myself to start at the very beginning and answer the following: 'how many people are affected by this health condition?', 'how is it caused?', 'what is the resultant effect on functioning?', and 'how do we measure the functioning aspects typically altered?' Now that we have some answers to these questions, I continue to refine the conclusions in this book to concrete statements that could be used to impact prevention from policy to strengthening systems of care, especially rehabilitation.

I would like to end by acknowledging that while situations do not change overnight – as is evident in the history of establishing systems of care in Sweden – I am hopeful. Hopeful that, as we found participation to be *possible*, despite the shortcomings in the current state of care provision in South Africa, so to can we be hopeful of changing systems of care in the future.

#### **1. INTRODUCTION**

Trauma to the human spinal cord causes an unprecedented change in the lives of those surviving the initial ordeal. These changes include an altered perception of oneself that may give rise to living in a 'changed world'[1, 2], the experience of limitations during activity, restrictions whilst attempting to be involved in situations of life [3-6], and a profound impact on the quality of, and satisfaction with, life [7]. In most cases, traumatic spinal cord injury (TSCI) results in an immediate decrement in health that is evident by a reciprocal heightened level of disability. In order to combat threats to life and one's functioning, it is necessary to deliver a comprehensive package of healthcare in a time-sensitive manner [8].

Apart from the devastating personal consequences of a TSCI, a massive economic burden is also imposed on society, with lifetime costs ranging from \$1.5 million for incomplete paraplegia to \$3 million for complete tetraplegia [9]. Spinal cord injury (SCI) has therefore become a global and public health concern with many national and international organisations working together to prevent it [10, 11]. The International Spinal Cord Society (ISCoS) recently launched a global mapping project that provides an adaptable structure for an active and ongoing data repository that aims to inform stakeholders about the development and coordination of prevention strategies [11]. In line with these efforts, the World Health Organisation (WHO), in partnership with the ISCoS, published the International Perspectives on Spinal Cord Injury Report, highlighting the preventable and survivable nature of injuries, the considerable personal and social impact, barriers to services and environments restricting participation and undermining quality of life, and suggesting that injury need not prevent good health and social inclusion [12]. To date, little is known about the epidemiology of TSCI and the functioning of survivors in South Africa, which hinders the development and testing of preventive strategies and the allocation of resources in responding to the needs of persons living with TSCI [13]. On the other hand, in countries like Sweden, with its record of investigating the burden [14, 15], functioning [1, 16] and living conditions based on societal services available to individuals [17], updating, for example, epidemiologic information is important for ensuring that current preventive strategies continue to apply to today's situation.

Moving the lens from primary prevention to the consequences and needs of the client requires a coordinated approach that is framed within a particular conceptual model that is capable of addressing the spectrum of problems associated with injury. The International Classification of Functioning, Disability and Health (ICF) is a model that provides the conceptual basis for evaluating the impact of injury and disease in terms of impairments, activity limitations and participation restrictions [18]. The use of outcome measures based on the measureable domains of the ICF is important for designing interventions that address dysfunction and evaluate outcomes. However, the utility of disease-specific outcome measures in South African rehabilitation has not gained much momentum [19, 20], which is unfortunate because these measures reflect relevant functioning aspects that are related to the health condition [21]. In the absence of using disease-specific measures, little is known about the operational variables targeted by generic outcome measures and the unmet needs of individuals with SCI after episodes of care.

While there are psychometrically sound outcome measures aimed at evaluating *activity* in the SCI population [22-24], including measures that assess a single component of activity, such as walking [25], the availability of measures for the evaluation of *participation* is sparse, mainly due to the personal and nuanced experiences that people attach to the concept of participation [18]. Furthermore, *participation* is thought to be highly contextual, with its breadth and depth influenced by the context in which individuals live. Although generic measures of participation have been used in the SCI population, it is not clear whether they reflect the relevant and typical functioning aspects of this group [26]. In the absence of a gold standard of measurement, the use of qualitative methods could play a valuable role in helping to understand whether participation is a possibility and a desired outcome that individuals seek, as well as how it is perceived, characterised and influenced [27].

The field of SCI care has changed significantly over the past few decades, especially with the recognition of specialised care necessary for augmenting health and functioning after injury. In order to align healthcare structures and processes for injury prevention and the optimisation of patient outcomes, it is important to base recommendations on evidence. The body of work presented here combined two approaches, epidemiologic and functioning from a patient perspective, to initiate the establishment of an evidence-based foundation for injury prevention and improved alignment of services that address the needs of survivors of TSCI.

#### **1.1 SPINAL CORD INJURY**

Spinal cord injuries are broadly classified into two classes depending on the aetiology of injury. They can be *traumatic*, when an external force is responsible for injuring nerves within the spinal column, or *non-traumatic* where injuries are typically caused by infections of the spinal nerve cells, cysts or tumours pressing on the spinal cord, interruption of the blood supply or congenital medical conditions [28, 29]. This thesis deals primarily with TSCI.

More generally, any SCI is typically characterised by a sudden loss of voluntary muscle strength, sensation and autonomic functions below the level of injury, which will vary depending on the neurological level of injury and extent of impairment [30]. The injury can be sub-classified as *tetraplegia* or *paraplegia*, depending on the level of the lesion. Typically, *tetraplegia* results in some degree of loss of function in all four limbs, including the trunk, due to a lesion in the cervical segments of the spinal cord. *Paraplegia* resembles some degree of loss of function preserved in the upper extremity. This is due to lesions at the level of the thoracic, lumbar or sacral segments of the spinal cord, and includes syndromes caused by damage to the most distal part of the spinal cord.

An important property of the classification of a SCI is the completeness of lesion, which is typically determined by the presence or absence of sacral sparing. The completeness criterion is also used as a crude measure of impairment. In an attempt to address the heterogeneity of possible SCI impairment patterns a standardised classification system has been proposed by the American Spinal Injury Association (ASIA) to conceptualise sublesional impairment after injury [31, 32].

ASIA Impairment Scale (AIS) category	Description
AIS A- Complete	No preserved sensory or motor function in the sacral segments.
AIS B- Incomplete	Sensory but not motor function is preserved, at least partially, below the neurological level, including the sacral segments.
AIS C- Incomplete	Motor function is partially preserved below the neurological level, with more than half the key muscles having a power grade less than 3.
AIS D- Incomplete	Motor function is partially preserved below the neurological level, with more than half the key muscles having a power grade equal or greater than 3.
AIS E- Normal	Normal sensory and motor functions.

Table 1. American Spinal Cord Association Impairment Scale

#### **1.2 CONCEPTUAL MODELS**

This thesis makes use of two conceptual models. In the first two studies, the epidemiologic approach to the Public Health Model of Prevention is used, while the functioning model, International Classification of Functioning, Disability and Health (ICF), serves as conceptual basis for study III & IV. Figure 1 illustrates the holistic overview of the conceptual basis of this thesis.

#### 1.2.1 Epidemiologic Approach to Public Health Prevention

Injury epidemiology is defined as the study of "the distribution and determinants of injuries and safety-related states or events in specified populations, with the primary purpose of preventing injuries and promoting safety" [33]. Injury prevention promotion makes use of a model where three interacting factors contribute to the injury; the host, the agent, and the environment [34]. The host considers the predisposing factors within the individual, whereas the agent describes the different mechanisms of injury, and the environment accounts for the context, which is the physical, biological and socio-economic environment within which the host and agent interact. This framework however, is not without criticism as a result of the fact that the triggering factors were only related to the event that caused the injury and not the pre- and post-event factors that may have contributed to the initial or recurrent injury.

In this thesis, we applied a descriptive epidemiologic approach to study the rate and aetiology of TSCI in a region in both South Africa and Sweden. The descriptive paradigm attempts to provide insight into the 'what', 'who', 'where', 'when', and 'why or how'. Within this paradigm, the 'what' refers to the health issue of concern. Here, special attention is given to case definition, which may ultimately influence the point estimate of incidence when comparing across studies. The 'who' is concerned with the person who sustained a TSCI, providing valuable information about those 'at risk'. The 'where' and 'when' provide insight into the geographical location under surveillance, as well as the time period of observation, which is required for calculating the rate at which TSCIs occur. Finally, the 'why or how' attempts to explain the causes, risk and protective factors, as well as modes of transmission (mechanisms). Given the broad overview that is provided by the descriptive epidemiologic approach, its importance is evident in the public health approach to disease and injury prevention. TSCI has been acknowledged as a public and global health concern and it is therefore important to position research in this population within the larger framework of ultimate prevention.

Seen in Figure1, the Public Health Model of Prevention is a step-wise framework targeting ultimate prevention, in which problem identification is the first step, followed by the identification of risk and protective factors, development and testing of preventive strategies, and assuring widespread adoption [35]. For the purpose of study aims I & II, 'problem identification' was addressed using a descriptive injury epidemiology approach.

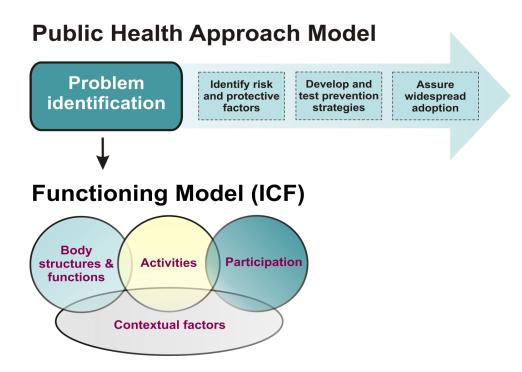


Figure 1. Conceptual approach of this thesis

#### 1.2.2 International Classification of Functioning, Disability and Health

The International Classification of Functioning, Disability and Health (ICF) was used as a framework to conceptualise certain aspects of health and residual functioning post injury

(Figure 1). The ICF is viewed from a bio-psychosocial standpoint that recognises the impact of disease or injury within both personal and environmental boundaries. Contained in this framework, functioning and disability are measured within the domains of impairments, that is, 'problems in body function or structure such as a significant deviation or loss', and activity limitations and participation restrictions that refer to 'difficulties an individual may have in executing activities' and 'problems an individual may experience in involvement in life situations', respectively [18]. Importantly, the ICF consists of a component that contextualises the personal and environmental (physical, social and attitudinal) influence on the experience of functioning and disability.

This ICF model was developed, firstly, to recognise health and disability as a continuum and not as separate classifications, in that when an individual experience a decrement in health, he or she might experience a heightened level of disability, and vice versa. Secondly, it provides a common language between stakeholders when discussing health and functioning and in the evaluation of disability. The ICF is currently considered the most exhaustive framework for evaluating human functioning and extensive research has been done to identify disease-specific aspects that are relevant for evaluation and monitoring. Specific to SCI, ICF core sets have been developed to assess the relevant and most typical functioning aspects that are altered after injury in different settings and contexts [36, 37].

In this thesis, we content-validated two outcome measures (study III) used in SCIrehabilitation that were developed prior to the implementation of the ICF in clinical practice. This was done to evaluate whether those measures could be adopted, conceptually, in clinical practice for the accurate assessment of relevant functioning aspects. In study IV, participation following a TSCI was explored in accordance with the use of the term in the ICF.

#### **1.3 EPIDEMIOLOGY**

Simply put, this branch of medicine is concerned with what befalls a population. It further attempts to investigate the distribution and determinants of health-related states or events in specified populations, with the eventual application of descriptive epidemiology to control health problems [38]. In this section, the literature concerning the incidence, prevalence, mortality and aetiology of injury is reviewed, with special reference to the current state of global knowledge.

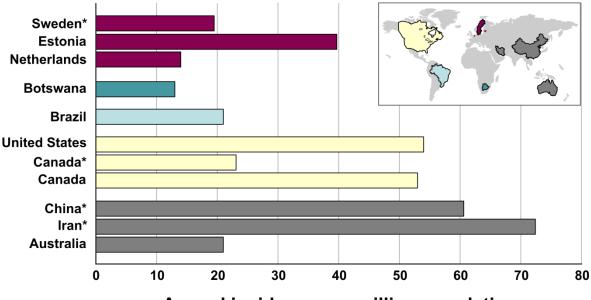
#### 1.3.1 Incidence

The incidence (or incidence rate) of TSCI is the number of new cases that occur in a specified demography in a given period of time, and differs tremendously among countries, not only with respect to frequency and pattern differences, but also with respect to other factors, including differences in case definition and methodologies used. Since almost all newly-injured persons with SCI require hospital care, population-based estimates appear to be feasible in terms of tracking 'almost all' with injuries but also, as reflected in the literature, seems to be the gold standard study design [14, 39-41].

Two recent worldwide reviews reported incidence rates ranging between 3.6 to195.4 and 2.1 to 130.7 per million population [40, 42]. Of importance, most of the literature pooled for the review studies originated from Europe, North America (United States and Canada) and Australia, leaving limited information on the burden of SCI in developing continents, such as Africa, South America and Asia.

In South Africa the epidemiology of TSCI is poorly understood. Apart from two retrospective hospital-based studies [43, 44] in the northern part of the country that attempted to determine aetiology alone, no other studies investigating other epidemiologic aspects such as incidence rate, prevalence, mortality and morbidity, have been conducted. The aforementioned study by Hart and Williams [44] found assault to be the leading cause of injury with gun-shots responsible for 36% of cases and stabbings 20%. Since the studies were retrospective, conducted more than 20 years ago, and hospital based, there is a need to perform prospective, population-based studies in order to assess the burden of TSCI in other areas of South Africa. These studies are necessary to inform the appropriate allocation of resources for this group [43, 44].

Contrary to the scarcity of knowledge in South Africa, epidemiologic data on TSCI are available for Sweden, and specifically Stockholm. A study by Divanoglou and Levi [14] that collected data during 2006/2007 found the incidence to be 19.5 per million population, which is below the worldwide average [45]. From a public health standpoint, updating epidemiologic data in order to detect changes in occurrence, patterns and distributions between genders and across age categories are necessary in order to continuously adapt and reform preventive strategies and align resources for specific sub-groups. Figure 2 presents a global overview of incidence estimates.



Annual incidence per million population

**Figure 2.** An unexhausted worldwide overview of annual incidence estimates of TSCI per million population. \*Indicates estimates based on sub-national survey data. Country references: Sweden (Divanoglou and Levi 2009); Estonia (Sabre et al. 2012); Netherlands (Nijendijk et al 2014); United States (Jain et al. 2015); Canada (Couris et al. 2009); Canada\* (Noonan et al.2012); Brazil (Botelho et al.2014); China (Li et al. 2011); Iran (Rahimi-Movaghar et al. 2010); Australia (New et al. 2015); Botswana (Löfvenmark et al. 2015) [14, 39, 41, 46-53].

#### 1.3.2 Prevalence

The prevalence, or total number of cases with a particular characteristic living in a specific area at a given time, of TSCI is reported to be on the rise, mainly due to the increase in life expectancy over the last few decades and an associated improvement in healthcare. From a healthcare service delivery perspective, having knowledge of the prevalence of such unforeseen injuries is essential for appropriately allocating resources and assessing the burden on society, since survivors could, equivocally, live almost as long as their able-bodied counterparts. However, only a few countries have invested in determining the prevalence of TSCI locally [11, 54].

The prevalence of TSCI is believed to range from 239 to 1009 per million population [11]. This difference in prevalence is not only due to the frequency of disease occurrence but is also strongly influenced by the methodologies used to determine the estimates. For example, in India the prevalence was estimated at 236 per million population but the source population was based on one rural district with a population size of approximately 64 000 [55]. Consequently, this leaves a knowledge gap concerning the other parts of the country, including urban areas where people use transport more often, which is one of the most common causes of TSCI.

The prevalence of TSCI in Africa is largely unknown. Despite the national door-to-door censuses that are conducted in South Africa every ten years, little is known about the prevalence of all communicable and non-communicable diseases. The lack of knowledge is partly due to the limitations of census items that do not attempt to specify health conditions but instead classify individuals as 'disabled' or 'non-disabled' [56]. However, the Quadriplegic Association of South Africa estimated that more than 50 000 people in South Africa lives with a SCI, which corresponds to a prevalence of approximately 1000 per million population [57]. The number of people living with a TSCI in Sweden is quite different with the prevalence being estimated at 240 per million population [15], which is among the lowest in the world [58]. However, it is important to note that the proposed figure was based on the greater Stockholm area alone, with no published national level data available.

#### 1.3.3 Aetiology

Due to the many potential mechanisms of sustaining a TSCI the historical reporting of aetiologic data was not standardised, creating challenges when comparing results across studies. In order to aid comparison, the ISCoS through its executive committee for the development of core data sets, developed and published the International Spinal Cord Injury Data Set as the minimum information necessary for meaningful comparison across studies [59, 60]. Specifically related to injury aetiology, the data set categorises causes as follows: (1) Sport, (2) Assault, (3) Transport, (4) Fall, (5) Other traumatic cause, (6) Non-traumatic SCI cause and (99) Unknown/Unspecified.

The main causes of TSCI are motor vehicle accidents (transport-related events), falls and violence (assault) [11, 42]. However, mechanisms of injury could be temporal. For example,

falls replaced motor vehicle crashes as the leading mechanism of injury in the United States [46]. The aetiology of TSCI in Africa has been summarised by Draulans and colleagues [61] who found that the leading cause of injury differs across countries. For example, motor vehicle accidents due to burst tires are the most common cause in Botswana and Nigeria [53, 62], while in Nigeria, TSCI due to collapsed tunnels in illegal mining operations was found to be the second most common cause [62].

In South Africa, according to a hospital-based study conducted more than two decades ago in the northern part of the country, the leading cause of TSCI was found to be violence, accounting for more than 50% of all SCIs [44]. At that time, the socio-political climate was thought to be responsible for the high prevalence of violence-related injuries. Given the fact that South Africa was not at war during the time of the study, and that the results were based on data collected from one hospital more than 20 years ago, more rigorous epidemiologic studies are warranted. In Sweden, the leading cause of injury is due to falls, accounting for almost 50% of all TSCI's [14]. It is important to determine if different patterns in patient characteristics and fall behaviour are noted in future studies.

#### 1.3.4 Mortality

Advances in medical practice have brought about an increase in life expectancy for people with TSCI. Notwithstanding the efforts made to equalise life expectancy, the standardised mortality rates of those with SCI are still up to three times higher than in the able-bodied population [63], and the majority who do not survive the initial event typically die within the first year after injury. An emerging body of knowledge is available, which continues to grow, concerning the description and understanding of influencing factors that have been linked to death after SCI [63-65].

Study results have consistently shown that increasing severity of the injury is predictive of higher mortality [66-68]. Furthermore, demographic factors like age [66, 67, 69] and gender [66, 70] are also been linked to a higher mortality, with older people and females being at a higher risk. Much of the literature on life expectancy and survival after SCI originates from high-income Western countries, which leaves a gap in the knowledge describing resource-constrained contexts where critical acute care factors, for example, the lack of specialised care, delay in spinal surgery, and absence of rehabilitation, are either slow in their implementation or completely lacking.

In the international perspectives report published by the WHO [12], little is known about whether TSCI's are survivable in South Africa and what the life expectancy of survivors is. There is therefore a need to determine this aspect of the burden of SCI in South Africa. In Sweden, evidence exists to support the benefits of a comprehensive systems approach. A prospective, population-based study found a 0% mortality within the first year after TSCI in the Greater Stockholm area [71]. However, further research is required to establish the disability-adjusted life years reflecting the SCI population in Sweden as a true measure of burden.

#### **1.4 CONSEQUENCES AFTER TSCI**

Conceptualising consequences in the aftermath of a TSCI needs to consider conditions associated with the injury. In other words, those that are directly linked to the TSCI pathology, as well as the secondary medical complications that arise due to unmanaged associated conditions. The most common direct sequelae are motor and/or sensory, and/or autonomic dysfunction. Consequently, residual sensory and/or motor impairments typically lead to bladder and bowel dysfunction. One of the most common secondary complications related to bladder dysfunction is urinary tract infections [72], which have been linked to a prolonged acute length of hospital stay [73] and rehospitalisation [74], which is associated with higher healthcare costs.

Another common associated condition is cardiovascular dysfunction, due to the autonomic dysregulation after TSCI causing orthostatic hypotension, low resting blood pressure, and reflex bradycardia [75]. Furthermore, depending on the neurological level of injury, pulmonary dysfunction is inevitable, especially for complete cases at C1-C3 [76]. Finally, sexual dysfunction is commonly reported, especially among men, with impaired sensation and infertility as the leading problems [77].

Despite significant advances made in the provision of specialised and comprehensive care provision to those afflicted with an SCI, secondary complications remain common. Pulmonary complications typically arise due to pulmonary infections and respiratory dysfunction, which is a common feature of individuals with tetraplegia and to a lesser extent those with injuries above T8 [78]. In addition, despite the implementation of preventive strategies, pressure ulcers remain a common occurrence after injury. In fact, it continues to be the leading complication, even in Western European countries where comprehensive management plans are available [79]. Other secondary medical complications after an SCI include but are not limited to, autonomic dysreflexia, deep vein thrombosis, and spasticity.

Associated conditions and secondary medical complications have been found to increase the risk of mortality after a TSCI [64, 80]. However, limited reports on the prevalence of complications in the aftermath of a SCI are available from the developing context. This information is necessary to inform healthcare services along the entire continuum of care, especially when survivors of TSCI are discharged home and into the community. One recent Cape Town-based study investigating the prevalence of secondary medical complications during acute care found pressure ulcers to be the leading complication, affecting 30% of the cases, followed by pulmonary complications (23%) and UTI's (17%) [81].

#### **1.5 SYSTEMS OF CARE**

Managing persons with SCI requires a coordinated and comprehensive approach that targets post-injury dysfunction, also referred to as a systems approach. While evidence-informed clinical guidelines are available from numerous professional organisations [8, 82, 83] these were not developed for specifying standards of care. As a result, large discrepancies in healthcare provision exist between countries. The next section attempts to provide an overview of the types of management available in the two countries.

#### 1.5.1 Care in South Africa

The public-funded healthcare system that caters for approximately 80% of South African citizens provides general care to survivors of SCI's. In the Western Cape Province there are only two appropriate units, one for acute cases, and one for rehabilitation [84]. However, not everyone who sustains a SCI is accepted to be managed in these units because of resource-constraints, and are therefore prioritised according to injury severity. This criterion-based system thus leaves a group of injured individuals to be managed at facilities that do not have the full organisational capacity [85] to handle the complexities of the injury. Table 2 summarises the priority scale for admission to the acute unit.

P1	Incomplete ASCI in need of urgent spinal cord decompression surgery
P2	ASCI with unstable cervical spine fracture in need of spinal fusion surgery
P3	ASCI with unstable thoracic/lumbar fracture in need of spinal fusion surgery
P4	ASCI with SCI-related complication e.g. spinal shock or respiratory failure
P5	ASCI with unstable fracture of the spine for conservative traction management
P6	ASCI for removal of bullet
P7	ASCI with stable fracture of the spine
P8	ASCI not fit for rehabilitation (e.g. infection or SCI-related complication)
Р9	Stable post-acute SCI fit for rehabilitation
P10	Stable post-acute SCI with pressure ulcer (s), otherwise fit for rehabilitation

Table 2. Acute traumatic spinal cord injury admission to acute unit: Priority scale

\*ASCI: acute spinal cord injury

Rehabilitation as an integral part of healthcare services has been neglected in South Africa, with no disease-specific policy plans outlining quality indicators. However, a starting point for the discourse on rehabilitation is South Africa's own National Rehabilitation Policy that emphasises equal opportunities, the ability to participate socially, and integration back into society [86]. Similar to the resource-constraints limiting access to acute spinal cord injury care, rehabilitation is also judged on an individual basis by taking into account potential recovery and other demographic factors. A local descriptive study by Joseph and colleagues found that persons with TSCI who improved their functional abilities were discharged home (80.3%) without follow-up appointments and have been judged by a multidisciplinary team to be at a level of societal integration following rehabilitation [87]. More research is needed to better inform rehabilitation services for persons with SCI by providing evidence to support the need for life-long rehabilitation.

#### 1.5.2 Care in Sweden

Specialised care is now available for persons living with SCI in Sweden, including the provision of health and support services through the acute, rehabilitation and life-long follow-up phases of living with the injury. This systems approach to the management of TSCI in Sweden was not established without advocacy and research evidence supporting the favourable outcomes of such a system [88]. In the mid 1990's, a series of studies under the Stockholm Spinal Cord Injury Project provided evidence on the need for providing life-long follow-up as a means of strengthening systems and addressing the unmet needs of survivors [15, 89-91]. In response to all the work providing a strong foundation for change, healthcare facilities delivering services to the SCI population were augmented by ensuring that the organisational (infra) structure and capacity were adequate for delivering good quality care. In addition to state-of-the-art medical and rehabilitation services, numerous societal services including disability pensions, home and work adaptations, transportation services and home nursing services, have all been made available in order to facilitate independence and autonomy, health and well-being after SCI [17].

To date, SCI care is still decentralised, and the lingering debate is whether centralisation would result in even better care and reduced health costs. A National Competence Centre for SCI has been initiated in Stockholm, bringing together highly-competent clinicians, researchers and policy-level workers from the university and academic settings. This centre provides opportunities for staff specialisation, pooling of knowledge, and more focus on research and innovation, all of which contribute to building systems and societies that work for the individual living with an SCI.

#### **1.6 OUTCOME MEASUREMENT**

Numerous outcome measures, both disease-specific and generic, are used in the SCI field for the assessment of human functioning and associated quality of life [92]. Despite the large number of measures available, there is much debate around their content validity. This is because a number of these measures have been developed prior to the ratification of the ICF as the standard language for the discourse of health and functioning. As a result, there is a need to retrospectively evaluate the extent to which the measures that have been proposed prior to the ICF could be conceptualised within the operative functioning model for prospective evaluations of health and functioning. In addition, the ICF is currently used for creating disease- and context-specific summaries of relevant and typical functioning aspects.

#### 1.6.1 The ICF core sets for SCI and standardised measures

With the widespread acceptance of the ICF and the lack of consistency in the range of other outcome measures, there is a need to carefully specify the relevant and typical functioning aspects that are altered after an SCI. To achieve this, the ISCoS and numerous other international organisations established a rigorous process that included a systematic review, an expert survey, focus groups and empirical studies that provided the consumers'

perspectives, for the development of SCI core sets directly derived from the exhaustive ICF model [59]. To date, ICF core sets for SCI have been developed for the early post-acute and long-term context.

For both core sets, comprehensive and brief versions have been made available [36, 37], both of which indicate what should be evaluated. These sets include functioning aspects at the impairment, activities and participation levels, as well as including environmental factors. It is important to note the discrepancies between the methods used for measuring functioning aspects contained in the core sets, since these do not prescribe how it should be evaluated. Gold standard outcome measures and instruments are typically preferred since their validity should have been established. Best practice protocols for verifying the content validity of measures in relation to the functioning categories of the ICF at large and the SCI core sets [93, 94] have been made available. Despite the advocacy of certain measures, for example functional scales such as the Spinal Cord Independence Measure III and the Quadriplegic Index of Function [92], the extent to which the targeted domains of the ICF core sets for SCI is covered remains unknown.

#### 1.6.2 Outcome measurement use in South Africa

The use of outcome measures in the South African healthcare context is slowly gaining momentum. The sub-optimal adoption of outcomes measures is partly due to the uncertainty of whether measures developed in the Western world reflect the typical patient problems experienced in local contexts [20]. To date, no specific guidelines for the use of outcome measures following an SCI exist for the South African context, thus leaving a knowledge gap related to the functioning and needs of survivors as they move through the care pathways.

In the absence of using specific outcome measures in SCI-rehabilitation in South Africa, the Western Cape Health Plan 2010 adopted a generic measure to plan and structure rehabilitation needs and goals, and for measuring end-result outcomes. One critique of using a 'one-size-fits-all' measure relates to the lack of knowledge concerning additional disease-specific aspects that may significantly influence the quality of and satisfaction with life. This measure has been used in local studies among spinal cord-injured persons despite explicitly indicating the functioning level and patient problems still present. As such, a knowledge gap exists concerning the content that this measure covers with respect to prototypical functioning aspects that are relevant to persons with SCI.

#### **1.7 PARTICIPATION**

The goal of most healthcare systems is to ensure health and well-being, and the breadth and depth of participation appear to be strongly related to the achievement of these [95]. On the basis of this, improving health and well-being seems straight forward if health professionals focus their attention on addressing issues that hinder participation. The reality however, is that participation, or involvement in life situations [18], encompasses a set of values and

activities that include active and meaningful engagement in choice and control, access and opportunity, and social connection and inclusion [27].

Research conducted on the SCI population found that perceived participation was represented in three categories: social participation; occupational participation; and socio-occupational participation [96]. In addition, no distinction has yet been made between the variations of the concept of participation. In other words, there is no formal distinction between the concepts of participation, social participation, integration and social inclusion. However, the umbrella concept appears to be a multidimensional construct that includes the experiences related to social interactions and specific activities performed by an individual with an SCI [96, 97]. Some even argue that participation is not experienced as an objective way of performing activities within a societal context. Rather, it could be perceived as an internal process of negotiating and balancing personal and societal values [96] which give meaning to the life situations the individual becomes re-involved in.

Measuring participation within the context of the ICF is concerned with observed performance [18]. With this conceptualisation of participation, it is only possible to categorise and measure participation by selecting operational variables or indicators that are observable from the outside and not by addressing the person's own subjective experience [98]. While the lived experience that is rooted within participation is acknowledged, the ICF currently captures little of these experiences, like meaning and autonomy [98, 99]. Similar to the experience of negotiating participation restrictions after TSCI, persons have to regain meaning by finding strategies to imagine a future worth striving for [100]. It appears that finding meaning – imagining a future containing important elements from the past – could be essential in defining the involvement in life situations that survivors wish to reclaim after injury.

South Africa developed its own National Rehabilitation Policy with core principles that include respecting the rights of persons with disabilities and facilitating full and effective participation and inclusion in society. Limited accounts of experiences related to participation are available from low- and middle-income countries, and therefore more information is needed to strengthen health systems and to facilitate social action plans that promote participation.

#### **1.8 THESIS RATIONALE**

The devastating consequences of TSCI led to many international organisations, including the WHO, ISCoS and ASIA, working towards global primary and secondary prevention strategies. From a primary prevention standpoint, informing policymakers on the 'who', 'when', 'where', and 'how' of TSCI requires context-specific data. To date, numerous studies [40, 42, 54] have highlighted the need for epidemiologic studies from Africa at large that would contribute to the global knowledge of this devastating injury. To our knowledge, no population-based incidence studies on TSCI have been done in South Africa.

Furthermore, this North-South collaboration between Stockholm, Sweden and Cape Town, South Africa has created the possibility for updating the epidemiologic features of TSCI in Sweden, this time using the international standards of reporting. The main underlying reason for the epidemiologic studies is to provide a comprehensive description of the cohorts that are necessary for comparing processes and outcomes of care in the future. This is particularly important since the evaluation of outcomes should take into account the differences in healthcare systems and the approaches that are followed.

The ratification of the ICF created a standard language for the communication of health and functioning among health professionals. This led to the development in 2002, of the International SCI Data Set project, that aimed to select typical and relevant elements for the description of health problems after injury. It is therefore essential to determine the appropriateness of operative outcome measures used across numerous health conditions in the South African healthcare context, since these were developed prior to the ICF endorsement. Given the lack of standardised outcome measures used in SCI rehabilitation, coupled with the lack of consensus on the concept of '*participation*', there is a need to explore how persons with TSCI perceive their functioning and ability to participate after receiving care.

#### **2. AIM**

To develop an evidence-based foundation for TSCI in South Africa that addresses prevention both in terms of injury occurrence and problems with functioning.

#### Specific aims

*Study I:* To determine the incidence, aetiology and injury characteristics of TSCI in Cape Town, South Africa, using the international standards of reporting.

*Study II:* To update the incidence, aetiology and injury characteristics of TSCI in Stockholm, Sweden, using the international standards of reporting.

*Study III:* To determine the extent to which two outcome measures, the ROL and SCIM III, could be mapped to the categories of the ICF and the brief ICF core set for SCI in the post-acute context.

*Study IV:* To explore the experiences of reclaiming participation in community-dwelling adults living with a TSCI in South Africa.

#### **3. METHODS**

#### **3.1 DESIGNS**

This thesis makes use of both quantitative and qualitative methodologies. In *Study I and II* a prospective, population-based design was adopted in order to determine the epidemiologic features of TSCI in the respective regions. *Study III* adopted a comparative content validity methodology, and *Study IV* used qualitative description [101, 102] to explore the experiences of reclaiming participation in a purposively-selected group of individuals with TSCI.

#### **3.2 SETTINGS**

The studies included in this thesis were conducted in the City of Cape Town (metropolitan) region, South Africa and the Greater Stockholm area, Sweden, with respective population sizes of approximately 3.86 and 2.20 million. South Africa is still considered a developing nation even though many parts, namely the cities, show rapid industrial growth, while Sweden is a highly (industrialised) developed nation. The precise contexts and locations are briefly described below.

*Study I:* The South African government-funded healthcare system provides services to approximately 80% of its citizens. All eligible acute survivors of TSCI are managed at the designated Acute Spinal Cord Injury Unit at Groote Schuur Hospital. The other tertiary hospital - Tygerberg Hospital - provides general orthopaedic and/or neurosurgery care to persons with TSCI. Both hospitals were included in the study.

*Study II:* The Swedish healthcare system provides specialised care to persons with TSCI. All acute survivors receiving care at the Spinal Injury Unit, situated at the Karolinska University Hospital, Stockholm, were screened for participation.

*Study III:* The mapping of outcome measures by experts was performed at a South African university.

*Study IV:* Community-dwelling survivors of TSCI were recruited from the City of Cape Town region. A not-for-profit disability organisation provided a registry of persons with TSCI residing in the catchment area and those satisfying the criteria were contacted and asked to participate in the study.

#### **3.3 PARTICIPANTS**

This section briefly outlines the identification of cases for the cohort studies (study I & II), the selection of experts for study III, and the purposive sampling process followed in study IV.

#### 3.3.1 Study I and II

Persons with injury had to fulfill the following criteria in order to be enrolled in the incidence cohort:

- 1. Confirmed acute traumatic spinal cord or cauda equina lesion by means of computerised evidence and/or clinical evaluation;
- 2. Evidence of neurological fallout, that is, American Spinal Injury Association Impairment Scale A to D;
- 3. Age 18 years and above;
- 4. Survival of at least seven days post injury;
- 5. Admitted to the designated Acute Spinal Cord Injury Units (and other facilities in Cape Town) in the respective regions of Cape Town, South Africa and Stockholm, Sweden for the surveillance periods of 12 and 18 months, respectively;
- 6. Legitimate resident of respective regions;
- 7. Provision of informed written consent to participate in the studies.

#### 3.3.2 Study III

Two experts were selected to participate in study III. This study concerned the extent to which two outcome measures, one local and one international, could be mapped and conceptualised within the ICF. Therefore, experts needed to have extensive knowledge of both the ICF principles and taxonomy. The experts in our study applied the ICF in their own research and taught the framework to both undergraduate and postgraduate students in rehabilitation sciences.

#### 3.3.3 Study IV

The seventeen purposively selected informants had to fulfill the following criteria in order to be included in the qualitative study exploring participation: 1) living with a TSCI for at least three years, 2) had to be an adult survivor (18 years and above), and 3) must have made a transition from hospital setting to residential or community life.

Qualitative description, used in study IV, attempts to provide a broad and thick overview of a particular phenomenon. For this purpose, we sought diversity among key informants with respect to ethnicity, age, gender, time since injury, classification of injury, and socioeconomic status. This purposive selection of informants represented characteristics that may have influenced the way in which participation was perceived, characterised, influenced and reclaimed by this group of participants.

#### **3.4 DATA COLLECTION INSTRUMENTS**

This thesis has only presented selected parts of a larger umbrella project investigating the epidemiologic features of TSCI in these two international contexts, while acute care outcomes in the context of different types of care provision and care pathways will follow. In keeping with the aims of this thesis, we made every effort to select instruments that reflected an international standard and that were grounded in either the epidemiologic approach or the ICF. Table 3 outlines all operational variables captured in this thesis.

		Epi			ICF	
Instrument	Data element	-	CF	BS and BF	Activity	Participation
	Birth date (age)	Х	Х			
	Injury date	Х				
	Gender	Х	Х			
	Acute admission		Х			
International	Final inpatient discharge		Х			
SCI	Days hospitalized		Х			
Core Data Set	Injury aetiology	Х	Х			
	Vertebral injury			Х		
	Associated injury			Х		
	Spinal surgery		Х			
	Ventilator assistance			Х		
	Neurological classification			Х		
Brief ICF core	25 second-level categories		Х	Х	Х	Х
set						
ROL	24 meaningful concepts		?	?	?	?
SCIM III	19 items		?	?	?	?
Qualitative						Х
study on						
participation						

Epi= Epidemiologic approach; CF= Contextual factors; BS= Body structures; BF= Body functions ROL= Rehabilitation Outcome Levels measure; SCIM III= Spinal Cord Independence Measure III

#### Description of outcome measures for mapping exercise

*Rehabilitation Outcome Levels* is a measure consisting of six levels (0-5) that represent functioning aspects along the continuum of care, taking into account the influence of disease from a bio-psychosocial standpoint. Each level includes goals and outcomes that should be achieved before an individual can move to higher levels [103]. Furthermore, lower levels are typically addressed in the immediate (trauma) care or acute phase whereas higher levels are managed during in-and out-patient rehabilitation. Although this measure was developed within a bio-psychosocial model, very little is known about whether it reflects the operational variables of the ICF.

*SCIM III* is a 19-item functional scale that evaluates the following areas of function: self-care, respiration and sphincter management, and mobility. The total score ranges between 0 and 100 with higher scores indicating better functional status. The first version of the measure was published in 1997 and no detailed description of its conceptualisation within the ICF is

available [22]. This measure has been found to be valid and reliable in various subgroups of SCI, that is, paraplegia and tetraplegia, complete and incomplete [104], and traumatic and non-traumatic SCI [24, 105].

#### **3.5 DESCRIPTION OF PROCEDURE**

#### 3.5.1 Epidemiologic Studies I & II

All newly-injured persons who met the inclusion criteria were identified for a one-year period. Surveillance of incident cases started in South Africa on the 15 September 2013 until the 14 September 2014 and was preceded by a pilot test (15 August until 14 September 2013). This was necessary to determine if all newly-injured persons were routinely admitted to the ASCI unit or whether they were acutely managed at the other tertiary hospital within the catchment area of the study. In Stockholm, Sweden, a systematic pathway of care is in function whereby all surviving persons (according to our criteria) are admitted to the Spinal Injury Unit at the Karolinska University Hospital. Despite the attempts to coincide the surveillance time in the two settings, data collection in Sweden only commenced on the 1<sup>st</sup> May 2014 and continued for 1 year. In addition, the preliminary findings revealed a low number of cases as we concluded the first year of data collection. Considering that one of the aims of the project was to investigate differences in the epidemiologic profiles between contexts that is necessary to compare outcomes, it was therefore decided to extend the collection of data for an additional six months. This ensured that we would have sufficient cases in each strata when categorising and dichotomising variables.

The graduate student (CJ) was responsible for coordinating the data collection in both settings. In Cape Town, the main research site (ASCI) was visited on a Monday and Thursday for the duration of the study period in order to identify incident cases. Once identified, but only after surviving seven days, informed consent was obtained from eligible participants and the first evaluation was performed by the attending specialist doctors, consisting of the International SCI Core Data Set and neurological evaluations conducted according to international standards [32]. In Stockholm, the SCI core data are routinely collected and reported in the electronic medical folders of patients. Since we only sought consent from eligible participants during the active rehabilitation phase, CJ and one of the attending doctors (also co-author on paper II) extracted the necessary core data of consented cases at least once a month. The neurological examination was typically performed by the attending doctor and/or physiotherapist within 72 hours of admittance to the Spinal Injury Unit.

#### 3.5.2 Mapping of outcome measures in Study III

The selected experts were given the initial [93] and updated [94] linking rules along with the two outcome measures (see section 3.3.2). They were asked to independently link each item to the most specific ICF category starting at the second level and continuing to the third level, where possible. After evaluating the linking results of the experts a consensus meeting was held to decide on the endorsement of a 'criterion' in the absence of agreement. Finally, the second-level codes of each measure were linked to the candidate categories as contained in the brief ICF core set for SCI in the post-acute context in order to assess the breadth and scope of the selected measures. The technique for validating the content of selected outcome measures was through applying the rules outlined in the mapping protocol summarised below. An example of the application of specific rules is provided.

Table 4. The rules for and	examples of linking health-status	measures to the ICF
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	Specific rule	Application of rule
1.	Requisite knowledge of the conceptual and taxonomical fundamentals of the ICF.	
2.	Each item should be mapped to the most precise category of the ICF.	The Barthel Index item ' <i>Feeding</i> ' should explicitly be mapped to 'd550 and 'd560'.
3.	If a single item encompasses multiple constructs, all possible constructs should be identified.	In the SF-36 (item 8) 'During the past 4 weeks, how much did pain interfere with your normal work (including work outside the home and housework)?' - 'pain', 'work outside the home' and 'housework' are linked to b280 (sensation of pain), d859 (work and employment other specified and unspecified) and d640 (doing house work), respectively
4.	All constructs of the item to be linked should be emphasised e.g. by using italics.	In the SF-36 (item 8) 'During the past 4 weeks, how much did <i>pain</i> interfere with your normal <i>work</i> (including both <i>work outside the home and housework</i> )?'
5.	Where applicable, the response options of an item should also be linked.	The item 'self-care' of the EQ-5D contains the response categories 'I had no problems with self-care', 'I have some problems washing or dressing myself' and 'I am unable to wash or dress myself'. Thus, not only 'self-care' but also the concepts 'washing myself 'and 'dressing myself 'are linked.
6.	If the content of an item is not specifically named in the ICF category, then the 'other specified' option at the $3^{rd}$ and $4^{th}$ level is linked.	Are you using the bicycle for transportation? In this instance 'bicycle' is not clearly categorised as transportation in the ICF, therefore the 3 <sup>rd</sup> leve code 'd4708' is endorsed.
7.	If the content of an item is more general then the higher level code is endorsed.	How do you receive communications? This does not specify verbal or n verbal communication, therefore 'd329' is endorsed.
8.	If the content is more general than any ICF category but it clarifies certain aspects (in parenthesis, for example), then the unspecified option is to be used.	The item 'usual activities (e.g. work, study, housework family or leisure activities)' of the EQ-5D the concepts 'work', 'study', 'housework' 'family' or 'leisure activities' are linked to the corresponding 'unspecified'-ICF categories in addition to the linkage of the concept 'usual activities'. For example, work is linked to the ICF category d8509 remunerative employment, unspecified.
9.	If the item is not sufficiently described for the endorsement of a code, then ' <i>nd</i> ' is indicated.	WHODASII items coded 'nd' Staying by yourself for a few days? Getting all the work done that you need to do?
10.	If an item is not covered by the ICF, then ' $nc$ ' is indicated	'How much do you enjoy life?' (WHOQOL-BREF) Such questions often found in health-related quality of life measures cannot be linked to the ICF, and are thus coded ' <i>nc</i> '.

\*(Cieza et al. 2002; Cieza et al. 2005). Some examples taken from Cieza, A., & Stucki, G. (2005). Content comparison of health-related quality of life (HRQOL) instruments based on the international classification of functioning, disability and health (ICF). *Quality of Life Research*, *14*(5), 1225-1237 [106].

### 3.5.3 Qualitative Study IV

The seventeen informants included in this study were purposively selected based on our criterion of diversity. Typically, all were telephonically approached to set up an initial meeting where the researcher (CJ) explained the purpose of the study and they were given the opportunity to ask questions. Informed consent was sought at the end of the first meeting and a follow up interview was arranged at a time and place that was convenient for the informant.

The interviews were individual, semi-structured and audiotaped, lasting between 42-69 minutes. All the interviews were conducted in either Afrikaans or English, two of the most widely spoken languages in the catchment region of South Africa, and performed by CJ. The participants were asked the same open-ended questions focusing on the experience of living with a TSCI in South Africa, with reference to the impact on functioning, limitation and restrictions, abilities to reclaim meaning and participation, and the intervening conditions along the course of injury. Probes were used to deepen the discussion until each participant shared their conceptualisation of 'meaning and participation after injury', 'how participation is perceived and characterised', and 'how it is influenced'.

# **3.6 DATA MANAGEMENT AND ANALYSIS**

# 3.6.1 Study I, II, III

Data were managed and analysed in STATA version 13 (STATA Corp, College Station, TX, USA). Both the descriptive and inferential statistics that were used in the studies are summarised below.

Statistics	Study I	Study II	Study III	Thesis
Descriptive				
• Counts	•	•	•	•
Percentages	•	•	•	•
• Mean and SD	•	•		•
• Median with range	•	•		•
Inferential				
• Crude, age- and gender-adjusted incidence rate with CI	•	•		•
• Incidence rate difference	•	•		٠
Chi-square	•	•		•
• Fischer's exact test	•	•		٠
Cohen's Kappa			•	•
• PABAK			•	•
• Mann-Whitney U test		•		•

 Table 5. Statistics used in this thesis

\*For inferential statistics, the significance level was set at p < 0.05; SD=Standard Deviation; CI= Confidence Interval; PABAK=Prevalence-Adjusted Bias-Adjusted Kappa.

## 3.6.2 Study IV

All Afrikaans and English audio recordings were transcribed verbatim by CJ and thereafter transferred to a web-based qualitative analysis tool called 'Saturate', which is software that is used to store, organise and retrieve data. The application allowed for collaborative coding, grouping of codes and the development of categories.

Inductive analysis was used to provide a broad and thick description of the phenomenon [101, 107]. The decision to work inductively stemmed from the premise that no testable conceptual model describing participation after SCI is available. Furthermore, participation takes into account the lived experience of an individual within a social context and limited information on this subjective and objective experience is available from the developing world. Therefore, we decided to adopt the inductive content analysis technique to investigate how participation is reclaimed, perceived, characterised, and influenced in a developing part of the world.

The analysis was performed by CJ, and the main supervisor assisted with the English transcripts only. Initially, the transcripts were read independently multiple times and meaningful passages and concepts were freely identified, and thereafter condensed. Central to this phase – preparation – was open coding, where all meanings of the lived experiences were considered [101]. The second step was to compare all codes between authors involved in the analyses, which led to the grouping of codes and the development of categories with their sub-categories. During the analysis we used the constant comparison technique which assisted with the grouping of properties in each protocol as it related to reclaiming participation after injury. The categories were found to represent a continuum along the path of reclaiming participation and an overarching theme was identified.

## **3.7 ETHICAL CONSIDERATIONS**

*Studies I and IV* and *Study II* were approved by the Research Ethics Committee at the University of the Western Cape, South Africa (nr:13/4/27) and the Regional Board of Ethics in Stockholm (dnr: 2014/137-31/1). The Stockholm ethical permit was amended by applying for a six-month extension for data collection. Concerning *Study III*, no ethical permission was required due to the fact that no test subjects were recruited.

The studies in this thesis that made use of human subjects fully endorsed the Helsinki Declaration [108]. Principles, among others, informed consent, privacy and confidentiality, and participants' option to withdraw from the study, were upheld throughout the studies. Although the risks associated with epidemiologic and observational studies are generally not too high compared to clinical and experimental studies, we explicitly, in the information sheet to participants, stipulated the potential risks (i.e. loss of privacy) and benefits (i.e. mainly societal benefit). The concepts of full information and exploitation are especially important when conducting research on vulnerable groups, such as those with disabilities and from economically disadvantaged backgrounds [109, 110]. In study IV, informants' privacy was protected to the best of our ability. Although anonymity may not be entirely achievable, informants' identity was protected by the use of pseudonyms.

#### 4. FINDINGS

This section presents only the main results of the studies, and more detailed presentations and descriptions can be found in the respective papers that are attached at the end of the thesis. However, to aid with the comparison of epidemiologic features between the contexts, an integration of findings is presented below. In addition, the two studies on functioning are distinctly presented.

### 4.1 STUDY I AND II

#### Incidence rates

The crude incidence rates of TSCI were 75.6 and 19.0 per million population for the City of Cape Town and Greater Stockholm area, respectively. The incidence rate difference of 56.6 (CI: 43.3-69.9) per million population indicates a statistically significant higher incidence in the region of South Africa, compared to the region in Sweden. Concerning male-specific rates, a 5.5 fold higher occurrence was observed in Cape Town compared to Stockholm, with between 82 and 131 more male cases victim to TSCI in Cape Town each year.

#### Comparison of cohorts using the Core Data Set

During the respective surveillance periods, 147 and 49 newly-injured individuals with TSCI were registered in the metropolitan area of Cape Town, South Africa, and the Greater Stockholm area, Sweden. Of these, 145 from Cape Town and 45 from Stockholm consented to participate, and the core data of each individual were captured.

As is clear in Table 6, the Cape Town TSCI cohort consisted of more males and was significantly younger than the one in Stockholm. The cohorts differed with respect to the distribution of cases across the categories of age (p < 0.001) and aetiology (p < 0.001). In Cape Town, the leading cause of injury was assault, accounting for approximately 60% of all injuries, compared with falls causing most injuries (58%) in Stockholm. Incident cases were observed across all categories of causes in the Cape Town cohort, whereas causes were almost exclusively limited to falls and transport-related events in Stockholm. No difference (p=0.19) was found in the proportion of injured-individuals with associated injuries between cohorts despite dissimilar leading causes of injury, with the one typically high velocity (gunshots) and the other low velocity (low falls). Furthermore, more spinal surgeries were performed in the Stockholm cohort compared to the one in Cape Town, with a significantly shorter 'time to surgery' after injury in Stockholm.

# Table 6. Comparison of core data

	Cape Town	Stockholm <sup>a</sup>	P value
	(study I)	(study II)	
Gender; n (%)			<0.001
Male	124 (85.5)	27 (60)	
Female	21 (14.5)	18 (40)	
Age at injury			<0.001 <sup>b</sup>
Mean (±s.d.)	33.5 (13.8)	54.9 (16.6)	
Median (min-max)	29.0 (18-93)	58 (18-85)	
Age categories; n (%)			<0.001
18-30	78 (54)	4 (9)	
31-45	41 (28)	10 (22)	
46-60	18 (12)	10 (22) 12 (27)	
≥61	8 (6)	19 (42)	
Acticlom: n (0/)			<0.001
Aetiology; n (%)	1 (0.7)	1 (2)	<0.001
Sport	· · · · ·	1(2)	
Assault	86 (59.3)	0(0)	
Transport	38 (26.3)	18 (40)	
Falls	17 (11.7)	26 (58)	
'Other trauma'	3 (2.0)	0 (0)	
Height of falls; n (%)			0.16
Same level to $< 1$ m	5 (29)	14 (54)	
1m to 3m	4 (24)	1 (4)	
> 3m (at least one floor)	7 (41)	10 (38)	
Missing	1 (6)	1 (4)	
Level of impairment; n (%)			0.03
Tetraplegia	77 (53.1)	32 (71)	0102
Paraplegia	68 (46.9)	13 (29)	
Neurological category; n (%)			0.09
Ventilation dependent	0 (0)	0 (0)	0.07
C1-C4 AIS A, B, C	28 (19.3)	9 (20)	
C5-C8 AIS A,B,C	23 (15.9)	2 (5)	
T1-S5 AIS A, B, C	41 (28.3)	10 (22)	
All AIS D	53 (36.5)	24 (53)	
Associated injury; n (%)			0.19
Yes	84 (57.9)	31 (69)	0.17
No	61 (42.1)	14 (31)	
Spinal surgery; n (%)			<0.001
Yes	75 (51.7)	43 (96)	<b>N0.001</b>
No	70 (48.3)	2 (4)	
	· · ·		
Time to surgery (days)	o oo		<0.001
Mean $(\pm s.d.)$	9.93 (9.5)	2.98 (5.1)	
Median (range)	7 (0-45)	1.0 (0-23)	
Length of hospital stay (days)			<0.001 <sup>b</sup>
Mean (±s.d.)	36.5 (36.8)	44.4 (25.0)	
Median (min-max)	24 (3-245)	42 (3-131)	

<sup>a</sup> The Stockholm data are from an 18-month study period; <sup>b</sup> The hypothesis testing was done based on the median due to the non-normality of data

### 4.2 STUDY III

#### Mapping of ROL and SCIM III to the ICF

Of the 24 meaningful concepts identified in the ROL, 21 were linked to ICF categories, while three which were found to be very broad in nature for the endorsement of a unique category and were thus coded '*nd*' (not definable- physical and general health). These categories were almost exclusively at the second level, 42 out of 45, with the remaining at the third level. With respect to the SCIM III, all 19 items were mapped to the ICF and a stark contrast was noted concerning the level of endorsed categories, in which the items were linked to more third-level categories, compared to what has been observed for the ROL. Of the 42 second level categories contained in the ROL, 13 and 29 unique categories represented functioning aspects within the '*body structure and function*' and '*activity and participation*' domains, respectively. Items of the SCIM III were linked to 20 and 32 unique second- and third-level categories, respectively, with approximately 80% associated with the '*activity and participation*' domain.

Overall, the inter-observer agreement for endorsing ICF categories to respective measures was higher for the SCIM III than the ROL. Specifically, the absolute agreement (with Cohen's kappa and PABAK) at the second level of both the SCIM III and ROL was 80% (0.61; 0.70) and 57% (0.20; 0.36), respectively.

#### Coverage of brief ICF core set for SCI in the post-acute context

As seen in Table 7, the ROL covered nine, and the SCIM III, 12 of the 25 candidate categories in the brief ICF core set, with the SCIM III demonstrating full coverage of the *`activity and participation'* domain, an area where the ROL had shortcomings. Not one of the measures fully covered the *'body functions and structures'* domain, and not a single environmental factor was included in each respective measure.

Drief ICE core act actogories*	ROL	SCIM III
Brief ICF core set categories*	KUL	SCHVI III

<b>Body functions and structures</b>		
b730- Muscle power function		
b620- Urination function		
b525- Defecation function		$\checkmark$
b280- Sensation function		
b440- Respiration function		$\checkmark$
b735- Muscle tone function		
b810- Protective functions of the skin		
s120- Spinal cord and related structures		
s430- Structure of respiratory system		
s610- Structure of urinary system		
	•	•

#### Activities and Participation

d420- Transferring oneself		$\checkmark$
d410- Changing basic body positions	$\checkmark$	$\checkmark$
d445- Hand and arm use		$\checkmark$
d530- Toileting	$\checkmark$	$\checkmark$
d550- Eating		$\checkmark$
d450- Walking	$\checkmark$	$\checkmark$
d510- Washing oneself	$\checkmark$	$\checkmark$
d540- Dressing	$\checkmark$	$\checkmark$
d560- Drinking		$\checkmark$

#### **Environmental factors**

e310- Immediate family
e355- Health professionals
e115- Products and technology for personal use
e120- Products and technology in and outdoor
e340- Personal care providers

Abbreviations: ROL=Rehabilitation Outcome Levels measure; ICF= International Classification of Functioning, Disability and Health; \*Brief ICF core set for SCI in the post-acute context;  $\sqrt{-1}$  covered; x=not covered

#### 4.3 STUDY IV

The findings of this study affirmed that informants sought to effectively participate following injury. However, the breadth and depth of their participation in life situations were restricted during the acute period immediately following the injury. Having experienced the losses and initial limitations, informants described their path to reclaiming participation as a 'journey that entered the light at the end of the tunnel'. The overall theme, 'Participation possibility', is the culmination of four critical aspects - also categories - to consider along the path of successfully reclaiming participation (Figure 3).



Figure 3. The path to reclaiming participation after a TSCI

As seen in the Figure 3, the first category of experiences related to reclaiming participation was '*dealing with the new self*'. Unanimously, participants described the injury as the most unexpected and life-changing event they had ever experienced, the reality of which caused negative emotional responses and necessitating the reconstruction of their identities and functioning capabilities. The consequences of injury left some participants feeling hopeless to the extent that they contemplated suicide as an option for dealing with the life-changing event.

"I couldn't believe what has happened; I was even in that space where I said I can take my own life...."

Despite the sense of loss of control and negative emotional responses, participants acknowledged the need to find meaning, where they could imagine projecting situations and elements of the past into the future, as a critical step towards reclaiming participation.

"I need to accept from now on that I am a physically-challenged person. There are number of obstacles and challenges that I have to face, and I said to myself, facing these, I have to understand the kind of disability that I have in order to move forward."

The path to participation was not an easy or once-off endeavor. The second category, '*a journey dominated by obstacles*', gives an account of the challenges participants had to endure and negotiate in almost all aspects of their lives. It was possible to classify these challenges according to two broad sub-categories; 'injury challenges' and 'environment

challenges'. Injury challenges typically described the experience of limitations when attempting to execute certain activities such as self-care, mobility and household tasks. One property of the limitations that was highlighted in most of participants' accounts was the deterioration of relationships with friends and family. One participant reported that his own limitations affected his relationship with his pet, an experience which had a noteworthy influence on him enjoying and fulfilling elements of the past.

"Even my relationship with my dog changed. Now he doesn't listen to me anymore, I think it is because I can't feed him anymore or take him for walks. I want to improve my relationship with him [dog]."

The second subcategory, 'environmental challenges', appeared to have influenced the breadth and depth of participation. These challenges were elements of the built, attitudinal and legislative environment which impacted on the time it took to create opportunities and find strategies that were necessary in order to reclaim participation. Negative devaluing attitudes of society towards those with disabilities recurred frequently as an issue that hindered full participation.

"They are talking that we smell, we are dirty, we are in a wheelchair and we can't go with them...they think less of us, even push us out of the line."

The third category, *'catalyst of participation'*, was what participants described as the positive intervening condition on the experience of participation. The benefits of the peer mentoring programme were perceived in terms of them – participants receiving the programme – gaining knowledge and insight into what it is like to live with a TSCI in South Africa, finding equal-minded friends, and wanting to become a (role) model after the programme.

"The peer support just gave me a sense, an idea of what is going to happen and what can be expected in the future concerning my disability."

*Becoming an agent* is the last critical component that is essential to reclaiming participation. It includes all experiences that highlight the importance of reconstructing meaning as a means of future goal setting and resisting exclusion. It also includes the objective of finding the strategies necessary to overcome the challenges preventing participants' full and effective participation. Agency was further exemplified as *'agency for self'* and *'agency for others'*, in which the latter form was more frequently expressed by participants who received peer support. Furthermore, those receiving peer support were more outspoken on the issue of respect for the rights of persons with disabilities, which led to their advocacy of establishing organisations that aim to keep policymakers accountable.

"We have decided that we are going to take government to court regarding the housing issue... We know that 10% of each housing project should cater for PwD's... This will ensure that 10% of houses are allocated to PwD's, and government will save lots of money."

#### **5. DISCUSSION**

#### **Main findings**

This thesis contributes to the global body of knowledge on TSCI epidemiology that is necessary for planning preventive strategies and informing policy. In addition, we explored functioning after TSCI from a methodological and patient perspective, which could assist with the adoption and development of authentic outcome measures, as well as to inform both health professionals and policymakers on the unmet needs of survivors of TSCI.

*Epidemiologic features (Study I and II):* The incidence of TSCI in a region of South Africa was found to be among the highest in the world – based on the reported literature – and the highest for the African continent, with 'assault' as the leading cause of injury. Males between the ages of 18-29 were at a higher risk of sustaining a TSCI. In Sweden, the incidence appeared to have remained stable when compared with a previous study that was conducted almost a decade ago, but is significantly lower compared with South Africa. The causes of injury in Sweden were limited to fall and transport-related events, which deviated significantly from the findings in South Africa and the last Swedish report.

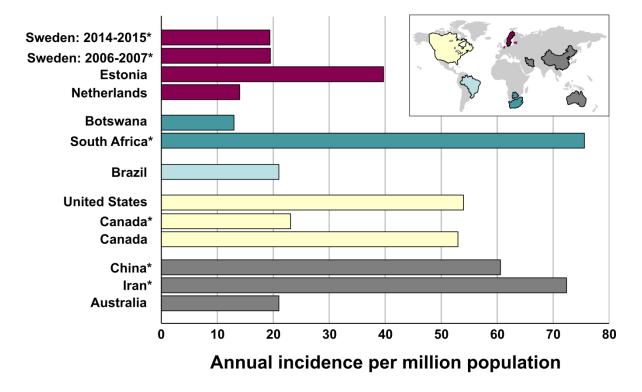
*Functioning perspectives (Study III and IV):* The SCIM III, a measure not currently in use in South Africa, could be mapped in its entirety to the ICF and covered all nine of the *Activities* and *Participation* categories in the brief ICF core set for SCI in the post-acute context. The ROL is an operative measure in SCI-rehabilitation in South Africa [13] that includes certain items that could not be linked to the ICF, with limitations related to coverage of the candidate categories in the brief ICF core set for SCI. In *Study IV*, the accounts of participants on their functioning identified *participation* as a relevant outcome. Given the absence of the full spectrum of involvements in life situations in newly-injured individuals, participation was deemed to be possible given the ability to negotiate four critical aspects along the journey of reclaiming participation. This study provided valuable information on the met and unmet needs of individuals in their pursuit of becoming re-involved in situations of the past and the factors that influenced these experiences.

# 5.1 EPIDEMIOLOGY OF TSCI

### Incidence

The first prospective, population-based study indicated a high incidence rate of approximately 76 per million persons in a region of South Africa. The incidence estimation is in stark contrast to what has been proposed for Africa in the global mapping project on TSCI epidemiology [45] and found in a recent study in Botswana [53]. Furthermore, as seen in Figure 4, the incidence estimation of TSCI in South Africa is among the highest reported figures in the world when comparing studies following similar designs and methodological quality.

The situation of TSCI occurrence is quite the same and different in Sweden. By comparing the incidence figures of the current study with the reference study that was conducted in 2006-2007, the annual rate of occurrence appears to be the same. Furthermore, the updated incidence figure continues to be slightly lower than other Nordic countries, such as Norway, Finland and Iceland [111-113]. The comparison between South Africa and Sweden yielded significantly different results with the annual crude incidence being a remarkable four times higher in South Africa. The reason for the high occurrence of TSCI in South Africa is not clear, but knowledge of injury determinants may provide useful information that would be necessary for guiding evidence-based prevention plans.



**Figure 4.** An unexhausted worldwide overview of annual incidence estimates of TSCI per million population (same reference studies as presented earlier).

#### Aetiology

The International SCI Data Sets Committee provided guidance on the grouping of injury aetiology [60], which allows the research community to compare findings across settings. According to the categories created to study aetiology, the leading cause of injury in South Africa was assault, that is, gun-shots and stabs, accounting for approximately 60% of incident cases. This was followed by transport-related accidents and falls causing 26% and 12% of injuries, respectively.

Assault as the leading cause of injury is surprising since South Africa is a country not at war. Despite this, in the year 2000, violence and injuries combined were the second leading cause of all death and disability-adjusted life years. Literature suggests the complex interaction of social dynamics, including widespread poverty, unemployment, income inequality, notions of masculinity, widespread alcohol misuse and weaknesses in the mechanisms of law enforcement. In combination, these inter-relating factors are responsible for an overall death rate in South Africa that is nearly twice the global average [114]. Furthermore, interpersonal violence alone dominates the South African injury profile with age-standardised mortality rates estimated at seven times the global rate [115]. The latter findings highlighting the contribution of violence to mortality are important for the discussion on the true burden of TSCI in South Africa. Considering an already high incidence of TSCI in South Africa and the fact that this study only included those who survived seven days post injury, we may have underestimated the true incidence of TSCI in the region of South Africa.

Transport-related injuries is also a major burden affecting all-cause mortality and morbidity in South Africa, and was found to be the second most common cause of TSCI in *Study I* of the thesis. In South Africa, the road traffic mortality rate of 39.7 per 100 000 is estimated to be 26% higher than the average in Africa and almost double the global rate [115]. One possible reason for this, which may also apply to assault, is its association with alcohol consumption. Although blood alcohol concentrations were not measured in the cohorts for this thesis, previous studies suggest that about 40 to 50% of the incident cases were typically preceded by alcohol consumption [41, 112].

The aetiologies of injury in Sweden were mostly limited to falls and transport. Falls continued to be the leading cause of injury when compared with the reference study that was conducted in the same region over 2006-2007 [14]. We noted a 26% increase in high falls ( $\geq$  3m) in the current study, compared with the reference. In addition, we found a significant difference between younger people who typically fell from high platforms, and those over 60 falling on the same level ground. However, the conditions surrounding the events, for example alcohol and drug use and/or attempted suicide, remain unclear. Literature is available to support these associations [116, 117]. As such, the prevention strategies targeting falls should incorporate restrictions and information on the use of commonly abusive substances.

The distribution of incident cases has changed since the last incidence report in Stockholm. A significant difference was observed in the proportion of cases across aetiologic categories between the current (study II) and the reference study, which may indicate the effectiveness of primary prevention actions with respect to determinants of injury that reduced over time.

Screening of the literature for updates on the epidemiology of TSCI in countries yielded unexpectedly few sources. There is therefore a need to perform these updates in order to share the successes and failures of primary prevention initiatives with the research community, especially since these programmes can be expensive [118-120].

### 5.2 APPROACHES TO PRIMARY PREVENTION

#### Haddon's matrix

Primary prevention campaigns and initiatives are typically costly and the results are often not very promising in curbing the occurrence of certain behaviours or injuries. One of the reasons is the lack of understanding around the contributing factors leading to injury. In helping us to understand these inter-related factors, Haddon developed a two-dimensional matrix as a conceptual model for framing countermeasures, with the first dimension describing the factors that influence injury, that is, the host, agent and environment. The second dimension is 'injury phase' that considers the influencing factors surrounding the pre-event, event, and post-event prevention by examining their interactions with the host, agent and vehicle [35, 121]. As an example of its effectiveness, when Haddon's framework was applied to federal motor vehicle safety standards, it was estimated to have saved 328,551 lives during 1960 - 2002 [122]. Given these promising results, the application of this matrix could be applied to the South African context in order to fight interpersonal and gun violence as leading cause of TSCI. Although no risk and protective factors were studies in this thesis, an illustration of its application is demonstrated below.

	Host	Vehicle/agent	Physical environment	Socioeconomic
<u>Injury phase</u> Pre-event	-Train people in conflict resolution -Educate people on the consequences of actions - Alcohol consumption	- Make weapons less easily concealed - Educate people in anger management	<ul> <li>Educate people not to walk solo at night when these events happen</li> <li>Have police patrol dangerous areas</li> </ul>	<ul> <li>Reduce access to weapons</li> <li>Alleviate poverty and unemployment</li> <li>Increase tax on alcohol</li> </ul>
Event	-Train people on self- defense methods - Wear protective gear over vital parts	- Reduce lethality of weapons (e.g. less lethal bullets and fewer rounds available to civilians)	-Surveillance cameras in high risk areas to provide assistance as soon as possible	-Enforce policies of misconduct - Ensure adequate security after events
Post-event	<ul> <li>Educate on signs of SCI to prevent further deterioration</li> <li>Teach first aid</li> </ul>	-Improve ability to trace weapon and suspect	- Surveillance cameras to track dumping of weapon and suspect -Have emergency telephones available in the environment	<ul> <li>Provide adequate healthcare systems for survivors</li> <li>Enforce laws to restrict certain freedoms of suspects</li> </ul>

Table 8. Applying Haddon's matrix to violence in South Africa

### The Socio-Ecological Model of violence

Prevention requires an understanding of the factors that influence violence and this model attempts to identify the interaction of factors between the individual, relationship, community and society. It allows for the understanding of a range of factors that put people at risk of violence or protect them from experiencing or perpetrating violent acts [123, 124]. The model suggests that in order to prevent violence, it is important to intervene across multiple levels at the same time. Here we will shortly describe the factors within each level that should be considered when planning prevention strategies in any given context.

*Individual:* These are characteristics that influence behaviour, such as biological, knowledge, beliefs, attitudes and perceptions.

*Relationship:* This level examines interpersonal relationships that may influence the risk of experiencing violence as either a victim or perpetrator. It is believed that a person's closest circle, including peers, partners and family, influences their behaviour.

*Community:* This level seeks to explore settings, such as schools, workplaces and neighbourhood, in which social relationships occur. It attempts to evaluate the influence of these settings on the behaviour of the person as either a victim or perpetrator.

*Societal:* Here the broad societal factors that help create an environment where violence is promoted or inhibited are investigated. Specific emphasis is placed on policies, such as educational, economic and social, that contribute to inequalities between groups in societies.

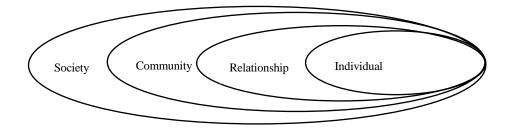


Figure 5. The Socio-Ecological Model

The descriptive epidemiologic approach was successful in highlighting TSCI as a public health concern and further provided valuable information on the determinants of injury in South Africa and Sweden. In order to curb the occurrence of this devastating health condition in these settings, these two models of prevention could be used as a foundation for developing contextually-sensitive programmes.

## 5.3 ARE WE MEASURING WHAT WE INTEND TO MEASURE?

Addressing secondary and tertiary prevention requires an understanding of the direct and indirect consequences of injury or disease. The ICF provides the framework for evaluating the 'what to measure' by considering the experience of living with a health condition, such as a TSCI, in a given context [18]. In *Study III* of this thesis, we evaluated whether the ROL, an operative measure that is currently used in South Africa for guiding interventions and measuring outcomes in SCI survivors undergoing rehabilitation, could be conceptualised

within the ICF and whether it measures what matters. Three out of 24 meaningful concepts could not be linked to an ICF category and the rest of the items were, at best, mapped to second-level categories. However, perhaps it should not be very surprising that certain items could not be linked, since the ROL was developed in 1995 without the ICF as reference [103]. Similar findings of meaningful concepts that cannot be linked to a particular ICF category are found in the literature [125], especially for health-related quality of life measures [106, 126]. Furthermore, the ROL did not cover in full any of the domains of the brief ICF core set for SCI in the post-acute context.

In contrast, the SCIM III was mapped to the ICF and the same brief core set for SCI and had more promising results. All items endorsed a particular category of the ICF, more third-level codes were endorsed for items compared with the ROL, and all *'activity and participation'* categories of the brief ICF core set for SCI in the post-acute context were covered. It appears that the SCIM III, a gold standard functional rating scale in SCI, is therefore the preferred choice of measurement, since it was developed specifically for the SCI population [22], unlike the ROL which is a generic measure.

So, when is a measure insufficient for evaluating a particular functioning construct and when should we recommend change? In *Study III*, we found that the generic measure covered some of the pertinent functioning aspects relevant to the SCI population. Notwithstanding the relevance of certain items, no published studies are available that support the psychometric properties of this measure that are specific to the SCI population. Apart from the content validity that was established in this thesis, little else is known on the reliability and responsiveness of this measure. In order to strengthen the healthcare system for persons with SCI in South Africa, the adoption of standardised outcome measures such as the SCIM III, and which is based on the ICF and the patient perspective on health needs, may be the next step in delivering patient-oriented care. A study investigating the awareness and adoption of outcome measures in physiotherapist working in South Africa found that impairment level outcome measures were mostly used and that sufficient knowledge of other types of measures was lacking [20].

In answering the question 'are we measuring what we intend to measure', we should perhaps pause and reflect upon whether we know what ought to be measured after SCI. The ICF and the core sets for SCI provide a solid foundation that is needed to understand the experience of living with an SCI. It is therefore necessary to fully endorse the ICF as the operational framework in healthcare settings by facilitating and encouraging its use and then to map out 'what and how to measure it' [127].

#### 5.4 PARTICIPATION AS END GOAL OUTCOME

Participation is a major goal in the medical rehabilitation of persons with health conditions such as SCI, and was found to be an outcome that was both sought after and possible to achieve in the societal context. Much of the literature debates the concept of participation and how it relates to other concepts such as integration and social inclusion, which in turn hinders the development of authentic measures that take into account meaningful experiences that impact the health and well-being of survivors [128]. Of late, qualitative studies have been

conducted that explore the subjective understanding of participation, and found that it not only encompasses ordinary objective performances, but also includes more abstract and nuanced experiences that are difficult to capture routinely [6, 97, 129, 130]. Because of this uncertainty in the conceptual understanding of participation, we decided to focus on a neglected part of the discourse which is how participation is reclaimed and what involvements in life situations individuals prioritise.

Informants described the experience of participation restrictions soon after sustaining the injury and expressed the need to first understand and address the 'new self'. Finding meaning appeared to be a critical aspect that was necessary in order to begin the search for a life worth living. Studies found that finding meaning in the midst of the spectrum of emotions that were experienced during rehabilitation was often not a once-off experience and that health professionals should be aware of the emotional challenges when searching for meaning [100, 131]. In this respect, they should find ways of ensuring that they do not become another burden to the survivor.

In this study, informants described the path to becoming re-involved in their life situations as a 'journey dominated by obstacles', in which the consequences of injury and environmental factors imposed major restrictions on functioning. Notwithstanding the ratification of policies that protect the right to full and effective participation [132], informants unanimously highlighted society's lack of effort in accommodating them as equal contributing citizens. They expressed concern that physical spaces were not accessible, negative attitudes were portrayed towards persons with disabilities, and that there were many system insufficiencies. Although most of these obstacles and challenges in this study were similar to what is found elsewhere in the world [133-136], we were able to describe the more nuanced experiences that greatly impacted on the participation of survivors.

Success in reclaiming participation does not only require the negotiation of obstacles but also relies on the identification and usage of facilitating factors in order to enjoy a wider spectrum of experiences. In our study, peer support was found to be an intervening condition that positively influenced the path to reclaiming participation. Much of the literature ascribes the benefit of peer mentoring to the 'similar other' in that the peer supporter had been successful in reclaiming meaning and establishing a life after injury [137]. In a recent population-based study of 1549 survivors of SCI peer support appeared to promote participation and life satisfaction, while the number of unmet needs related to SCI was associated with a need for peer support [138]. Apart from promoting participation, peer support was found to improve self-efficacy and reduce secondary complications during the first year after SCI [136, 139]. In light of these findings rehabilitation professionals should encourage persons who have sustained an SCI to attend peer support groups, and health departments should consider peer support as an integral part of rehabilitation that may directly impact major goals, including participation and reducing the length of hospital stay and doctor visits.

In this study, the fourth critical component necessary for reclaiming participation was agency, which was sub-categorised as 'reconstructed meaning', 'resistance to exclusion', and 'becoming a strategist'. Although the concept of agency is much debated, partly due to its abstractness and vagueness [140], participants expressed subjective attributes that appeared to be linked to critical aspects that aid participation. These attributes were synonymous with the

concepts of motivation, will, intentionality, choice and freedom. We also found that agency represented clear social and relational elements, for example resisting exclusion from society and family or friends, confirming the idea that participation is more than objective performances and that it includes elements of social inclusion in the local context [140]. A recent study involving persons with SCI confirmed our findings and found that participation extended beyond ordinary performance and included both rights (for example, acceptance) and duties (for example, contribution to society) perspectives [97].

High levels of participation is one of the hallmark features of any given healthcare system, and this study provides insight into the challenges that people with a TSCI face in achieving this important outcome. Considering the fact that participation is only effectively challenged when survivors of SCI return home after hospitalisation and rehabilitation, it may be useful to incorporate the concept of life-long (rehabilitation) follow-up. This component of rehabilitation is already part of many healthcare systems in developed countries, and is a critical service that assists with the breakdown of patient- and context-specific barriers to participation.

# 5.5 METHODOLOGICAL CONSIDERATIONS

# 5.5.1 External validity of study I & II

External validity predominantly speaks to the generalisability of findings to the sampling frame. In general, population-based cohort studies – as conducted in this thesis - ensure a strong degree of extrapolating findings to the population from which the cohort was selected. Important aspects to consider in enhancing the external validity are case definition and clear plans on how cases will be identified. This is important because it influences the extent to which results are representative of all individuals in the a priori defined specific population [141, 142].

Case definition used in the epidemiologic studies performed in this thesis has been used before in studies among adults with TSCI [14, 143]. By doing so, systematic error is reduced and opportunities are afforded to compare cohorts. However, it is important to interpret the findings of the two studies with the selection bias that is introduced when the decision is made to study adults alone, as well as those surviving at least seven days after injury. As a result, knowledge gaps remain concerning paediatric TSCI and those who die within seven days following the injury. Neglecting to take into account these potential cases greatly underestimates the true burden of TSCI, which is at the core of injury prevention research.

In addition, the registration of acute TSCI cases in South Africa was limited to the publicfunded healthcare system that caters for approximately 80% of all citizens. Although those with private medical care were not included in the sampling frame, it remains unclear whether the epidemiologic features of those with private care mirror those patients who are managed in the public-funded system. It may also be interesting to study similarities and differences in TSCI epidemiology between those with and without private medical care, since they often live in the same geographical locations, which may mean similar exposures associated with TSCI. For example, they experience the same traffic situations, transport options and engagement in violence-related activities.

### 5.5.2 Internal validity of study III

The mapping of outcome measures to the categories of the ICF and core set by only two experts may have threatened the internal validity of the findings. We observed that the reliability was not optimal, especially when mapping items of measures to third-level ICF categories. Cohen's kappa is typically used to convey evidence of agreement beyond chance [144]. However, in our study we found that it was conservative in its approximation of agreement. Furthermore, we noted that one of the raters was more liberal in endorsing codes while the other had fewer codes in total, which may have caused a systematic bias resulting in a higher prevalence of responses for one rater. Because of this, we computed the PABAK that took into account both prevalence and bias [145].

It was important to include a consensus meeting as part of the methodological steps to ensure the endorsement of a criterion category in instances where disagreements were present. The findings further demonstrate how differently items could be interpreted, which may influence the way in which rehabilitation is planned and prioritised. Amidst these findings, strategies of enhancing the internal validity of assessments should be at the core of instrument development.

## 5.5.3 Trustworthiness of study IV

Trustworthiness of the analysis was improved by addressing credibility, transferability, dependability and confirmability [146]. Credibility is the process by which the study findings reflect reality, and was addressed by using an interview guide consisting of similar questions exploring participation restrictions and their influences in other studies [96, 136]. This ensured that the phenomenon studied was clearly operationalised. Furthermore, the researchers engaged with the data for prolonged periods, which resulted in the need to triangulate data between different sources by involving a wide range of informants. The sampling variation employed in this study allowed for the exploration of rich and broad experiences of reclaiming participation that took into account the contributions of a range of people. To further enhance the credibility of the interpreted findings, both member checks and validation of the overall theme were performed via a subgroup of the initial sample [147].

The transferability of findings, or the extent to which the findings could be applied to other contexts, was done by providing sufficient contextual information throughout the process. Since participation entails the lived experiences of individuals within a societal context, we clarified the local legislative policies advocating participation of individuals with impairments. Enhancing the dependability of findings in order to ensure that the study may be reproduced in the same setting and yield similar results, we provided a detailed outline and audit trail of the research design and its implementation, as well as the operational detail of data gathering [148].

Confirmability is the process of ensuring objectivity, and involved taking steps to ensure that the findings reflect the experiences and ideas of the informants and not that of the researchers. The researchers discussed their predispositions during the peer debriefing sessions and CJ kept a reflective diary that included information on methods chosen, participant selection, and analysis strategies; all of which were used to enhance the premise that the findings were derived from the interviews [148].

### 5.6 IMPLICATIONS OF RESEARCH

- The first prospective, population-based cohort study on adults with TSCI in a region of South Africa revealed an extremely high incidence rate for a country not at war. The findings on the distribution and determinants of TSCI could be used to develop primary prevention strategies targeting the priority groups.
- The updated population-based study conducted in a region of Sweden found that the incidence had remained stable when compared with the previous report, but that the distribution of the determinants of injury, along with residual neurological levels of impairment, were significantly different. This study therefore highlights the need for an 'update' of both primary and secondary prevention strategies that reflect the requirements of the current cohort.
- The use of generic measures of functioning shown to have important limitations with respect to the relevant and typical functioning aspects that need to be considered for persons with SCI. In contrast, a gold standard functional rating scale was found to cover the entire spectrum of relevant aspects in one particular domain. There is therefore a need to adopt targeted measures for the evaluation of functioning in order to address the unmet needs of survivors of TSCI.
- Informants reported *participation* as an outcome that was possible to achieve in this societal context. The voices of those who had successfully reclaimed *participation* may contribute to the development of health services that include rehabilitation and peer-mentoring programmes, and that assist with the breakdown of barriers.

#### **5.7 FUTURE RESEARCH**

We have been successful in performing and describing regional population-based cohorts of adults with acute TSCI based on international standards. Future national population-based cohort studies are warranted in order to determine the country profile of TSCI that is necessary for developing national-level prevention programmes. These studies should address the limitations of the current work by including paediatric TSCI, those dying prior to hospitalisation and within seven days of injury, and those with private healthcare insurance, if the entire burden of TSCI in South Africa and Sweden is to be determined. In addition, further research is required in order to identify the factors influencing the leading causes of injury, by applying models such as Haddon's matrix and the Socio-ecological Model.

In line with studying the burden, studies investigating mortality and disability-adjusted life years lost due to TSCI in South Africa are required for a better understanding of the devastating effects of TSCI. This information is required for the discourse on the implementation of a systems approach towards the holistic management of TSCI.

The use of gold standard outcome measures in SCI rehabilitation in South Africa has not gained much momentum [20], a finding which is evident in other more developed settings [21]. With the mapping protocols providing the platform to evaluate the content validity of outcome measures, it is evident that disease-specific standardised outcome measures evaluate relevant functioning aspects to a greater degree than generic measures. It is therefore important to explore the unmet needs of survivors who underwent rehabilitation in order to strengthen the services necessary for achieving optimal outcomes. Moreover, in promoting good practice and as part of quality assurance, the evaluation of barriers to the implementation of outcome measures in the South African healthcare context is warranted.

The qualitative study provided valuable information on which aspects to consider when reclaiming participation after a TSCI. For this study, participation was not clearly defined and characterised but instead was perceived as an abstract concept that contained both performance indicators and subjective lived experiences. It is therefore important that further research is conducted in order to understand the nature of involvement in life situations and the way in which it is prioritised. This information will help guide the adoption and development of authentic measures of participation, and will also inform policymakers on the unmet needs of survivors in the local context.

### 6. CONCLUSIONS

- The incidence of adults with TSCI in a region of South Africa is high when compared with both Africa and the world at large.
- The leading cause of TSCI in South Africa was found to be assault. It is therefore important to assess the role of the socio-economic and political climate in fueling violent behaviours.
- The incidence of TSCI in Sweden remained stable when compared with the last report that was completed almost ten years ago. However, differences in the distribution of injury causes and neurological level were found, which may be useful for planning future prevention programmes.
- The content of an operative outcome measure used in SCI rehabilitation in South Africa was not fully conceptualised within the ICF and therefore was found to have limitations in its coverage of functioning aspects contained in the brief ICF core set for SCI. In addition, it was found that a gold standard functional rating scale not yet adopted in the context could be fully conceptualised within the ICF and covered all candidate categories of the 'activities and participation' domain of the brief core set.
- There is a need to adopt outcome measures capturing prototypical functioning aspects relevant to the SCI population.
- *Participation* is an outcome that persons with TSCI seek and is possible to reclaim following injury. Health professionals should understand the critical factors undermining and facilitating *participation* and use this information to facilitate the achievement of this outcome.

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#### 8. REFERENCES

- 1. Suarez NC, Levi R, Bullington J: **Regaining Health and Wellbeing after Traumatic Spinal Cord Injury**. *J Rehabil Med* 2013, **45**:1023-1027.
- 2. Potgieter C-A, Khan G: Sexual Self-esteem and Body Image of South African Spinal Cord Injured Adolescents. *Sex and Disabil* 2005, 23:1-20.
- 3. Anderson KD: Targeting Recovery: Priorities of the Spinal Cord-Injured Population. *J Neurotrauma* 2004, **21**:1371-1383.
- 4. Dahlberg A, Kotila M, Kautiaien H, Alaranta H: **Functional independence in persons with spinal cord injury in Helsinki**. *J Rehabil Med* 2003, **35**:217-220.
- 5. Carpenter C, Forwell SJ, Jongbloed LE, Backman C: **Community participation after spinal cord injury**. *ArchPhys Med Rehabil* 2007, **88**:427-433.
- 6. Barclay L, McDonald R, Lentin P: Social and community participation following spinal cord injury: a critical review. *Int J Rehabil Res* 2015, **38**:1-19.
- 7. Hammell KW: Quality of life after spinal cord injury: a meta-synthesis of qualitative findings. *Spinal Cord* 2007, **45**:124-139.
- 8. 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 2008, **31**:403-479.
- 9. Krueger H, Noonan VK, Trenaman L, Rivers C: **The economic burden of traumatic spinal cord injury in Canada**. *Chronic Dis Inj Can* 2013, **33**:113-122.
- 10. Viljoen W, Patricios J: **BokSmart implementing a National Rugby Safety Programme**. *Br J Sports Med* 2012, **46**:692-693.
- 11. 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* 2011, **49**:493-501.
- 12. **International Perspectives on Spinal Cord Injury**. In. Edited by Organisation WH. Geneva; 2012.
- 13. Joseph C, Scriba E, Wilson V, Mothabeng J, Theron F: Learning Health Systems for SCI in Republic of South Africa. *Am J Phys Med Rehabil* 2016 (Submitted).
- 14. Divanoglou A, Levi R: Incidence of traumatic spinal cord injury in Thessaloniki, Greece and Stockholm, Sweden: a prospective population-based study. *Spinal Cord* 2009, **47**:796-801.
- Levi R, Hultling C, Nash MS, Seiger A: The Stockholm spinal cord injury study:
   1. Medical problems in a regional SCI population. *Paraplegia* 1995, 33:308-315.
- 16. Lundström U, Lilja M, Petersson I, Lexell J, Isaksson G: Leisure repertoire among persons with a spinal cord injury: Interests, performance, and well-being. *J Spinal Cord med* 2014, **37**:186-192.
- 17. Nordgren C, Levi R, Ljunggren G, Seiger A: **Societal services after traumatic spinal cord injury in Sweden**. *J Rehabil Med* 2003, **35**:121-126.
- 18. WHO: **International Classification of Functioning, Disability and Health**. Geneva: World Health Organisation 2001.

- Joseph C, Rhoda A: Outcome measures used to assess disability post stroke within the framework of the ICF: a literature review. *J Commun Health Sci* 2011, 6:39-52.
- 20. Inglis G, Faure MR, Frieg A: **The awareness and use of outcome measures by South African physiotherapists**. *S Afr J Physiother* 2008 **64**:5-11.
- 21. Jette DU, Halbert J, Iverson C, Miceli E, Shah P: Use of standardized outcome measures in physical therapist practice: perceptions and applications. *Phys Ther* 2009, **89**:125-135.
- 22. Catz A, Itzkovich M, Agranov E, Ring H, Tamir A: **SCIM-Spinal Cord Independence Measure: A new disability scale for patients with spinal cord lesions**. *Spinal Cord* 1997, **35**:850-856.
- 23. Bluvshtein V, Front L, Itzkovich M, Aidinof E, Gelernter I, Hart J, *et al*: **SCIM III is** reliable and valid in a separate analysis for traumatic spinal cord lesions. *Spinal Cord* 2011, **49**:292-296.
- 24. Itzkovich M, Gelernter I, Biering-Sorensen F, Weeks C, Laramee MT, Craven BT, *et al*: **The Spinal Cord Independence Measure (SCIM) version III: reliability and validity in a multi-center international study**. *Disabil Rehabil* 2007, **30**:1926-1933.
- 25. van Hedel H, Wirz M, Dietz V: Assessing walking ability in subjects with spinal cord injury: validity and reliability of 3 walking tests. *Arch Phys Med Rehabil* 2005, **86**:190-196.
- 26. Magasi SR, Heinemann AW, Whiteneck GG: Participation Following Traumatic Spinal Cord Injury: An Evidence-Based Review for Research : Report on the National Institute on Disability and Rehabilitation Research Spinal Cord Injury Measures Meeting. J Spinal Cord Med 2008, 31:145-156.
- 27. Hammel J, Magasi S, Heinemann A, Whiteneck G, Bogner J, Rodriguez E: What does participation mean? An insider perspective from people with disabilities. *Disabil Rehabil* 2008, **30**:1445-1460.
- 28. Adams RD, Salam-Adams M: Chronic nontraumatic diseases of the spinal cord. *Neurol Clin* 1991, **9**:605-623.
- 29. Dawson DM, Potts F: Acute nontraumatic myelopathies. *Neurol Clin* 1991, **9**(3):585-603.
- 30. Kirshblum SC, Burns SP, Biering-Sorensen F, Donovan W, Graves DE, Jha A, *et al*: International standards for neurological classification of spinal cord injury (revised 2011). *Journal Spinal Cord Med* 2011, **34**:535-546.
- International Standards for the Neurological Classification of Spinal Cord Injury Revised 2011 (Booklet). Atlanta, GA: American Spinal Injury Association: 2011.
- 32. 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* 2010, **33**:346-352.
- 33. Sadeghi-Bazargani H: **Injury epidemiology and publishing injury research**. *J Inj Violence Res* 2012, **4**:1-1.
- 34. Gordon JE: **The Epidemiology of Accidents**. *Am J Public Health Nations Health* 1949, **39**:504-515.

- 35. Hanson DW, Finch CF, Allegrante JP, Sleet D: Closing the Gap Between Injury Prevention Research and Community Safety Promotion Practice: Revisiting the Public Health Model. *Public Health Rep* 2012, **127**:147-155.
- 36. Kirchberger I, Cieza A, Biering-Sorensen F, Baumberger M, Charlifue S, Post MW, *et al*: **ICF Core Sets for individuals with spinal cord injury in the early post-acute context**. *Spinal Cord* 2010, **48**:297-304.
- 37. Cieza A, Kirchberger I, Biering-Sorensen F, Baumberger M, Charlifue S, Post MW, *et al*: **ICF Core Sets for individuals with spinal cord injury in the long-term context**. *Spinal Cord* 2010, **48**:305-312.
- 38. Last JM: **Dictionary of epidemiology (4th ed)**. New York Oxford University Press; 2001.
- 39. Nijendijk JH, Post MW, van Asbeck FW: **Epidemiology of traumatic spinal cord injuries in the Netherlands in 2010**. *Spinal Cord* 2014, **52**:258-263.
- 40. Jazayeri SB, Beygi S, Shokraneh F, Hagen EM, Rahimi-Movaghar V: Incidence of traumatic spinal cord injury worldwide: a systematic review. *Eur Spine J* 2015, 24:905-918.
- 41. Sabre L, Pedai G, Rekand T, Asser T, Linnamagi U, Korv J: **High incidence of traumatic spinal cord injury in Estonia**. *Spinal Cord* 2012, **50**:755-759.
- 42. 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* 2013, **41**:65-85.
- 43. Velmahos GC, Degiannis E, Hart K, Souter I, Saadia R: Changing Profiles in Spinal Cord Injuries and Risk Factors Influencing Recovery after Penetrating Injuries. *J Trauma* 1995, **38**:334-337.
- 44. Hart C, Williams E: **Epidemiology of spinal cord injuries: a reflection of changes in South African society**. *Paraplegia* 1994, **32**:709-714.
- 45. Lee BB, Cripps RA, Fitzharris M, Wing PC: **The global map for traumatic spinal cord injury epidemiology: update 2011, global incidence rate**. *Spinal Cord* 2014, **52**:110-116.
- 46. Jain NB, Ayers GD, Peterson EN, Harris MB, Morse L, Garshick E, *et al*: **Traumatic Spinal Cord Injury in the United States, 1993-2012**. *JAMA* 2015, **313**:2236-2243.
- 47. Couris C, Guilcher S, Munce S, Fung K, Craven BC, Verrier M, *et al*: Characteristics of adults with incident traumatic spinal cord injury in Ontario, Canada. *Spinal Cord* 2010, 48:39-44.
- 48. Noonan VK, Fingas M, Farry A, Baxter D, Singh A, Fehlings MG, *et al*: **Incidence and prevalence of spinal cord injury in Canada: a national perspective**. *Neuroepidemiology* 2012, **38**:219–226.
- 49. Botelho RV, Albuquerque LD, Junior RB, Junior AA: **Epidemiology of traumatic** spinal injuries in Brazil: systematic review. *Arg Bras Neurocir* 2014, **33**:100-106.
- 50. Li J, Liu G, Zheng Y, Hao C, Zhang Y, Wei B, *et al*: **The epidemiological survey of acute traumatic spinal cord injury (ATSCI) of 2002 in Beijing municipality**. *Spinal Cord* 2011, **49**:777-782.

- 51. Rahimi-Movaghar V, Moradi-Lakeh M, Rasouli MR, Vaccaro A: **Burden of spinal** cord injury in Tehran, Iran. *Spinal Cord* 2010, **48**:492-497.
- New PW, Baxter D, Farry A, Noonan V: Estimating the incidence and prevalence of traumatic spinal cord injury in Australia. *Arch Phys Med Rehabil* 2015, 96:76-83.
- 53. 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* 2015, **53**:150-154.
- 54. Wyndaele M, Wyndaele JJ: Incidence, prevalence and epidemiology of spinal cord injury: what learns a worldwide literature survey? *Spinal Cord* 2006, 44:523-529.
- 55. Razdan S, Kaul RL, Motta A, Kaul S, Bhatt RK: **Prevalence and pattern of major neurological disorders in rural Kashmir (India) in 1986**. *Neuroepidemiology* 1994, **13**(3):113-119.
- 56. **Statistics South Africa** In. Pretoria: South Africa Government; 2011.
- 57. Quad-Para Association of South Africa comments on 2009/10 budget speech. [Retrieved on 21 January 2016]
- 58. Singh A, Tetreault L, Kalsi-Ryan S, Nouri A, Fehlings MG: **Global prevalence and** incidence of traumatic spinal cord injury. J *Clin Epidemiol* 2014, **6**:309-331.
- 59. Biering-Sorensen F, Scheuringer M, Baumberger M, Charlifue SW, Post MWM, Montero F, *et al*: **Developing core sets for persons with spinal cord injuries based on the International Classification of Functioning, Disability and Health as a way to specify functioning**. *Spinal Cord* 2006, **44**:541-546.
- 60. DeVivo M, Biering-Sorensen F, Charlifue S, Noonan V, Post M, Stripling T, *et al*: International Spinal Cord Injury Core Data Set. *Spinal Cord* 2006, 44:535-540.
- 61. Draulans N, Kiekens C, Roels E, Peers K: **Etiology of spinal cord injuries in Sub-Saharan Africa**. *Spinal Cord* 2011, **49**:1148-1154.
- 62. Igun GO, Obekpa OP, Ugwu BT, Nwadiaro HC: **Spinal injuries in the Plateau State, Nigeria**. *East Afr Med J* 1999, **76**:75-79.
- 63. van den Berg ME, Castellote JM, de Pedro-Cuesta J, Mahillo-Fernandez I: **Survival** after spinal cord injury: a systematic review. *J Neurotrauma* 2010, **27**:1517-1528.
- 64. Lidal IB, Snekkevik H, Aamodt G, Hjeltnes N, Biering-Sorensen F, Stanghelle JK: Mortality after spinal cord injury in Norway. *J Rehabil Med* 2007, **39**:145-151.
- 65. Wilson JR, Cadotte DW, Fehlings MG: Clinical predictors of neurological outcome, functional status, and survival after traumatic spinal cord injury: a systematic review. *J Neurosurg Spine* 2012, **17**:11-26.
- 66. Sabre L, Rekand T, Asser T, Korv J: **Mortality and causes of death after traumatic spinal cord injury in Estonia**. *J Spinal Cord Med* 2013, **36**:687-694.
- 67. Frankel HL, Coll JR, Charlifue SW, Whiteneck GG, Gardner BP, Jamous MA, *et al*: Long-term survival in spinal cord injury: a fifty year investigation. *Spinal Cord* 1998, **36**:266-274.

- 68. Daverat P, Gagnon M, Dartigues JF, Mazaux JM, Barat M: **Initial factors predicting survival in patients with a spinal cord injury**. *J Neurol, Neurosurg Psychiatry* 1989, **52**:403-406.
- 69. Furlan JC, Fehlings MG: **The impact of age on mortality, impairment, and disability among adults with acute traumatic spinal cord injury**. *J Neurotrauma* 2009, **26**:1707-1717.
- 70. O'Connor PJ: **Survival after spinal cord injury in Australia**. *Arch Phys Med Rehabil* 2005, **86**:37-47.
- Divanoglou A, Westgren N, Seiger Å, 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 2010, 33:117-127.
- 72. Montgomerie JZ: Infections in patients with spinal cord injuries. *Clin Infect Dis diseases* 1997, **25**:1285-1290.
- 73. Wu Q, Ning GZ, Li YL, Feng HY, Feng SQ: Factors affecting the length of stay of patients with traumatic spinal cord injury in Tianjin, China. *J Spinal Cord Med* 2013, **36**:237-242.
- Savic G, Short DJ, Weitzenkamp D, Charlifue S, Gardner BP: Hospital readmissions in people with chronic spinal cord injury. *Spinal Cord* 2000, 38:371-377.
- 75. Teasell RW, Arnold JM, Krassioukov A, Delaney GA: **Cardiovascular consequences of loss of supraspinal control of the sympathetic nervous system after spinal cord injury**. *Arch Phys Med Rehabil* 2000, **81**:506-516.
- 76. Lanig IS, Peterson WP: **The respiratory system in spinal cord injury**. *Phys Med Rehabil Clin N Am* 2000, **11**:29-43.
- 77. Brown DJ, Hill ST, Baker HW: Male fertility and sexual function after spinal cord injury. *Prog Brain Res* 2006, **152**:427-439.
- 78. Cardozo CP: **Respiratory Complications of Spinal Cord Injury**. *J Spinal Cord Med* 2007, **30**:307-308.
- 79. van Weert KC, Schouten EJ, Hofstede J, van de Meent H, Holtslag HR, van den Berg-Emons RJ: Acute phase complications following traumatic spinal cord injury in Dutch level 1 trauma centres. *J Rehabil Med* 2014, **46**:882-885.
- 80. Fielingsdorf K, Dunn RN: Cervical spine injury outcome--a review of 101 cases treated in a tertiary referral unit. *S Afr Med J* 2007, **97**:203-207.
- 81. 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* 2015 doi: 10.1038/sc.2015.189. [Epub ahead of print].
- 82. **Pressure ulcer prevention and treatment following spinal cord injury: a clinical practice guideline for health-care professionals**. *J Spinal Cord Med* 2001, **24**:S40-101.
- 83. Outcomes following traumatic spinal cord injury: clinical practice guidelines for health-care professionals. *J Spinal Cord Med* 2000, **23**:289-316.

- 84. Southern Africa Spinal Cord Association. [website http://www.sasca.org.za/ viewed on 21 January 2016]
- Hardcastle TC, Steyn E, Boffard K, Goosen J, Toubkin M, Loubser A, *et al*: Guideline for the assessment of trauma centres for South Africa. S Afr Med J 2011, 101:189-194.
- 86. **National Rehabilitation Policy**. In. Edited by Health Department. Pretoria Republic of South Africa; 2001.
- 87. Joseph C, Rhoda A, Mji G, Statham S, Mlenzana N, De Wet C: **Changes in activity limitations and predictors of functional outcome of patients with spinal cord injury following in-patient rehabilitation**. *S Afr J Physiother* 2013, **69**:47-53.
- 88. Bjerner B, Astrom J: **Treatment of paraplegic patients at the Danderyd rehabilitation clinic**. *J Rehabil Med* 1970, **2**:27-28.
- 89. Levi R, Hultling C, Seiger A: **The Stockholm Spinal Cord Injury Study: 2.** Associations between clinical patient characteristics and post-acute medical problems. *Paraplegia* 1995, **33**:585-594.
- 90. Levi R, Hultling C, Seiger A: **The Stockholm Spinal Cord Injury Study. 3. Health**related issues of the Swedish annual level-of-living survey in SCI subjects and controls. *Paraplegia* 1995, **33**:726-730.
- 91. Levi R, Hultling C, Seiger A: The Stockholm spinal cord injury study: 4.
   Psychosocial and financial issues of the Swedish annual level-of-living survey in SCI subjects and controls. *Paraplegia* 1996, 34:152-157.
- 92. Alexander MS, Anderson K, Biering-Sorensen F, Blight AR, Brannon R, Bryce T, *et al*: **Outcome Measures in Spinal Cord Injury: Recent Assessments and Recommendations for Future Directions**. *Spinal cord* 2009, **47**:582-591.
- 93. Cieza A, Brockow T, Ewert T, Amman E, Kollerits B, Chatterji S, *et al*: Linking health-status measurements to the international classification of functioning, disability and health. *J Rehabil Med* 2002, **32**:205-210.
- 94. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustun B, Stucki G: **ICF linking rules:** an update based on lessons learned. *J Rehabil Med* 2005, **37**:212-218.
- 95. Sacristán JA: **Patient-centered medicine and patient-oriented research:** improving health outcomes for individual patients. *BMC Med Inform Decis Mak* 2013, **13**:1-8.
- 96. Van de Velde D, Bracke P, Van Hove G, Josephsson S, Vanderstraeten G: **Perceived** participation, experiences from persons with spinal cord injury in their transition period from hospital to home. *Int J Rehabil Res* 2010, **33**:346-355.
- 97. Ruoranen K, Post MW, Juvalta S, Reinhardt JD: **Participation and integration from the perspective of persons with spinal cord injury from five European countries**. *J Rehabil Med* 2015, **47**:216-222.
- 98. Hemmingsson H, Jonsson H: **An occupational perspective on the concept of participation in the International Classification of Functioning, Disability and Health--some critical remarks**. *Am J Occup Ther* 2005, **59**:569-576.
- 99. Perenboom RJ, Chorus AM: Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). *Disabil Rehabil* 2003, **25**:577-587.

- 100. Angel S, Kirkevold M, Pedersen BD: Getting on with life following a spinal cord injury: Regaining meaning through six phases. *Int J Qual Stud Health Well-being 2010*, 4:39-50.
- 101. Sandelowski M, Barroso J: **Handbook for synthesizing qualitative research**: Springer Publishing Company; 2006.
- 102. Sandelowski M: Whatever happened to qualitative description? *Res Nurs Health* 2000, **23**:334-340.
- Landrum P, Schmidt N, Mclean A: Outcome-Oriented Rehabilitation: Principles, Strategies, and Tools for Effective Program Management. Aspen, Gaithersburg; 1995.
- 104. Catz A, Itzkovich M, Agranov E, Ring H, Tamir A: **The spinal cord independence measure (SCIM): sensitivity to functional changes in subgroups of spinal cord lesion patients**. *Spinal Cord* 2001, **39**:97-100.
- 105. Almeida C, Coelho JN, Riberto M: Applicability, validation and reproducibility of the Spinal Cord Independence Measure version III (SCIM III) in patients with non-traumatic spinal cord lesions. *Disabil Rehabil* 2016:[Epub ahead of print].
- 106. Cieza A, Stucki G: Content comparison of health-related quality of life (HRQOL) instruments based on the international classification of functioning, disability and health (ICF). *Qual Life Res:* 2005, **14**:1225-1237.
- 107. Elo S, Kyngas H: The qualitative content analysis process. J Adv Nurs 2008, 62:107-115.
- 108. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. *JAMA* 2013, **310**:2191-2194.
- 109. Coughlin SS: Ethical issues in epidemiologic research and public health practice. *Emerg Themes Epidemiol* 2006, **3**:16.
- 110. Denny CC, Grady C: Clinical research with economically disadvantaged populations. *J Med Ethics* 2007, **33**:382-385.
- 111. Hagen EM, Eide GE, Rekand T, Gilhus NE, Gronning M: A **50-year follow-up of the incidence of traumatic spinal cord injuries in Western Norway**. *Spinal Cord* 2010, **48**:313-318.
- 112. Koskinen EA, Alen M, Vaarala EM, Rellman J, Kallinen M, Vainionpaa A: Centralized spinal cord injury care in Finland: unveiling the hidden incidence of traumatic injuries. Spinal Cord 2014, 52:779-784.
- 113. Knutsdottir S, Thorisdottir H, Sigvaldason K, Jonsson H, Jr., Bjornsson A, Ingvarsson P: Epidemiology of traumatic spinal cord injuries in Iceland from 1975 to 2009. Spinal Cord 2012, 50:123-126.
- 114. Seedat M, Van Niekerk A, Jewkes R, Suffla S, Ratele K: **Violence and injuries in South Africa: prioritising an agenda for prevention**. *Lancet* 2009, **374**:1011-1022.
- 115. Norman R, Matzopoulos R, Groenewald P, Bradshaw D: **The high burden of** injuries in South Africa. *Bull World Health Organ* 2007, **85**:695-702.
- 116. Garrison A, Clifford K, Gleason SF, Tun CG, Brown R, Garshick E: Alcohol use associated with cervical spinal cord injury. *J Spinal Cord Med* 2004, 27:111-115.

- 117. Stroud MW, Bombardier CH, Dyer JR, Rimmele CT, Esselman PC: **Pre-injury alcohol and drug use among persons with spinal cord injury: Implications for rehabilitation**. *J Spinal Cord Med* 2011, **34**:461-472.
- 118. Elder RW, Shults RA, Sleet DA, Nichols JL, Thompson RS, Rajab W: Effectiveness of mass media campaigns for reducing drinking and driving and alcoholinvolved crashes: a systematic review. *Am J Prev Med* 2004, **27**.
- 119. Yadav R-P, Kobayashi M: A systematic review: effectiveness of mass media campaigns for reducing alcohol-impaired driving and alcohol-related crashes. *BMC Public Health* 2015, **15**:1-17.
- 120. Whittam K, Dwyer W, Simpson P: Effectiveness of a media campaign to reduce traffic crashes involving young drivers. *J Appl Soc Psychol* 2006, **36**.
- 121. Haddon Jr W: **The changing approach to the epidemiology, prevention, and amelioration of trauma: the transition to approaches etiologically rather than descriptively based**. *Am J Public Health Nations Health* 1968, **58**:1431-1438.
- 122. Sleet DA, Dahlberg LL, Basavaraju SV, Mercy JA, McGuire LC, Greenspan A: Injury prevention, violence prevention, and trauma care: building the scientific base. *MMWR supplements* 2011, **60**:78-85.
- 123. Dahlberg LL, Krug EG: **Violence--a global public health problem**. In: World report on violence and health, Geneva, Switzerland, World Health Organization [WHO], 2002: 1-21.
- 124. Centers for Disease Control and Prevention, National Center for Injury Prevention and Control, Division of Violence Prevention [Retrieved from http://www.cdc.gov/violenceprevention/].
- 125. Moriello C, Byrne K, Cieza A, Nash C, Stolee P, Mayo N: Mapping the Stroke Impact Scale (SIS-16) to the International Classification of Functioning, Disability and Health. *J Rehabil Med* 2008, **40**:102-106.
- 126. Stucki A, Stucki G, Cieza A, Schuurmans MM, Kostanjsek N, Ruof J: **Content comparison of health-related quality of life instruments for COPD**. *Respir med* 2007, **101**:1113-1122.
- 127. Prodinger B, Ballert CS, Cieza A: Setting up a cohort study of functioning: From classification to measurement. *J Rehabil Med* 2016, **48**:131-140.
- 128. Piškur B, Daniëls R, Jongmans MJ, Ketelaar M, Smeets RJ, Norton M, et al: Participation and social participation: are they distinct concepts? Clin Rehabil 2014, 28:211-220.
- 129. Reinhardt JD, Ruoranen K, Graf S, Horsewell J, Leiulfsrud A, Post MWM: 'It takes two to tango ...' revisited: a qualitative study on integration and participation of people living with spinal cord injury in Switzerland. *Disabil & Soc* 2013, **28**:893-907.
- 130. Ripat JD, Woodgate RL: Self-perceived participation among adults with spinal cord injury: a grounded theory study. *Spinal Cord* 2012, **50**:908-914.
- 131. Angel S, Kirkevold M, Pedersen BD: **Rehabilitation as a fight: A narrative case** study of the first year after a spinal cord injury. *Int J Qual Stud Health Well-Being* 2009, **4**:28-38.

- 132. Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly: UN General Assembly; 2007.
- 133. Lofvenmark I, Norrbrink C, Nilsson Wikmar L, Lofgren M: 'The moment I leave my home there will be massive challenges': experiences of living with a spinal cord injury in Botswana. *Disabil Rehabil* 2015. [Epub ahead of print].
- 134. Whiteneck G, Meade MA, Dijkers M, Tate DG, Bushnik T, Forchheimer MB: Environmental factors and their role in participation and life satisfaction after spinal cord injury. *Arch Phys Med Rehabil* 2004, **85**:1793-1803.
- 135. Reinhardt JD, Ballert C, Brinkhof MW, Post MW: **Perceived impact of environmental barriers on participation among people living with spinal cord injury in Switzerland**. *J Rehabil Med* 2016, **48**:210-218.
- 136. Barclay L, McDonald R, Lentin P, Bourke-Taylor H: Facilitators and barriers to social and community participation following spinal cord injury. *Aust Occup Ther J* 2016, **63**:19-28.
- 137. Veith EM, Sherman JE, Pellino TA, Yasui NY: Qualitative analysis of the peermentoring relationship among individuals with spinal cord injury. *Rehabil Psychol* 2006, **51**:289.
- 138. Sweet SN, Noreau L, Leblond J, Martin Ginis KA: **Peer support need fulfillment among adults with spinal cord injury: relationships with participation, life satisfaction and individual characteristics**. *Disabil Rehabil* 2016, **38**:558-565.
- 139. Ljungberg I, Kroll T, Libin A, Gordon S: Using peer mentoring for people with spinal cord injury to enhance self-efficacy beliefs and prevent medical complications. *J Clin Nurs* 2011, **20**:351-358.
- 140. Emirbayer M, Mische A: What Is Agency? *Am J Sociol* 1998, **103**:962-1023.
- Lieb R: Population-Based Study. In: Encyclopedia of Behavioral Medicine. edn. Edited by Gellman MD, Turner JR. New York, NY: Springer New York; 2013: 1507-1508.
- 142. Rothman KJ: Epidemiology: an introduction: Oxford University Press; 2012.
- 143. Selvarajah S, Hammond ER, Haider AH, Abularrage CJ, Becker D, Dhiman N, *et al*: **The burden of acute traumatic spinal cord injury among adults in the united states: an update**. *J Neurotrauma* 2014, **31**:228-238.
- 144. Cohen J: A Coefficient of Agreement for Nominal Scales. *Educ Psychol Meas* 1960, **20**:37-46.
- 145. Sim J, Wright CC: The Kappa Statistic in Reliability Studies: Use, Interpretation, and Sample Size Requirements. *Phys Ther* 2005, **85**:257-268.
- 146. Lincoln YS, Guba EG: Naturalistic inquiry: Sage; 1985.
- 147. Guba EG: Criteria for assessing the trustworthiness of naturalistic inquiries. *ECTJ* 1981, **29**:75-91.
- 148. Shenton AK: **Strategies for ensuring trustworthiness in qualitative research projects**. *Educ Inform* 2004, **22**:63-75.