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Traumatic spinal cord injuries in rural Tanzania

Occurrences, clinical outcomes and life
situations of persons living in the
Kilimanjaro region

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“A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles.” –Christopher Reeve

To my family, who have always been behind my fight for a successful service, and to all persons who endure the hardship of living with traumatic spinal cord injury in inaccessible and resource-constrained areas – You are the heroes!

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Abstract

Background: Traumatic spinal cord injury (TSCI) is one of the most troubling health conditions, as it leaves the inflicted individual with irreversible sensorimotor impairment. Major known causes of TSCI are road traffic accidents, falls and assaults, but etiology varies geographically with variation in socioeconomic infrastructure safety. Instant evacuation from accident scenes, timely transportation and acute specialized intensive care are crucial to sustaining the life of the injured person. Those who survive the most fatal, acute phases are continuously at risk for complications such as pressure ulcers, urinary tract and other infections, spasms and neuropathic pain. Living with a spinal cord injury requires continuous medical and rehabilitation services throughout life to facilitate health, functioning, independence and participation in the community. Rural areas of Tanzania and other low-income countries are characterized by inadequate emergency, medical and rehabilitation services, and are mostly inaccessible by wheelchair. These features expose persons who sustain TSCI in these areas to a high risk of death instantly or during acute phases, SCI-related complications and a poor quality of life (QoL). However, little is documented on the epidemiology, outcomes and QoL of persons with SCI in these settings. The studies in this thesis aimed to create an understanding of the epidemiology and clinical outcomes of SCI, as well as living with the condition, in typical rural areas of a low-income country.

Methods: Four studies were conducted, with two being hospital-based and two being carried out in the community. Both qualitative and quantitative methods were used. A retrospective study assessed the magnitude, etiology and clinical outcomes of SCI for the past five years (2010-2014) by using patients' data from the archives of the Kilimanjaro Christian Medical Centre (KCMC). In the same settings, another study assessed the same variables prospectively for one year (2017), with greater focus being placed on classifying the severity of injury and health complications. In the community, a qualitative study was used to conceptualize coping resources for persons with SCI in one study, while in another the WHOQoL-BREF questionnaire was used to assess the quality of life of these persons quantitatively.

Results: The **retrospective study** obtained 213 full patient records in which the leading cause of injury was falls at 104(48.8%), followed by road traffic accidents at 73(34.3%). The annual incidence for the Kilimanjaro region (population 1,640,087) was estimated at more than 26 persons per million for this period. The most documented complications were pressure ulcers at 19.7%, respiratory complications at 15.0% and multiple complications at 13.1%. The in-hospital mortality rate was 24.4%. The **prospective study** involved 87 persons

who sustained SCI in 2017, of whom 66.66% were due to falls (especially from a position of height), 28.7% to road traffic accidents and 4.6% to other causes. The annual incidence rate based on the Kilimanjaro region (population 1,910,555) was estimated at more than 38 new cases per million people. The majority of the injuries occurred at the cervical (56.3%) and lumbar (31%) levels. Most of the injuries (59.8%) were incomplete, while 40.2% were complete. The **questionnaire study** reports that the majority of the participants rated their quality of life as neither poor nor good at 39(48.8%) and poor life at 20 (25%). The mean score for domains of QoL showed the highest scores in social relations and psychological well-being, while the lowest scores were rated for physical health and environment. There was no significant mean difference in the score of domains based on sociodemographic characteristics, except for physical, in which quadriplegia scored lower than paraplegia ($p = 0.038$). The **qualitative interview study** identified acceptance as the core category for identification and utilization of both internal and external coping resources for persons with TSCI in the community. Internal coping resources were: secured in God, increase in awareness of health risks, problem-solving skills and social skills. External coping resources were: having a reliable family, varying support from the community, a matter of possession and left without means of mobility.

Conclusion: Most of the traumatic SCIs in the rural area of Kilimanjaro are due to falls, followed by road traffic accidents. SCI-related complications are common, and hospital mortality is still high. Persons with SCI face various challenges pertaining to health and accessibility that affect them physically, psychologically, socially and environmentally. However, some have managed to accept their conditions, they have identified and utilized available internal and external coping resources to survive the hostile conditions of these settings. Establishment of emergency and critical care services, trauma registries, community-based rehabilitation and population-based surveys would address major issues pertaining to TSCI in these areas.

Key words: Traumatic spinal cord injury, rural. Low income countries, outcomes, quality of life.

Abbreviations

ADL	Activities of Daly Living
AIDS	Acquired Immunodeficiency Syndrome
AIS	American Impairment Scale
ASIA	American Spinal Cord Injury Association
CT-scan	Computed Tomography scan
HIV	Human Immunodeficiency Virus
ICF	International Classification of Functioning and Disability
ISCOS	International Spinal Cord Society
KCMC	Kilimanjaro Christian Medical College
LIC	Low Income Countries
LOS	Length of Stay
MRI	Magnetic Resonance Imaging
ORU KCMC	Orthopedic Rehabilitation Unit at KCMC
QoL	Quality of Life
RTA	Road Traffic Accident
SCI	Spinal Cord Injury
TB spine	Tuberculosis of the spine-Pott's disease
TSCI	Traumatic Spinal Cord Injury
UTI	Urinary Tract Infection
WHO	World Health Organization
WHOQoL-BREF	WHO Quality of Life questionnaire short version

Definitions of terms

Incident scene	Incident scene is the place where the injury occurred. It is the place where the injured person was found.
Evacuation	The activities involved to move the injured person from the danger or accident scene before transportation.
Acute TSCI	Refers to the early hours and the first few days after TSCI. At this period, the individual is fragile and requires intensive care to stabilize the cardiorespiratory, vascular, digestive and other vital systems[1-3].
Sub-acute phase	Is the phase at which the person with a TSCI is out of organ failure and still has the potential for further neural and functional recovery. This phase can last as long as 18 months. The patient is normally in the general ward, spinal rehabilitation unit or at home while continuing with active rehabilitation [1].
Chronic phase	This is a period exceeding 18 months whereby hope for neural recovery is faint. Normally the person with TSCI is in the community and the priorities are on community re-integration rather than on medical treatment and therapy [1].
High TSCI	This is an injury at the cervical region above the nerve root C5. High TSCI is considered the most serious and life threatening due to its interference with cardiorespiratory functions [2].
Snowballing	Sampling technique used to identify hidden populations. In this case, the initial participants identify subsequent eligible study subjects with similar characteristics, to be included in the study [4-6].
Fall from height	This refers to a fall from a height of more than one meter above the ground. This could be from a tree, balcony, or construction site, or a dive from a cliff.

Enkel sammanfattning på Svenska

Bakgrund: Traumatisk ryggmärgsskada medför ett allvarligt hälsotillstånd, där individen förlorar sin rörelseförmåga med irreversibel sensorimotorisk försämring som följd. Viktiga kända orsaker till traumatisk ryggmärgsskada är trafikolyckor, fall och överfall. Orsakerna varierar från land till land där även socioekonomisk infrastruktur och säkerhet i samhället har betydelse. Ett omedelbart omhändertagande på olycksplatsen, snabb transport till sjukhus och akut specialiserad intensivvård är avgörande för att rädda livet för den skadade personen. De som överlever akutfasen står kontinuerligt i risk för komplikationer såsom trycksår, urinvägs- och andra infektioner, spasmer och neuropatisk smärta. Att leva med ryggmärgsskada kräver kontinuerlig medicinsk vård och rehabilitering för att bevara hälsa, funktion, oberoende och deltagande i samhället. Landsbygdsområden i Tanzania och andra låginkomstländer präglas av otillräckliga akutmedicinska- och rehabiliteringsresurser och samhället är oftast otillgängligt för den som är rullstolsburen. Detta medför att personer med ryggmärgsskada, boende på landsbygden i ett låginkomstland, löper risk för död antingen omedelbart vid olyckstillfället eller i akut och kronisk fas som följd av komplikationer och dålig livskvalitet (QoL). Studierna i denna avhandling syftade till att skapa förståelse för förekomsten och kliniskt utfall vid traumatisk ryggmärgsskada och livssituationen för personer som ådragit sig denna skada i ett typiskt landsbygdsområde i Tanzania.

Metoder: Fyra studier genomfördes i denna avhandling. Två studier var sjukhusbaserade och två genomfördes i samhället. Både kvalitativa och kvantitativa metoder användes. En retrospektiv studie utvärderade antal patienter, etiologi och klinisk bild under fem år (2010-2014) genom att studera patientdata från journalarkiv vid Kilimanjaro Christian Medical Center (KCMC). På samma sätt bedömdes i en annan studie samma variabler prospektivt för ett år (2017) med större fokus på att klassificera svårighetsgraden av skador och hälsokomplikationer. I samhällsstudierna användes kvalitativ intervjustudie för att studera coping och strategier för att leva med traumatisk ryggmärgsskada i ett samhälle med låg socioekonomi samt samhällelig infrastruktur, och ett frågeformulär utformat av WHO, WHOQoL-BREF-för att studera livskvalitet.

Resultat: I den retrospektiva studien fanns fullständiga data för 213 personer, där den främsta orsaken till ryggmärgsskada var fall 48,8% följt av trafikolyckor 34,3 %. Den årliga incidensen för ryggmärgsskador i Kilimanjaro-regionen (befolkning 1 640 087) uppskattades till mer än 26 personer per en miljon invånare under perioden 2014-2017. De vanligast dokumenterade komplikationerna var trycksår 19,7 %, respiratoriska komplikationer 15,0% och multipla komplikationer 13,1%. Dödligheten på sjukhus var 24,4%. Den

prospektiva studien omfattade 87 personer som vårdades för ryggmärgsskada år 2017, varav 66,7 % berodde på fall (särskilt från höjd), 28,7% på trafikolyckor och 4,6 % på andra orsaker. Ettårsincidensen baserad på Kilimanjaro-regionens befolkning (1 910 555) uppskattades till mer än 38 nya fall per en miljon invånare. Majoriteten av skadorna var lokaliserade till halsryggs- 56,3 % och ländryggsregionen 31 %. De flesta av skadorna 59,8% var inkompleta och 40,2 % kompletta ryggmärgsskador. Frågeformuläret visade att ungefär hälften av de svarande 48,8 % bedömde livskvaliteten som varken dålig eller bra och endast 25 % att de hade ett dåligt liv. Den genomsnittliga poängen för de olika domänerna i frågeformuläret visade högst poäng för sociala relationer och psykologiskt välbefinnande medan lägst poäng bedömdes för fysisk hälsa och miljö. Det fanns ingen signifikant medelskillnad i poäng avseende sociodemografiska förhållanden med undantag för fysisk omgivning ($p = 0,038$) vid jämförelser mellan ryggmärgsskada i halsryggs- och ländryggsregionen. Den kvalitativa intervjuundersökningen identifierade acceptans som huvudkategori där både interna och externa copingresurser var viktiga för personerna för att kunna leva i samhället. Interna hanteringsresurser var att förlita sig på Gud, öka medvetenheten om hälsorisker vid ryggmärgsskada, ökad problemlösningsförmåga och social kompetens. Externa copingresurser var att ha en pålitlig familj, stöd från samhället, och möjlighet röra sig i samhället.

Slutsats: De flesta traumatiska ryggmärgsskador i Kilimanjaro landsbygdsregion beror på fall följt av trafikolyckor. Komplikationer i samband med ryggmärgsskada är vanliga och sjukhusdödligheten är fortfarande hög. Personer med ryggmärgsskada står inför olika utmaningar om hälsa och tillgänglighet som påverkar dem fysiskt, psykiskt och i sociala relationer. För att lyckas är det viktigt att acceptera den nya livssituationen, identifiera och utnyttja tillgängliga interna och externa resurser för att överleva i de svåra omständigheter som en ryggmärgsskada innebär i ett underutvecklat land. Upprättande av akuta vårdtjänster, traumaregister, samhällsbaserad rehabilitering och befolkningsbaserade undersökningar skulle kunna belysa de stora problemen som finns kring omhändertagande och rehabilitering av personer med ryggmärgsskador.

Nyckelord: Traumatisk ryggmärgsskada, landsbygd, låginkomstländer, kliniska utfallsmått, livskvalitet

Muhtasari

Utangulizi: Kuumia uti wa mgongo ni miongoni mwa changamoto kubwa ya kiafya kwani inapomuacha muhanga na madhara yasiyorekebika katika mwili. Sababu kuu zinazojulikana kusababisha kuumia uti wa mgongo ni ajali za vyombo vya moto, kuanguka na kupigwa ingawa sababu zinaweza kutofautiana kulingana na ukanda, tofauti za maisha kijamii na kiuchumi katika miundombinu ya kiusalama. Uokoaji wa haraka kutoka eneo la ajali, usafirishwaji kwa wakati na huduma maalumu ya awali ni muhimu katika kunusuru uhai wa mtu aliyejeruhiwa. Wale wanaonusurika kufa katika kipindi cha mwanzoni mara kwa mara wapo hatarini kupata madhara kama vidonda mgandamizo, maambukizi kwenye njia ya mkojo na pengineko, kukakamaa misuli na maumivu yatokanayo na mishipa ya neva. Kuishi na uti wa mgongo ulioumia kunahitaji huduma za kitabibu na utengemavu bili ukomo kwa kipindi chote cha maisha ili kuwa na afya bora, utendeaji, kujitegemea na ushiki katika jamii. Maeneo ya vijijini Tanzania, na nchi nyinginezo zenye hali duni kiuchumi zinatambulika kwa kuwa na uhaba wa huduma za dharura, kitabutu na utengemavu, pia kwa kiasi kikubwa maeneo mengine hayafikiki kwa viti-mwendo. Vitu hivi vinawaweka watu walioumia uti wa mgongo katika maeneo haya kuwa katika hatari kubwa ya kufa papo hapo au katika kipindi cha mwanzo tu baada ya ajali, kupata madhara yatokanayo na kuumia uti wa mgongo na kuwa na hali duni kimaisha. Hata hivyo, ni kwa uchache imeandikwa kuhusu epidemiolojia, matokeo na hali ya maisha ya watu walioumia uti wa mgongo kwenye maeneo haya. Tafiti ndani ya hili andiko zililinga kujenga uelewa kuhusu epidemiolojia, matokeo ya tiba na maisha ya kuumia uti wa mgongo hususani maeneo ya vijiji katika nchi zenye uchumi duni.

Muongozo wa utafiti: Tafiti nne zilifanyika hospitali na kwenye jamii. Mbili kati ya hizi zilihusha hospitali na nyingine mbili zilifanyika kwenye jamii. Mahojiano pamoja na takwimu zilitumika. Kwa kutizama nyuma, utafiti juu ya ukubwa wa tatizo, visababishi na matokeo ya tatizo kwa miaka mitano iliyopita (2010-2014) ulifanyika kwa kutumia takwimu za wagonjwa katika hospitali ya rufaa KCMC. Katika mazingira ya hospitali, utafiti mwingine uliangalia vipengele hivivi kwa tizama mwaka mmoja mbele (2017), ukilenga zaidi kuainisha ukubwa wa kuumia pamoja na athari zake. Kwa upande wa jamii, mahojiano ya kina yalitumika katika utafiti mmoja kupata uhalisia wa nyenzo zinazotumiwa na watu waishio na uti wa mgongo ulioumia, utafiti mwingine ulitumia dodoso la Shirika la Afya Duniani la kutathmini ubora wa maisha (WHOQoL-BREF) kwa njia ya mahojiano.

Matokeo: Utafiti uliojikita kuangalia kipindi cha nyuma kwa kuhusisha takwimu za wagonjwa 213, ulibainisha sababu kuu ya kuumia kuwa ni, kuanguka 104(asilimia 48.8), ikifuatiwa na ajali za barabarani 73 (asilimia 34.3). Kwa

mwaka, mkoani Kilimajaro (yenye watu 1,640,087) kiwango cha kuumia kilikadiriwa kuwa zaidi ya watu 26 kwa kila watu milioni moja. Miongoni mwa madhata makubwa yaliyoainishwa yalikiwa vidonda mgandamizo asilimia 19.7, madhara kwenye mfumo wa upumuaji asilimia 15.0 na mengineyo mchanganyiko yalikuwa asilimia 13.1. Hospitalini kiwango cha vifo kilikwa asilimia 24.4. Utafiti uliotizama upeo ulihusisha watu 87 walioumia uti wa mgongo mwaka 2017 ambao asilimia 66.7 walioumia kutokana na kuanguka (kutoka juu), asilimia 28.74 ajali za barabarani na asilimia 4.6 sababu nyinginezo. Kiwango cha kuumia kwa mwaka mkoani Kilimanjaro (idadi ya watu 1,910, 555) kilikadiriwa kuwa zaidi ya wahanga wapya 38 kati ya watu milioni moja. Idadi kubwa ya kuumia ilishusisha semenu ya shingo asilimia 56.3 na kiunoni asilimia 31. Kwa kiasi kikubwai (asilimia 59.8) kuumia kulikuwa kwa moja kwa moja na asilimia 40.2 kwa kiasi. Utafiti uliotumia dodoso, ulionyesha kuwa idadi kubwa ya washiriki kuwa na hali ya maisha isiyo duni wala nzuri 39 (asilimia 48.8%) na hali duni 20 (asilimia 25). Wastani wa hali ya maisha ulionyesha kuwa bora kwenye eneo la mahusiano ya kijamii na hali ya kisaikolojia, wakati wastani wa chini uliripotiwa katika eneo la afya ya mwili na mazingira. Hapakuwepo na uhusiano kati ya hali ya maisha iliyoripotiwa katika vipengele vya kijamii-kiuchumi isipokuwa kwa kipengele cha hali ya mwili ambapo walioumia eneo la chini na juu katika mwili walionyesha kuwa na hali duni zaidi ya walioumia sehemu ya chini ya mwili. Mahojiano ya kina yalibainisha kuwa kujikubali ilikuwa ni kiini cha kutambua na kutumia mbino binafsi na za ziada kukabilina na hali ya kuumia kwa katika jamii. Mbinu binafsi za kukabilina na kuumia zilibainishwa kuwa; kumtegemea Mungu, ongezeko la uelewa katika afya na madhara, mbinu za utatuzi wa matatizo na mbinu za kijamii. Mbinu za ziada katika kujimudu zilikuwa; kuwa na familia yenye msaada, usaidizi tofauti tofauti kutoka kwa jamii, kuwa na mali pamoja na kukosa namna ya kujongea.

Hitimisho: Kwa kiasi kikubwa kuanguka pamoja na ajali za barabarani ziliongoza kuumia uti wa mgongo katika maeneo ya vijijini, mkoni Kilimanjaro. Madhara yatokanayo na kuumia uti wa mgongo kupo na idadi ya vifo hospitalini bado ni kubwa. Watu walioumia uti wa mgongo wanakumbana na changamoto mbalimbali kiafya pamoja na kiuwezo inayopelekea kuwaathiri kimwili, kisaikolojia, kimausiano, kijamii na kimazingiral. Hata hivyo, baadhi wamefanikiwa kukubali hali yao, kubainisha na kutumia mbinu binafsi na za ziada kukabilina na kuishi katika mazingira magumu. Kuanzishwa kwa huduma maalum ya mwanzo, masjala za majeruhi, huduma za utengemavu kwenye jamii pamoja na tafiti zitaweza kutatua mambo muhimu hususani kuhusu kuumia uti wa mgongo katika mazingira haya.

Maneno muhimu: Kuumia uti wa mgongo, vijiji, nchi zenye hali, duni, matokeo, hali ya maisha.

Original papers

This thesis is based on the following papers:

- I. Moshi H, Sundelin G, Sahlén K-G, Sörlin A. *Traumatic spinal cord injury in the north-east Tanzania – describing incidence, etiology and clinical outcomes retrospectively*. *Global Health Action*, 2017. 10(1): p. 1355604.
- II. Moshi H, Sundelin G, Sahlén K-G, Sörlin A. Incidence of traumatic spinal cord injury and prevalence of medical complications among hospitalized patients at Kilimanjaro: A one-year prospective study. Manuscript
- III. Moshi H, Sundelin G, Sahlén K-G, Sörlin A. Quality of life of persons with traumatic spinal cord injury in rural Kilimanjaro, Tanzania: A community survey. Manuscript Submitted
- IV. Moshi H, Sundelin G, Sahlén K-G, Anthea R, Sörlin A. *Coping Resources for Persons With Traumatic Spinal Cord Injury in A Tanzania Rural Area*. *Global Journal of Health Science*, 2018. 10(5): p. 138-153.

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Paper IV Canadian Center of Science and Education

Thesis at a glance

	Paper I	Paper II	Paper III	Paper IV
Title	<i>Traumatic spinal cord injury in the north-east Tanzania – describing incidence, etiology and clinical outcomes retrospectively</i>	Incidence, severity and outcomes of traumatic spinal cord injury in rural Kilimanjaro-Tanzania: A one-year prospective study.	Quality of life of persons with traumatic spinal cord injury in rural Kilimanjaro, Tanzania: A community survey.	<i>Coping Resources for Persons With Traumatic Spinal Cord Injury in A Tanzania Rural Area.</i>
Aim	To describe incidence, etiology and clinical outcomes in TSCI in rural Tanzania	To register the clinical outcomes following the ASIA impairment scale, during 1 year	To describe the QoL of persons living long with TSCI	Explore factors behind successful living of persons with TSCI
Study design	Retrospective	Prospective	Survey study	Qualitative study
Measurement	KCMC patient records	KCMC patient records	WHOQoL BREF questionnaire	Interviews
Result	Incidence rate estimated to 26/ 1 million population. Primary cause of TSCI was due to falls.	Incidence rate at 38/million Pressure ulcers, respiratory problems and UTI were the most common complications	In all four domains, persons with TSCI in rural areas of Kilimanjaro reported low QoL.	Acceptance was the core category

Introduction

A traumatic spinal cord injury (TSCI) is a sudden (often permanent) forceful damage to the spinal nerves that has long-lasting and overwhelming consequences. The immediate outcomes of TSCIs could be death at the accident scene, during transportation or in the early days of hospitalization. Those who do survive remain with partial or fully impaired sensory and motor functions that lead to activity limitations and participation restrictions throughout life [7, 8]. The impaired functioning of the neuromuscular system may also lead to spasms and neuropathic pain. Persons with TSCIs are continuously exposed to SCI-related complications such as pressure ulcers, urinary tract infections (UTI), pulmonary infections and deep vein thrombosis [9]. There are also rare and yet significant complications that they face, such as heterotrophic ossification and chronic dizziness (due to sympathetic dysfunction). The combination of these physiological, functional impairments and the likelihood of complications and death has a negative psychological impact on the individual and family [10]. While advances have been made in the treatment and rehabilitation of consequences resulting from TSCIs [11], recovery of a severed nerve is still a challenge for which there is still not an adequate solution [12-14]. Massive cost is incurred by individuals, families, governments, insurance companies and scientists in treating and caring for individuals who sustain TSCIs [15, 16].

The consequences of TSCIs can be viewed from various angles. Firstly, they may lead to death of relatively young persons of between 15 and 45 years of age on average [7, 17, 18]. Death at this age is, of course, a major loss to affected families and communities. This is the age at which young persons are starting to assume responsibilities in academics, work and family after having had so much invested in them. If the individual is fortunate enough to survive, the entire future life is very demanding in terms of medical and rehabilitation services. Direct costs associated with TSCIs include acute medical and surgical management, continuous checkups and treatment of secondary complications, and the replacement or repair of assistive devices for mobility, functioning and self-care [15, 19-21]. In a scenario where a young parent suffers a TSCI, the socioeconomic life of the affected individual and his or her dependents is affected. Such a situation has a widespread and long-term effect on dependents, especially children. Not only is the ability to care for self and others deterred but also one's sexual life. This combination of physical, socioeconomic and sexual dysfunction has a negative psychological impact affecting self-esteem, body image and perceived roles among others. For this reason, psychological conditions such as anxiety, increased anger, depression and suicidal thoughts are common among persons with TSCI.

The magnitude of TSCIs has been little studied, with most reports having been issued on work conducted in high-income countries. The fewest reports on the incidence and prevalence of TSCI have emanated from Africa and other low- and middle-income regions [22-24]. A general look at individual studies and systematic reviews reveals that the majority have reported on incidence rates rather than prevalence [18, 25-30]. This is an indication that most reports have been hospital- and registry-based rather than population survey and cohorts. Regardless of the setting, most reports have failed to account for those who die before reaching the hospital. The difficulty of doing so may be due to the fact that in most settings radiological investigation of the vertebral column is not a common procedure during post mortem. Another observation is that incidents of traumatic spinal cord injury have been on the rise in many countries, simultaneously with increases in the aging population and the use of motorized vehicles. However, when compared to other neurological conditions of the central nervous system such as stroke and head injury, TSCI is of a lower incidence. Nevertheless, life-long consequences of TSCI to individuals, families, healthcare institutions and society at large makes it one of the major health threats [31].

Although road traffic accidents (RTAs) are the leading cause of TSCIs, causes of TSCI is not uniform across the world. Leading causes of TSCI change with the times and the predominant socioeconomic activities. For example, recent reports have shown a trend in which there is an increase of incidents of TSCI due to falls, as well as affecting people of older age, being incomplete and happening at the cervical region [30, 32, 33]. While in other settings this trend can be explained by reduction in TSCIs due to RTAs, in most areas this is due to an increase in the aging population as a result of increased life expectancy. While low falls resulting in TSCIs are more prevalent in high-income countries, there are more incidents of falling from height leading to TSCIs in low-income settings. This is a result of unsafe construction sites and the tradition of climbing trees for various socioeconomic reasons.

TSCIs pose a greater threat in rural Tanzania and other low-income countries (LIC) in general. First, prevention of TSCIs in these settings is complex because most of the trauma are a result of poorly constructed residential or work structures as well as risky, yet crucial and meaningful, socioeconomic activities. Another challenge is a lack of paramedic services for evacuation and the difficulty of providing basic life support during transportation of persons with TSCIs to hospitals [34]. The majority of TSCI patients are transported to hospitals in personal vehicles, and are handled by laypersons who may not know what to do and what not to do. Many hospitals in LIC may not have appropriately trained personnel, equipment and medication to manage a case of TSCI at the acute and most fragile phase [3]. Specialized SCI rehabilitation units are scarce and lack basic care and therapy equipment. It is costly to manage and rehabilitate a person

with a TSCI, as this is typically a health condition. With their inadequate budgets, most governments in these settings cannot meet even the most basic needs of this group [35].

In Tanzania and other sub-Saharan Africa settings, TSCI competes for healthcare resources with communicable diseases such as malaria and HIV-AIDS, which are already of national and international concern [36]. Furthermore, non-communicable diseases such as diabetes, obesity and hypertension have started to become the focus of attention in these regions [37, 38]. For this reason, trauma and TSCI in the rural areas of Tanzania and other sub-Saharan Africa have been overshadowed by other health concerns. For these (and other reasons) trauma and TSCI in these settings are relatively less prioritized in terms of prevention programs, research studies and rehabilitation services. This may partly explain the scarcity of studies focusing on trauma from this setting, as well as the unmet rehabilitation needs of people suffering from trauma. While the lack of epidemiological studies makes prevention difficult, the lack of awareness of hospital and community protocols for persons with TSCIs casts a shadow over the planning of rehabilitation services.

Traumatic spinal cord injury

Traumatic spinal cord injury (TSCI) is a sudden life-transforming insult of spinal neurons with long-lasting and broad physical, psychosocial and economic consequences [3, 39]. Damage to spinal neurons causes various degrees of motoric, sensory and autonomic dysfunction to organs below the level of lesion [12]. Such an injury normally happens as a result of a forceful partial or total destruction of spinal nerves after a derangement of structures responsible for its protection or nourishment [9]. Although mechanical force is the primary cause of nerve damage, a sequence of biochemical and morphological changes follow thereafter to cause a secondary injury to otherwise healthy neurons.

Classification of TSCIs can be based on the severity, location along the spinal column and type of skeletal injury [40, 41]. Severity of injury refers to the completeness of sensorimotor function and is normally identified by thorough neurological assessment [9]. The International Spinal Cord Society (ISCoS), recommends the use of the American impairment scale (AIS) in this regard [42]. The scale rates both sensory (0 to 2) and motor (0 to 5) functions for determination of both completeness and level of injury along the vertebral column [42, 43]. One important rule for determining the completeness of the injury is to assess the functioning of the most caudal part of the spinal cord (sacral sparing). The classification of the neurological functions is defined by sensory levels A to E and the muscle power grades 0 to 5 based on the AIS scale [44].

The injury could be in the cervical (tetraplegia), thoracic or lumbar regions (paraplegia). The higher the injury along the vertebral column, the more severe is the resulting disability and the risk of complications and death [3, 45]. For example, injury at the cervical region affects autonomic functions, respiration, whole trunk, and upper and lower limbs, while SCI at the lumbar (paraplegia) affects lower limbs and the small part of the trunk. For this reason, while persons with paraplegia are almost fully independent, those with quadriplegia are highly dependent on caretakers and other assistive devices for activities of daily living (ADL).

Another classification of TSCI considers the type and the extent of displacement or dislocation of the fractured vertebrae. The fracture could be compressed, burst, comminuted and wedged with or without displacement [46]. These types of skeletal injury depend on the magnitude and direction of the applied force. The accuracy in this classification is dependent on robust radiological investigations such as computed tomography scan (CT scan) and magnetic resonance imaging (MRI). Knowledge of the type and exact location of musculoskeletal injury in the spinal column is important for deciding appropriate management and taking necessary precautions for a better prognosis [47].

Causes of TSCI

Causes of TSCI are twofold: The initial mechanical distortion of neurons (primary) and the future biochemical insults that lead to future injury of the nerve fibers not injured in the first incident [48].

Mechanism and primary causes of TSCI

Due to its delicacy, the spinal cord is securely protected in a neural tube surrounded by meninges, cerebrospinal fluid and musculoskeletal structures. It typically takes a strong mechanical force to disrupt these protective structures for the spinal cord within to be injured. The tearing of a section in the vertebral column and the spinal cord occur as a result of compression, rotation, tension or sheering, or a combination of more than one destructive force [39, 49]. Such forceful tissue injuries distort the musculoskeletal plan of a segment in the vertebral column exposing the spinal cord, blood vessels and other soft tissues to mechanical injury. These destructive forces are normally a result of RTAs, falls, heavy load landing on the person's back or head, and other less common mechanisms. Globally, RTAs are the leading cause of TSCIs, followed by falls, but in some areas, such as Cape Town, South Africa, assaults are the most prevalent cause [50]. A trend has been observed in recent years in which incidents of TSCI due to falls are on the increase, affecting more of the aging population [32]. Other mechanical causes of TSCI are tearing by sharp, penetrating objects such as bullets or knives [39, 50-52]. However, there is no single predominantly leading

cause of TSCI in all settings globally [53]. This variation in the leading causes of TSCI can be explained by the fact that there is a geographical variation in the predominance of risky social, economic and cultural activities, as well as infrastructures, in the studied settings [54]. For this reason, different leading causes of TSCI are reported from different world regions, as shown in map figure 1 below [53].

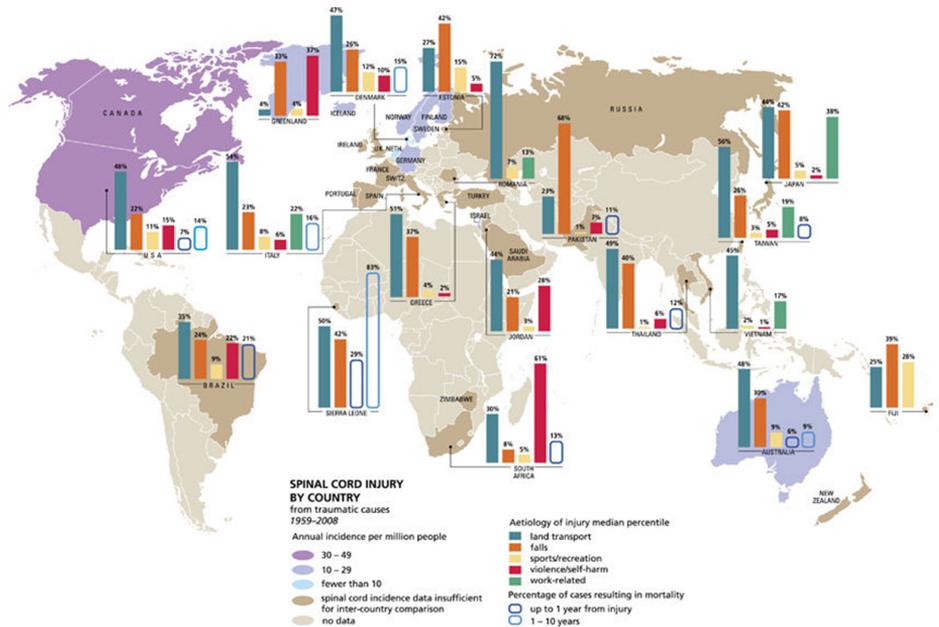


Figure 1: Spinal Cord Injury by WHO Global Regions from traumatic causes, 1959-2011 [53]

Secondary causes of TSCI

Nerves that survive the initial mechanical trauma are faced with a cascade of trauma due to inflammatory agents and other physiological changes in the next few days or weeks [48, 55]. Firstly, persistent hypovolemia due to autonomic dysfunction or vessel injury leads to ischemia, hypoglycemia and hypoxia to the remaining viable nerves [56-58]. In this state, spinal neurons that were not injured mechanically in the primary insult die due to ischemia and hypoxia. Secondly, a number of anti-inflammatory chemicals released at the injury site are known to cause further nerve death [55, 58, 59]. There is also morphological evidence of progressive degeneration of injured spinal tissue over time [48, 60].

Various neuroprotective therapies have been tried, and some have shown to yield good results, while others (such as the use of methyl prednisolone) remain controversial [12, 58]. Efforts to prevent secondary TSCI in rural LIC are rarely documented, suggesting that there is hardly anything that is done in this regard [55]. This could be due to lack of information and/or appropriate medication in this regard. With no intervention to minimize the risk of secondary TSCI, mild cases are likely to become severe (complete); hence, there are reduced functional abilities.

Short- and long-term effects of TSCI

Although injuries at any level of the vertebral column constitute an emergency, adverse clinical presentation and risk of death increases with depending on the location of the injury along the vertebral column [45, 61]. For example, a person with a lumbar injury loses sensorimotor function in the lower limbs, bowel and bladder only. On the other hand, TSCIs at the level above the mid-thoracic and cervical regions interrupt autonomic as well as sensorimotor functions below the level of lesion [62].

An immediate threat to the life of a person with a TSCI is cardiorespiratory failure due to the involvement of the autonomic nervous system and/or dysfunction of the phrenic nerve [1, 3, 7, 63]. The autonomic nervous system guides the functioning of organs responsible for the regulation of blood pressure, body temperature, digestion and respiration. Interrupted autonomic functions may lead to the failure of multiple systems and early death or interrupted system functions over the lifetime of survivors. While autonomic dysfunction may lead to hypovolemia and tissue hypoxia, the impaired function of the phrenic nerve leads to a dysfunctional diaphragm, hence the person has difficulty breathing [45]. Cardiorespiratory failure and hypovolemia may explain why many persons who sustain TSCIs die before reaching the hospital or in the first 72 hours of hospitalization [64, 65].

With sensorimotor loss, a person with a TSCI faces a continuous risk of pressure ulcers. Pressure ulcers are known to be the most dangerous threat to health and life after the injury, especially in LIC [66-69]. Another common complication is urinary tract infections, following the need to use catheters for bladder management [21, 23, 70]. The prevalence of urinary tract infection depends largely on a patient's immunity, the catheterization method that is used and sterility level [71, 72]. Neuropathic pain is relatively common among persons with TSCI and have extensive adverse effects [73, 74]. Spasms are another complication experienced by a significant number of persons with TSCI, especially those with injuries above the lumbar region [75]. Spasms can be very severe, interfering with sleep, affecting posture and bodily functions, and

sometimes leading to contractures. There are many other less common but potentially harmful complications such as pulmonary infections [20, 76], deep vein thrombosis [77, 78] and heterotrophic ossification [79].

After discharge from the hospital, persons with TSCIs in rural Tanzania struggle to locate and afford wheelchairs, which are a prerequisite for mobility. Most of them depend on donated or cost-subsidized imported wheelchairs that are typically inappropriate for the person or the environment in which they are going to be used [11, 80, 81]. For those who are fortunate enough to obtain a wheelchair, they still face the challenge of inaccessibility within and away from the home. Inappropriate wheelchairs and/or restrictive environments account for participation restriction, hence users experience high rates of unemployment, reduced social networks, disengagement from community events and poor quality of life [11]. Furthermore, an inappropriate wheelchair is a known cause of pressure ulcers, poor posture and contractures. Equipment for basic self-care such as catheters and urine bags can hardly be accessed and afforded once the individual has been discharged to the community. This deficiency forces individuals to use unsafe bladder management devices, leading to incidents of UTI.

Evacuation, transportation and management of a person with TSCI

Services that are provided to persons who sustain TSCIs depend on various factors such as geographical location, public awareness and the availability of community emergency services. Generally, delays and mishandling of the injured person are some of the reasons for pre-hospital deaths or worsened prognoses. On the other hand, a timely and proper handling of person with TSCI increases the odds of survival and better functional outcomes afterwards.

Evacuation and transportation

The manner in which the injured individual is handled during evacuation and transportation to the health facility plays an important role in survival and prognosis afterwards [7, 82, 83]. It is strongly recommended that persons with acute TSCIs should be transferred and transported lying flat on a hard surface with the body stabilized to minimize spinal movement [7]. There should be an attempt made to handle immediate life-threatening conditions such as cardiovascular and respiratory failure during evacuation from the incident scene and transportation to the health facility [82-84]. This requires a paramedic squad equipped with the appropriate knowledge, skills and tools for the task [45].

In high-income countries, there is normally a known system that deals with trauma and other emergencies requiring instant response. For example, the Queensland Service Model of Care in Australia and the model systems in America are examples of SCI-specific working structures [85, 86]. These model systems guide the evacuation, transportation, management and rehabilitation of persons with TSCIs, as well as returning them back to their communities. Even in countries with no specified model of care, there are at least ambulance services. The scenario is quite different in the rural settings of low-income countries where there are neither model systems nor ambulance services. Persons with TSCIs are normally handled at the accident scene and transported to the health facility by volunteer laypersons who may not know what to do or what to avoid. In such areas, there is evidence of persons with TSCIs being transported to health facilities in personal vehicles in the sitting or semi-sitting position regardless of the location of injury [87, 88]. This situation increases the risk not only of worsened injury but also of death [89, 90].

Intensive care in the acute phase

The first 72 hours are very crucial for survival and neurological recovery for persons with TSCIs [48, 83, 89]. This acute period is even more crucial for persons with injury at the level where autonomic nervous system is impaired. This is because there are immediate changes that affect the functioning of vital organs responsible for circulation, respiration and digestion [48]. Due to their fragility, persons with acute TSCIs require intensive cardiovascular and respiratory care, especially in the first 72 hours [3]. There are controversies surrounding the management of acute high TSCIs [91], but generally such case requires prompt critical care [3, 48]. The controversies are on whether or not methyl prednisolone should be administered and the timing of the surgery [55]. Early evacuation from the incident scene and immediate oxygen therapy during transportation and during critical care in the hospital are the key to survival for any person with a high TSCI [3]. In LIC, particularly in rural areas, persons with TSCIs are admitted to hospitals or health centers where health personnel have been neither recruited nor equipped for such a sensitive task [92]. This situation adds to the risk of early death for those who survive the challenges of evacuation and transportation [89].

Sub-acute and active rehabilitation phases

Generally, persons with TSCIs who survive the first few critical days are more likely to make it to discharge from the hospital with varying degrees of temporary or permanent impairment. However, surviving a TSCI after the acute phase means continuously facing SCI-related complications such as infections, pressure ulcers and deep vein thrombosis [21, 67, 68, 93]. These complications account for

prolonged hospital stays, reduced functional levels and most of the deaths that occur after the most critical acute phase [61, 94, 95].

It is recommended that soon after a person with a TSCI has arrived to the hospital there needs to be intensive care for the functioning of vital body systems until s/he stabilizes. There is no clear-cut timing for surgical intervention, but it has been shown that neurological recovery stands a better chance with early rather than late surgery [19, 96, 97]. Surgery aims to relieve the nerves at the fracture site from any skeletal or edematous compression. Further, early fixation and mobilization reduces hospital stays and risks of bed-related pressure ulcers and hypostatic pneumonia. In Cambodia, for example, following immediate spinal fixation procedures, the in-hospital mortality for 2013/2014 among 80 cases was zero, and there was improvement in sensorimotor function [98]. However, there are still reports where the conservative management of TSCI is considered being superior to or having the same outcomes as surgical intervention, especially for the elderly population [99-101].

Lacking expertise, equipment and other necessities for surgery [99, 102], the regimen for treatment and caring for persons with TSCIs in most LIC hospitals, such as those in Tanzania, is one of conservative management. This approach involves a prolonged bedrest with nurses routinely turning patients and helping them to bathe and to empty their bowels and bladders [101]. It is important to confine the patient to bed to minimize discomfort and facilitate healing of musculoskeletal tissues [9]. Meanwhile, physiotherapists offer exercise, nurses provide care and medication on a daily basis, and doctors prescribe medications for any emerging complications [99, 101]. A conservative approach requires not only considerable time from medical, nursing and rehabilitation staff but also prolongs the hospital stay. In any case, an increased length of stay (LOS) is expensive for the individual, family, employers, insurance companies and health system. While following the conservative approach, hospitals in Tanzania are lacking in basic needs such as pressure relieving mattresses, pillows and appropriate beds for treating patients with TSCIs [11]. Due to these deficiencies, persons with TSCIs are continuously exposed to discomfort and an increased risk of pressure ulcers and deformities.

Treatment and rehabilitation of a person with TSCI requires expertise with more than just the standard training at formal medical and paramedic schools. This is because the health needs of a person with a TSCI are very diverse and unique. Managing urological, sensorimotor, bowel, skin, immobility and psychological disturbances calls for a multidisciplinary team approach [103, 104]. Medical doctors, surgeons, nurses, therapists, social workers and others who are involved in management and rehabilitation are normally trained or oriented in various aspects of TSCI.

Quality of Life after discharge from the hospital

Living with an SCI in a rural, inaccessible environment imprisons the remaining abilities of individuals, creating a state of dependency on others even if they might have been independent. An inability to pursue education and disengagement from income-generating activities creates a disability-poverty cycle concerning the individual and the family [105]. The basic medical and rehabilitation services they need continuously are either not available or are inaccessible. For this reason, persons with TSCIs in the rural settings of low income countries have a relatively low QoL and a higher mortality rate [106]. For example, in Brazil, community follow-up of 434 persons with TSCIs that lasted over four years showed that more than 17% had died mainly due to chest and other infections. It was also shown that persons with tetraplegia had greater odds of dying compared to those with paraplegia [95]. Generally, poverty and inaccessible environment should be viewed as two major causes of dependence, social exclusion, poor QoL and death for persons with TSCIs in rural LIC [66]. These factors are interconnected, and one may not work without the other. For example, a person may know that cushioning and proper catheterization prevents pressure ulcers and UTI, respectively. However if they cannot afford or access cushioning and catheterization materials, the prevalence of these complications will persist. Again, poverty may lead to a wheelchair being unaffordable, which in turn causes social exclusion and adds to the risk of depression [11].

Combined challenges in health, socioeconomic, rehabilitation and environment affects the quality of life (QoL) of the individual in all domains of life [66]. Although QoL is the ultimate goal of rehabilitation, there is a scarcity of reports on the lives of persons with TSCIs in rural areas of Tanzania. Lacking this information leaves the rehabilitation team with little information on what can be done to improve QoL.

Thesis rationale and aims

Rationale

In public health, identification of the problem as well as quantification and determination of its root cause are the key primary steps in designing a program for its prevention. As is the case for many other health conditions, epidemiology of trauma and TSCI in the rural areas of Tanzania is underreported. There is not much published on the cause of TSCIs and so it is hard to plan the prevention. This is even more difficult because the leading cause of trauma and TSCI is dependent on the predominating infrastructure, and socioeconomic and cultural activities. Identification of the causes of TSCI specific to rural Tanzania will aid in designing a focused prevention intervention.

There is a scarcity of reports on magnitude and clinical outcomes following TSCIs in rural Tanzania. A lack of understanding of the current magnitude of TSCIs in Kilimanjaro makes it difficult to establish a trend over time to ascertain whether the incidents are decreasing, increasing or stable. The same is true for the prevalence of SCI-related complications. Knowing which complications are most prevalent or on the increase will allow for a focused effort towards reduction. Without this information, rehabilitation services will lack focus and feedback on improved or worsening conditions.

Another area that has been neglected in rural Tanzania is the lived experiences of persons with disabilities, TSCIs in particular, despite the challenging socioeconomic and environmental situations for these people. Not following up on and performing thorough inquiries on the life experiences of these people leaves a gap of knowledge with respect to what can be done to improve their lives. Information on areas that may need special attention to improve QoL for these people is a key to successful comprehensive community-based rehabilitation for person with TSCIs. Therefore, this thesis is important for a focused prevention of the occurrence of TSCI incidents and clinical complications. It also highlights areas that require attention to improve quality of life after discharge from the hospital.

Aims

This thesis aimed to investigate TSCIs in one rural setting of Tanzania in terms of their occurrence, clinical outcomes and life situations of persons after their discharge from the hospital. To attain this goal, four specific aims were set as follows:

1. To determine the common causes of TSCIs in a rural area of Kilimanjaro
2. To estimate the magnitude of TSCIs in Kilimanjaro based on admissions at Kilimanjaro Christian Medical Center
3. To describe clinical outcomes for persons with TSCIs following management and rehabilitation in the hospital
4. To explore life situations from the perspective of persons with TSCI

Setting

Data for this thesis was collected at the Kilimanjaro Christian Medical Center (KCMC) and from persons in the community who had sustained a TSCI. The hospital data collection intended to describe the magnitude, causes of TSCIs and the clinical outcomes in terms of neurological levels, comorbidities, mobility outcomes and mortality. Data collection in the community aimed to arrive at an understanding of life with a TSCI in resource-constrained settings in terms of QoL and coping strategies.

Christian Medical Center

The Kilimanjaro Christian Medical Center is one of the largest consultant hospitals and is located at the foot of Mount Kilimanjaro in northeast Tanzania. The hospital's capacity is more than 630 beds and is still expanding. To date, KCMC is the only hospital in the country with a dedicated Orthopedic Rehabilitation Unit (ORU), which has 25 beds and provides multidisciplinary rehabilitation for persons with TSCIs. However, the unit is not equipped with the staff and equipment needed for managing the most acute cases. For this reason, newly admitted cases of TSCI are first admitted to the orthopedic general wards and intensive care unit for closer observation. When patients are stable enough, according to the discretion of the multidisciplinary team, they are transferred to the ORU (if space is available). However, all patients in the ORU, the orthopedic general ward and the ICU are reviewed by the multidisciplinary team at least once a week. The author of this thesis is a senior physiotherapist and a part of the ORU multidisciplinary team. Other members of the team are nurses, a neurologist, an orthopedic surgeon, an occupational therapist, a urologist and a social worker. The wheelchair and mobility aids technologists are consulted when the need arises.

A side view of Kilimanjaro Christian Medical Center (left) and a front view of the Orthopedic Rehabilitation Unit for SCI (right)



Management of persons with TSCIs at KCMC and at LIC hospitals has been and is still largely done through a conservative approach. According to this approach, a person with a TSCI is confined to bed between 6 and 12 weeks before ambulation. This length of time is necessary to allow for a fractured vertebrae to heal and to reduce the mobility and pain of the injured segment. Management and rehabilitation of TSCIs at KCMC is divided into four stages, which are intensive care, immobilization, active physiotherapy and self-care program, as shown in Appendix I.

Kilimanjaro region

Being as it is at the slope of Mount Kilimanjaro, the rural areas of this region are characterized by hills. As in other Tanzanian rural settings, most of the roads are narrow and rough, and consist of sticky mud during the rainy season. It is impossible for any wheelchair user to propel his device outside the home when it rains. This is so because the mud sticks to the caster wheel(s) of the chair and stops it from moving any further.

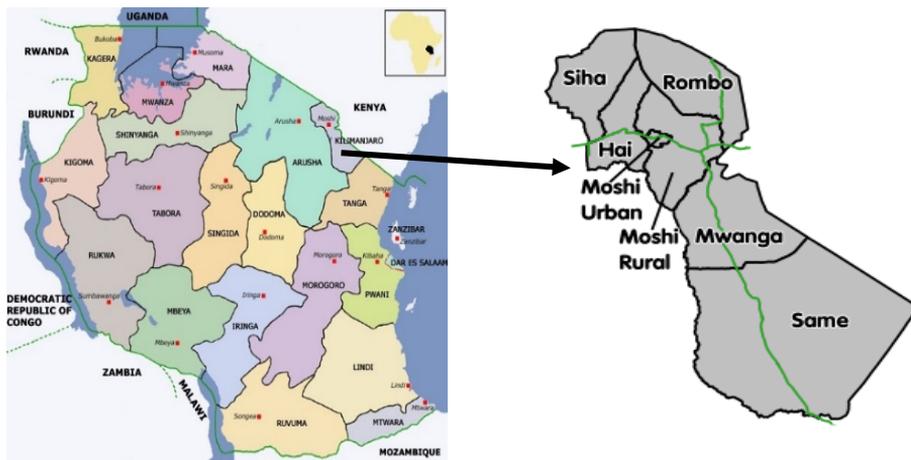


Figure 2: Tanzania (on the left) and Kilimanjaro region (on the right).
Source: <http://www.tpsftz.org/zoom.php?region=13&txt=Kilimanjaro> and <http://geography.about.com/library/cia/blctanzania.ht>

There are neither street names nor house addresses in the rural areas of Tanzania, and of Kilimanjaro, in particular. To locate a home, one has to follow instructions based on landmarks such as shops, marketplaces, rivers or big trees, as provided by people who know the direction to a particular destination. In searching for a person with a spinal cord injury, one must face two challenges. The first is finding a way of making someone understand the type of person being sought. This means explaining to people what a spinal cord injury is, how it comes about and how an affected individual appears to others.

Conceptual Framework

This thesis is based on the international classification of functioning, disability and health (ICF) by the World Health Organization (WHO). This conceptual framework was developed as an effort to include prevention, management and rehabilitation of health conditions in a single model [107, 108]. The ICF can be used to evaluate patients with TSCIs in acute, sub-acute and chronic phases of management and rehabilitation [108]. According to this model, each health condition can be described in three levels: impairment, activity limitation and participation restriction. Below is a conceptualization of SCIs within the ICF framework.

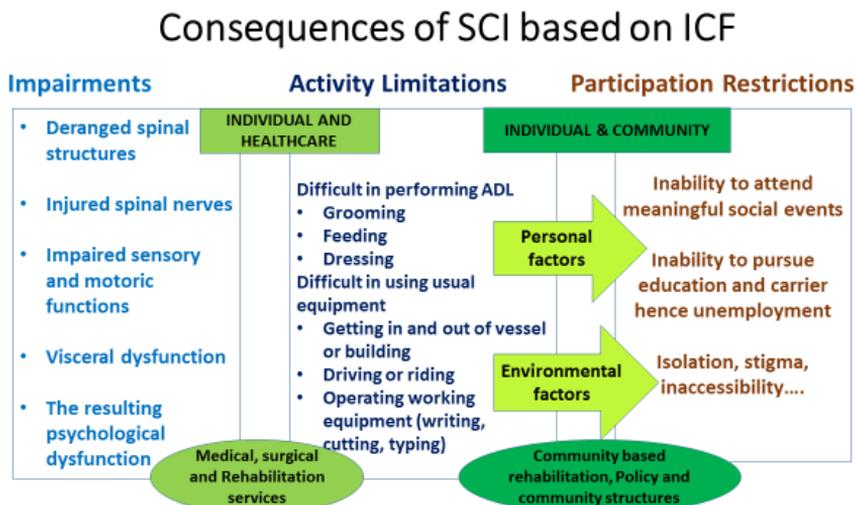


Figure 3: Diagrammatic representation of the conceptual framework.

Following the above conceptual framework, the four studies were designed to address the problem of TSCI at three levels in two contexts. The first context (hospital) nested the retrospective study (I) and prospective study (II), which addressed impairments such as neurological deficits and SCI-related complications. While in the hospital (conservative bed rest), persons with TSCIs are also restricted in a number of activities that they can carry out; hence, they

have activity limitations. The second context (community) nested the questionnaire study (II) and qualitative interview study (IV). These two studies assessed the interaction between persons with TSCIs and their social and physical environments. In this way, factors that facilitate (coping resources) and barriers to participation (the most affected domain of QoL) were identified.

Materials and methods

Design

All four studies in this thesis are descriptive in nature. Both the retrospective and prospective studies were hospital-based and conducted at the Kilimanjaro Christian Medical Center. The retrospective study captured data from patients' records (2010-2014), while the prospective one followed up hospitalized persons with TSCIs for one year (2017). Both the questionnaire and the qualitative studies were community-based in the Kilimanjaro region. The questionnaire study administered the Kiswahili version of WHOQoL BREF to all accessible persons with TSCIs, while in-depth interviews were used for the qualitative interview study.

Ethical approval and considerations

This thesis was ethically approved by the Research Ethics Review Committee of the Kilimanjaro Christian Medical University (CREC), registration number 620. All necessary official permissions were sought in writing and granted. Patients were informed of the studies and requested to sign a consent form upon agreeing to voluntarily participate. All handling of information regarding patient records including data entry, validity checks etc. has taken place in patient records archives at KCMC. Confidentiality and anonymity has been maintained throughout the studies and reporting of the results.

Retrospective study

Design: Study I was a hospital-based description of a five-year (2010-2014) retrospective data collection from patients' records.

Study population and sampling: This study used health records of all persons with TSCIs admitted at the Kilimanjaro Christian Medical Center (KCMC) from January 2010 to December 2014. The ward register shows 288 cases for the specified period.

Tool for data collection: A data collection sheet was constructed based on the international SCI core data set [109, 110]. The data set includes sociodemographic data, age at the time of injury, time since the SCI, length of stay and severity. Due to inconsistency in neurological assessment and documentation using the American spinal injury assessment scale (AIS A-E), this variable was eliminated from the study. Other variables, such as in-hospital complications, investigations, death and ambulatory state upon discharge, were added to the data collection sheet.

Procedure for data collection: Names of persons with TSCIs were identified through ward admission books. At KCMC, all patients must be registered in the ward admission register upon arrival. The ward admission register records each patient's name, hospital registration number, age, sex, address and provisional diagnosis. The identified names and hospital registration numbers with the diagnosis "spinal cord injury" were listed and submitted to the health records department, where patients' folders (hard copies) are filed. The health recorder looked for the files and collected them for the researchers to extract data. As the system is still using hard copies, some of the files (26%) could not be located during the period of data collection.

Data analysis: Data was analyzed descriptively using a computer software Statistical Package for Social Science (SPSS), specifically the 22nd version [111], and results are presented as numbers and percentages. Persons were grouped by 15 increments for age, and the results for age and LOS were presented by mean, standard deviation, median and range as per the international SCI core data set. Computations of the significance of mean differences among categorical variables against LOS were performed by one-way analysis of variance (ANOVA). This was done after exploring the normality of the data of the compared groups. ANOVA was used in cases where normal distribution could be assumed (skewness and kurtosis of between -1.96 and 1.96). The significance of observed differences was computed by chi-square, with a 95% confidence interval.

Incidence rate was calculated for Kilimanjaro, for which 218 cases of TSCI had been registered at KCMC for the specified five-year period. The population of Kilimanjaro was taken following the 2012 census as the midpoint between 2010 and 2014. The entire Kilimanjaro population (1,640, 087) was considered as being at risk for TSCI regardless of age or sex. This assumption was based on the fact that there is an array of causes of injury that persons of all sociodemographic characteristics are prone to. Knowing that incidence rate may vary from one sociodemographic group to another, age- and sex-adjusted incidence rates were also calculated. The incidence rate is calculated by taking the number of new cases from the Kilimanjaro region in a given year over the population size, per the 2012 census.

Prospective study

Design: This was a hospital-based descriptive, prospective study in which data was collected for one year (2017) from all patients admitted to KCMC.

Study population and sampling: The study population for this study was all persons who were admitted to KCMC with a diagnosis of TSCI in the year 2017.

Tool for data collection: A data collection sheet was constructed that consisted of key components of the international SCI core data set [109, 110] to be used in data collection for the retrospective study. Other variables, such as associated injuries, in-hospital complications, skeletal injury, death and ambulatory state upon discharge, were also included. Additionally, a chart was developed to register the date of starting and healing, and the location of pressure ulcers and their locations in the body [112, 113]. A pressure ulcer was defined per the American spinal cord injury neurological assessment scale, which was used to assess each patient's neurological level and severity.

Sampling and procedure for data collection: Every morning and at the end of each day, the researcher went through the ward admission register to identify any patient admitted due to a TSCI. The identified patient was located, and the initial assessment (ASIA) impairment scale was filled in. During this assessment, the patient was also requested to describe what had occurred from the occurrence of the accident to arrival at the hospital. The data collection sheet had to be filled in to show who helped the patient from the accident scene, what was done and how the patient was transported to the hospital. Each patient was inspected for associated injuries and their location on the body. All patients were inspected (at the pressure points) by the researcher or by nurses who agreed to report on pressure ulcers on a daily basis. Patients were asked to report any new complaint such as constipation, pain and spasms. A follow-up folder was made for each patient in which every significant new finding was recorded. Each patient was followed-up from admission to discharge. Except for those who clearly had respiratory failure or septicemia death, incidents were not clearly stated.

Data analysis: Data that was collected using data sheet was then cleaned and entered into the Statistical Package for Social Science (SPSS version 25) for analysis. The results were presented as numbers and percentages, as in the retrospective study. There were 15 increments of age, and the results for age and LOS were presented by mean, standard deviation, median and range, per the international SCI core data set [109, 110]. Mean time for pressure ulcer appearance and its healing were also computed. Due to delays and inconsistency, it was not possible to follow-up the occurrence and resolution time of other comorbidities whose diagnoses required lab or radiological investigations. Pain and spasms were as reported and described by the patient. The mean difference between two groups was analyzed by using a non-parametric test (Mann Whitney U test), as it was noted that most of the data were substantially skewed [114].

For the retrospective study, incidence rate was calculated for the Kilimanjaro region based on the estimated 2017 population, which was 1,910,555. The reference from which this population size was based is the 2012 Tanzania National Census and a constant annual population growth of 3.1 % since then

[115, 116]. However, calculation of the incidence rate for 2017 considered age \geq 10 years, as the youngest child admitted with TSCI that year was 12 years old. We assumed that, for the year 2017, the risk of TSCI to children $<$ 10 years old ($N=464600$) was negligible. This assumption reduced the population at risk from 1,910,555 (the total Kilimanjaro population) to 1,445,954 ($<$ 10 years old excluded).

Questionnaire study

Design: This was a descriptive cross-sectional study that was conducted in the community.

Study population and sampling: The population for this study included all persons with TSCIs in the rural Kilimanjaro region. Due to the unavailability of reliable registers and studies on TSCIs in typical Tanzanian rural areas, it was difficult to estimate the sample size. For this reason, the researchers aimed at including any accessible person with a TSCI in the community. Snowball sampling was used to identify and access the participants.

Tool for data collection: In this study, the WHOQoL BREF questionnaire in Kiswahili was used to assess the QoL in four domains, namely physical health, psychological health, social relationships and environment. Together with this tool, other sociodemographic information that was considered necessary for QoL was included. These included level of education, duration of disability, age at which the injury was sustained and marital status, as well as previous and current employment status. The WHOQoL has been used extensively to assess QoL among normal and ill persons in different countries. Its validity in assessing QoL among TSCI persons has been assessed favorably in various studies [117-119]. When compared with other tools, the WHOQoL BREF was found to have greater discrimination for QoL-defined groups such as SCI [120]. The reliability of WHOQoL has been determined for different populations of persons with TSCIs. Some examples are Pakistan [118], India [121] and adolescents in Nigeria [122]. In other settings, the WHOQoL BREF has been described as reliable in a study in Spain [123] and valid in one study in Korea [124], and in a systematic review by Boakye and colleagues [125], it was reported as being one of the best validated instruments for use in SCI QoL studies. In three multi-country studies [125-127], this tool has been described as most acceptable and as being an established instrument and cross-culturally valid in assessing QoL of persons with SCIs.

Procedure for data collection: The first few names for this study were obtained from the hospital, the Kilimanjaro Association for the Spinally Injured (KASI) and Friends of Para (FOP) documents. Those who were identified by these sources were contacted via cell phone at which time the researcher asked to make

an appointment to meet with them and for instructions on how to get to their homes. Participants who did not have a telephone were physically visited in their homes at which time they received an explanation of the study and were asked if they would be willing to participate. To get to the home of a participant required asking people one encountered along the way, as there are neither street names nor house addresses in the village. A few of the participants that had been identified had already died by the time that we could pay a visit to them.

All participants who were accessed as being appropriate for the study consented and participated in the study. Although WHOQoL BREF is supposed to be self-administered, in our case the researcher had to read the questions and response options to the participant and fill in the answer. This was due to some having tetraplegia, which made them unable to use their upper limbs. Furthermore, some could only read with difficulty (illiteracy) and requested the researcher to fill in the questionnaire. A few participants filled in the questionnaire by themselves.

Data analysis: All of the data were entered into the Statistical Package for Social Sciences (SPSS) version 23 [111], and the analysis was performed according to the WHOQoL instructions [128]. Age was categorized as <45 years and \geq 45 years. Raw scores for each domain ranged from 4 to 20, and the raw scores were transformed into the mean scores for each domain.

Dichotomization was performed for variables like employment, marital status, duration of disability, and age, and the mean scores for each domain were compared using the independent samples t-test. Numerical data such as age and time since injury were analyzed descriptively using means, standard deviations and ranges. The nominal variables are presented as the number of cases and as proportions.

Qualitative interview study

Design: This was a qualitative interview study using data from cross-sectional in-depth interviews that were conducted in the home of each of the 10 purposively selected participants.

Study population and sampling: This study targeted all persons with TSCIs who had lived the longest in the community (Kilimanjaro region). These were identified from orthopedic surgeons who had treated persons with TSCIs at KCMC for many years and the registries of the Disabled People Organization (DPOs). The researcher purposively selected 10 (the oldest) from the 15 interviews for a qualitative grounded theory analysis. Purposive sampling is a

nonprobability strategy used in qualitative research to select persons who are considered the most aware and experienced in the topic being studied [129].

The ten persons were selected to include differences in sex, age and marital status, level of education and level of injury (paraplegia and tetraplegia). The selection of the ten interviews also aimed to include at least one participant from each of the six rural districts of the Kilimanjaro region. Moshi Municipal was not reprinted in this sample, as it is semi-urban with relatively accessible roads and public buildings. After each interview, the interviewee was shown the list of remaining participants in order that they might think of others that they would recommend to be interviewed. If individuals who were recommended were considered more eligible than others already on the list, they became replacements.

Tool for data collection: The researcher prepared an interview guide in English that was translated to Kiswahili by a language teacher before its use. A pilot interview was conducted with two persons (regarded as low literacy) in the community using the Kiswahili interview guide to assess its clarity. Very few changes were made before using it. Although the interview guide was used to ensure coverage of all domains of life, the interview was kept very open so as to benefit from detailed description.

Procedure for data collection: The persons who were identified as being eligible for the study were called (in the cases of those who had access to a phone) or located at their homes, as in the questionnaire study III, to request their participation in the study. The majority consented immediately, and the interview took place that same day. On the day of interview, the researcher and his assistant arranged for the most convenient place (within the home) to interview the participant. The families of the participants were asked to continue with their daily routines and were informed that the interview would not interfere in any way with activities that they had planned. This was important, as we wanted to observe anything that would give more meaning to what we heard. A recorder was used to preserve the conversation so that the researcher could concentrate on listening to the interviewee. At the same time, the researcher wrote down important points and observations in a notebook. Noting these important points allowed for a quick summary at the end of each interview that could be confirmed or rectified by the interviewee. Although the interview guide had some prompts, these were often not used, as the researcher made the interview as open as possible (with frequent use of such directions as “tell me more”. “tell me why”, “tell me how”, etc.).

After each interview, the researcher and his assistant set aside time for reflection. At this time, an interview summary was completed, and reflection on the whole

scenario was written down [130]. Although there were some differences (between the researcher and his assistant) in making meaning of what was observed or heard, these were resolved after thorough discussion. Some differences in perceived meaning were recorded, as they are in the case summary.

Data preparation for analysis: The interviews were conducted in Kiswahili. The voice-recorded conversations were transcribed as scripts. The shortest script was 9 pages, while the longest was 15. Each transcribed interview was translated verbatim in English by the researcher and his assistant. The two (English and Kiswahili) scripts for each interview were submitted to a language teacher who checked the texts and corrected where necessary. The corrected English scripts were filed as ready for analysis.

Data analysis: The approach of classic grounded theory, where data analysis of previous interviews informs subsequent interviews [131-133], had to be modified in this study since data had already been collected before the analysis began. Memos and reflections were used for the analysis in all phases. The software Open Code 4.03 was used in the first phase [134]. A thorough literature review was carried out to find theories that could explain results that had been found thus far.

Table 1: Summary of the qualitative analysis

Phase 1 OPEN CODING	Phase 2 AXIAL CODING	Phase 3 FORMATION OF CATEGORIES	Phase 4 IDENTIFYING THE CORE CATEGORY
<p>Reading the interviews</p> <p style="text-align: center;">↓</p> <p>Two researchers coded two interviews, then agreed on codes and coding process</p> <p style="text-align: center;">↓</p> <p>Principal investigator continued with coding</p>	<p>Repeated reading of codes</p> <p style="text-align: center;">↓</p> <p>Combining a number of codes describing a process or event</p> <p style="text-align: center;">↓</p> <p>Formation of axial codes</p>	<p>Repeated reading of axial codes</p> <p style="text-align: center;">↓</p> <p>Assessing the relationship between codes</p> <p style="text-align: center;">↓</p> <p>Merging and formation of inclusive codes or categories</p>	<p>Repeated reading of memos, case summaries, reflective notes and categories</p> <p style="text-align: center;">↓</p> <p>Conceptualizing the meaning behind all analyzed materials</p> <p style="text-align: center;">↓</p> <p>Identifying a broader theme/core category that explains most or all of the rest</p>

The constructed categories in phase 3 and the core category shaped the results for the qualitative study. The categories were described with the aid of verbatim quotes from the participants and a diagrammatic representation to show the interaction between them

Results

This chapter contains a summary of the key results of the four papers that are attached at the end of this thesis. It also contains some new results that were not included in respective papers to give a deeper understanding of this thesis.

Retrospective and prospective studies

Studies I and II looked at more or less the same variables, which are occurrence, type, hospital management, outcomes and mortality. The main difference between the two papers is that Paper I was retrospectively conducted, while paper II was prospective. For this reason, it was possible to follow-up on neurological recovery/deterioration and development of pressure ulcers in paper II which was not possible in paper I.

Incidence rate of TSCI at Kilimanjaro

The Kilimanjaro Christian Medical Center (KCMC) attends to patients from northeast Tanzania, which is made up of Kilimanjaro, Arusha, Manyara and Tanga, as well as some of a neighboring country, namely Kenya. For the five years from 2010 to 2014, there were 188 new cases that were registered in the hospital admission books, 218 of which were from Kilimanjaro. The figure below shows the number of cases for each year.

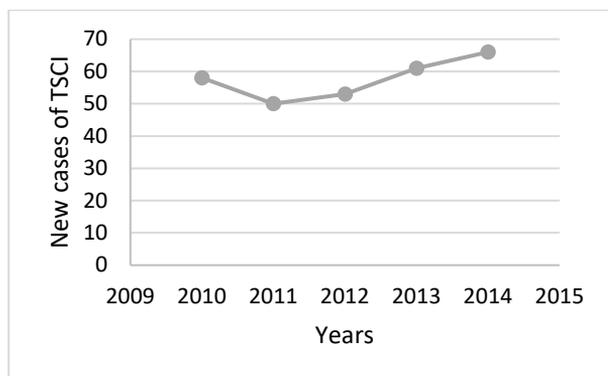


Figure 4: Number of cases of TSCI admitted to KCMC, 2010-2014

In contrast to other studies, where children under five are excluded, the whole Kilimanjaro population was considered at risk for TSCI in the calculation of the incidence rate for this study. This was due to the range of traumatic causes in

rural LIC, which can result in TSCIs to children under five. Such causes include a child being injured by a poorly constructed house collapsing or being knocked down by cattle; also, motorized and non-motorized vehicles are not uncommon in these settings. As noted in paper I, there were 218 new cases over a five-year span, and paper II noted 56 for the year 2017 from the Kilimanjaro region only. The incidence rate for the Kilimanjaro region was calculated as shown in the table below.

Table 2: Estimated incidence of TSCIs in the Kilimanjaro region (2010-2014) and 2017

Year	Estimated population size	New cases	Estimated incidence rate per 1,000,000
2010	1,564,643	46	30
2011	1,602,365	41	26
2012	1,640,087	49	30
2013	1,687,649	52	31
2014	1,735,211	30	17
2017	1,445,954 *	56	38

* Calculation for incidence in 2017 considered that a population of < 10 years old (464600) had a negligible risk of experiencing TSCI. They were excluded from the calculation.

This gave an estimated incidence rate of 26 (population size 1,640,087) new cases for the period 2010-2014 and 30 (population size 1,827,650) for 2017. In the prospective paper (II), there were 87 new cases of TSCI, the majority of which (56; 64.4%) were from Kilimanjaro, as shown in the figure below:

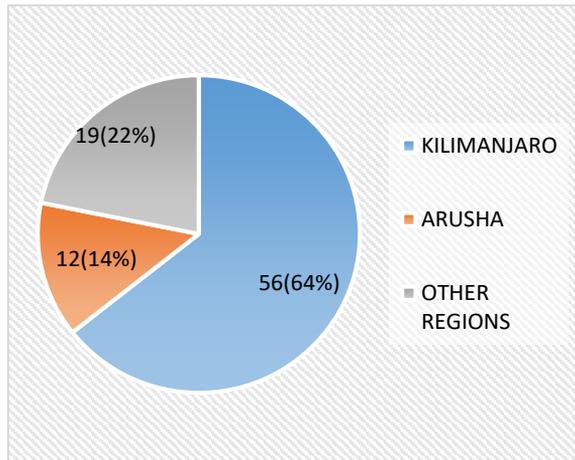


Figure 5: Distribution of persons with TSCI based on three major regions (2017)

Although it has been suggested that the risk for children to sustain TSCIs is minimal, the situation is different in rural LIC. However, the 26 and 50 new cases that are reported annually and are highlighted in papers I and II, respectively, are an underestimation. This is obviously so, bearing in mind that there are other cases in which a person either dies before reaching the hospital or is treated elsewhere outside the region. Referral for persons with TSCIs in Kilimanjaro is in such a way that all cases seen in any other health centers or hospitals in the region are referred to the Kilimanjaro Christian Medical Center as quickly as possible. However, hospitals that have improved service for persons with TSCIs, such as equipment and trained personnel, tend to retain some of these cases if they are considered stable. All these factors indicate that the 26 annual cases are an underestimation.

Etiology of TSCI

Falls (especially from trees) are the most common cause of TSCIs, according to both the retrospective and prospective studies, followed by RTAs. Further analysis of injuries due to falls showed that the majority of males fell from height while most of females had other forms of fall (especially with a load on the head).

Table 3 Etiology of TSCI for men and women

Sex	Road Traffic Accidents	Fall from height	Other falls	Other trauma	Assaults
Retrospective study (2010-2014)					
Males	62(36%)	56(32.6%)	27(15.7)	15(8.7%)	12(7%)
Females	11(26.8%)	5(14.6%)	14 (34.1%)	7(14.6%)	4(9.8%)
Prospective study (2017)					
Males	20 (29%)	37(53.6%)	10(14.5%)	2(2.9%)	0(0%)
Females	5(27.8%)	4(22.2%)	7(38.9%)	1(5.6%)	1(5.6%)

There were causes of injury in studies I and II that are not clearly classified elsewhere, as they are unique to these settings. For example, a tree, a heavy bag from atop a lorry or a wall of a poorly constructed house falling on the victim. There were also incidents of cattle and wild animal attacks causing TSCI.

Evacuation and transportation from incident scene to the first health facility

In the prospective study, participants were asked how they were removed from the incident scene, as well as first aid and transportation to the first health facility. Generally, it was noted that most of these activities were done by laypersons using the equipment and transportation vehicles that were at hand, as summarized in the figure below:

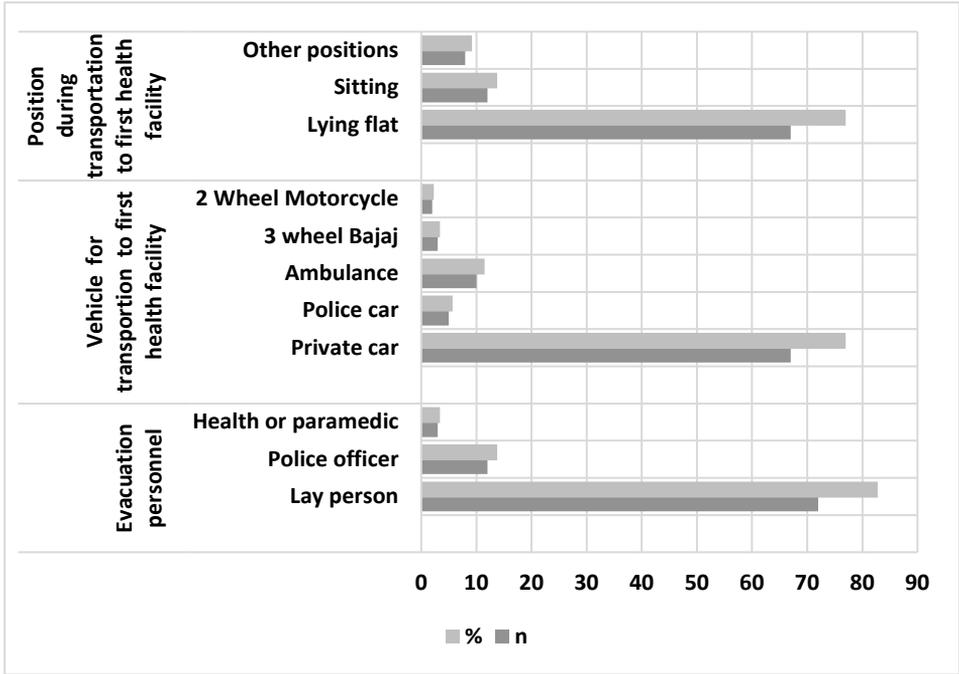


Figure 6: Evacuation from scene of the accident to hospital

Clinical and rehabilitation Outcomes

Studies I and II assessed clinical outcomes in terms of severity and the level of the injury along the vertebral column. The two studies also report on clinical complications, mortality and ambulatory status upon discharge.

Severity of the injury

Neurological completeness of the injury could not be evaluated for the retrospective study, as the ASIA impairment scale was not consistently used by then. This scale was used in study II, where it was found that 35 cases (40.20%) had complete TSCI (AIS “A”) and 8 (9.20%) did not have any neurological deficit (AIS “E”). The rest 44(50.6%) had incomplete TSCI at various sensory and motoric degrees (ASIA “B, C, D”). Table 4 below displays the spinal level commonly affected, ambulatory status and mortality.

Table 4: Distribution of level of injury, clinical complications, ambulatory state

Variable	Study I (2010 – 2014) n(%)	Study II 2017 n(%)
Level of injury		
Cervical	96(45%)	49(56.3%)
Thoracic	46(21.6%)	11(12.6%)
Lumbar	71(33.3%)	27(31.00%)
Clinical complications		
Pressure ulcers	47(22.07%)	33(37.9%)
Respiratory complication	29(13.62%)	27(31.0%)
UTI	40(18.78)	29 (33.3%)
Deep vein thrombosis	11(5.16%)	8(9.2%)
Ambulatory state and mortality		
Walk unaided	44(20.7%)	18(20.7%)
Walk aided	51(23.9)	20(23%)
Wheelchair dependent	52(24.4%)	34(39.1%)
Bedridden	14(6.6%)	0(0%)
Died	52(24.4%)	15(17.2%)

The questionnaire and qualitative interview studies

The context for studies III and IV is the rural communities along the slopes of Mount Kilimanjaro. The two studies assessed the lives of persons with TSCIs in their communities. Study III shows that the QoL for persons with TSCIs in rural Kilimanjaro in the four domains of life is relatively poor. Below (Table 5) is the reported scores of QoL for this study compared to findings from a global survey (73 countries) of healthy and ill subjects using the WHOQoL-BREF. Each domain is scored out of 20.

Table 5: Most effected domains WHOQoL –BREF study III

Domains of life assessed by WHOQoL-BREF	Study III Persons with TSCIs at Kilimanjaro	Reference WHO Global survey [135]	
		Healthy	Illness
Physical	11.48	15.4	13.1
Psychological	12.76	14.8	13.7
Social relationships	12.62	14.8	14
Environment	9.59	14.1	13.8

Noting that the lives of persons with TSCIs in rural Kilimanjaro are affected in each domain, the worst being the environment, study IV looks at coping resources used by such individuals. Study IV identified the resources displayed below. Acceptance was identified as the core for identification and utilization of the rest of coping resources



Figure 7: Successful coping with traumatic spinal cord in rural area of low income country

Discussion

This thesis is based on studies on the occurrence, outcomes and life of persons with TSCIs in a typical rural area of a low-income country. The thesis is expected to add to the understanding of TSCIs in these regions in order to inform strategies on prevention, clinical management and rehabilitation of SCI of the situation on the ground. Therefore, the information in this thesis can be used not only for prevention and improvement of clinical and rehabilitation outcomes but also to augment QoL after discharge from the hospital.

Incidence of TSCIs in the Kilimanjaro region and hospital mortality are substantially high. Falls are the leading cause of TSCI. Unlike in males who normally fall from trees, females frequently sustain such injuries following a fall with a load on their head. Nevertheless, a considerably large number of TSCIs are also registered in this region. Generally, there is hardly any trauma management system in the community and so injured persons are normally helped and transported to the hospital by anybody. While in the hospital, persons with TSCIs still face prevalent medical complications, such as pressure ulcers, and urinary, respiratory and other infections. After discharge, the injured person has to face the challenge of poverty and inaccessible health and rehabilitation services within a hostile environment for a wheelchair user [11]. For this reason, their QoL is negatively affected in all domains, particularly the environmental aspect. However, a number of coping resources are available for persons with TSCIs in rural resource-constrained areas. Identification of such resources, accepting self, and being accepted by the social and physical environment are key to a successful life.

This thesis reports an underestimated annual incidence rate of between 17 and 38 new cases of TSCIs in a population of one million. These figures are regarded as an underestimation as there is the possibility that cases are not counted due to pre-hospital deaths or admission elsewhere. However, within this range is the reported annual incidence rate of 25.5 and 23.25 cases per million for low-income countries by systematic reviews conducted five years ago [25] and this year [136], respectively. There are few individual epidemiological studies on TSCIs in low-income countries, and most of the published ones are hospital-based [136]. In recent years two studies from Cape Town and Botswana reported annual incidence rates of 75 and 13 cases per million, respectively [27, 50, 137]. Population-based studies in rural LIC are scarce, possibly due to reasons such as lack of comprehensive birth and death registries, and accessibility challenges. Survey studies are difficult to conduct as there are hardly any residential addresses and telephone service is available to only a few. There are also difficulties in transportation on inaccessible, unnamed rural roads.

In areas where SCI care and rehabilitation services are not centralized, using data from one or two large hospitals provides only a snapshot of the situation on the ground and may thus not reflect the entire population of the studied region. More population-based studies on TSCIs in the rural regions of LIC should be promoted to ensure that TSCIs are addressed more generally. Study III of this thesis used snowballing sampling [4, 5], and it is expected to have reached most of the persons living with TSCIs in the Kilimanjaro region at present. In this community survey, only 89 persons with TSCIs were identified (prevalence), the majority of whom had paraplegia. Assuming that snowballing was 95% accurate in identifying the subjects, there is a possible disparity between incidence and prevalence. This disparity is perceived by bearing in mind that there are at least 34 persons with TSCIs discharged as wheelchair users to the community annually, the majority of whom have quadriplegia. The relatively low prevalence could reflect the high mortality rate post discharge or immigration of the individuals from their inaccessible rural environment. Persons with TSCIs may attempt to move away from the rural area (where there is the poorest scoring environment domain of QoL) to more accessible townships. A future cohort study is recommended to confirm or refute these assumptions.

Fall from height and low falls as the leading cause of TSCIs in the Kilimanjaro rural area

The majority of people in rural Tanzania, and Kilimanjaro in particular, employ themselves in the informal sector, with minimal safety status during their daily activities. In regions where long-term cash and food crops such as coffee and banana are grown, cattle is kept inside a den (cattle house), away from the plants. While in the den, cattle have to be fed on a daily basis. Traditionally, women carry heavy loads of grass on their heads to feed the cows, and men climb trees to obtain branches with leaves to feed their goats and sheep. A man who climbs trees to pick fruit, honey or firewood for selling or for family use may not know or have what it takes to prevent himself from falling down. A mother with her head loaded with a bag of crops from the farm, firewood, a bucket of water or animal feed may not have what could prevent her from falling while walking. These activities are carried out on a daily basis and are the means through which the majority of the population meets their economic needs. In the first two studies, this thesis of falling from trees and falling while walking (especially with a load on the head) are the leading cause of TSCIs. Adults and children may have a limited understanding of the injury risk of their daily activities and environment. When people do not perceive a risk, it is likely that they won't take any precautions [138]. However, there may be those who know what to do to minimize the risk of trauma but lack appropriate safety and protective tools. This means safety education should go hand in hand with strategies to make accessible the necessary protective tools. To achieve these, both personal and collective efforts

are required. Personal efforts include learning about risk of trauma and changing personal behavior such as excessive alcohol consumption. Collective effort ensuring a safe, rural working environment and substituting risky income-generating activities with safer ones requires a wider community will (policy).

The risk of trauma and TSCI in the rural areas of Tanzania

Generally, most of the traumatic incidents in rural LIC are driven by ignorance and poverty, which lead to risky socioeconomic activities in unsafe environments. Most rural areas of LIC have a variety of risky features for trauma and TSCI. Vast area of these settings are characterized by poorly constructed roads with hardly any warning signs. The limited road space is also overcrowded by pedestrians, as well as motorized and non-motorized vehicles. The majority of the vehicles are also poorly maintained and are prone to breaking down at any time. This combination of risky features exposes every road user to trauma and SCI. No wonder that despite the relatively small number of motorized vehicles in the rural settings of LIC, there is still a significant number of RTAs resulting in fatal injuries, including TSCIs. In this thesis, RTAs are the second leading cause of TSCI after falls. In recent years, rural Africa and Tanzania have experienced an influx of two- and three-wheeled motorized vehicles, which are used as a means of public transport in both small towns and rural areas. This unprecedented increase of traffic is happening in road space that has remained the same for many years and without any added safety measures. Moreover, motorcyclists are frequently reported as negligent in terms of safe road use, and their passengers hardly use helmets [139]. No wonder there are reports that there are more RTAs involving motorcycles than four- and three-wheeled vehicles in some of the rural areas of LIC [42, 140, 141].

Transportation, hospitalization and management of TSCIs in rural Tanzania

Trauma care systems in rural LIC are relatively underdeveloped to match the number and types of injuries occurring on a daily basis [142-144]. Rural LIC is comparatively far behind when it comes to accessing and affording surgical management for both traumatic and non-traumatic conditions when compared to developed countries [90, 144, 145]. Where appropriately trained personnel, equipment and ambulances are unavailable, persons with SCI have a higher risk of death before or within the first 72 hours of arriving at a health facility. There is evidence of delays in transporting injured persons to appropriate health facilities due to the socioeconomic, geographical and individual status of rural LIC [144, 146]. It is also common for the injured person to be handled by untrained persons and transported to the hospital in personal cars by volunteering passersby [144].

Between 45% and 56% of the injuries found in this setting were at the cervical region, and more than 40% were complete. Injury at the cervical region is at high risk for pre-hospital death or increased injury completeness if they are not handled and transported to the hospital in a timely and appropriate manner [90]. Although it is beyond the scope of this thesis, the current unavailability of emergency and ambulance services in this and other rural LIC should help us to anticipate many lives that are lost before arriving to the hospital [90, 143, 144].

Unavailable or inaccessible surgical management is caused by various setting-specific challenges. For example, an appropriate operating theater may be available, but without any trained surgeons for this task. In some situations, even reliable radiological investigations cannot be made. It has been shown that, in many rural areas of LIC, there is either unavailability or unaffordability of CT scans and MRI, hence there is a reliance on plain X-rays, which reveal very limited details about the injured tissues [47, 147]. This limitation makes it difficult to identify cases that would benefit from specific surgical management for better prognosis. All person with TSCIs admitted to KCMC in the period of study from 2010-2014 and 2017 were managed conservatively with a length of hospital stay (LOS) of between 8 and 286. Although a considerable number of persons with TSCIs would have benefited from surgery, recovering some neurological functions and a shortened hospital stay [148], this is not possible in many rural LIC. This is due to the fact that there are hardly any neurosurgeons, appropriate operating theaters, medications and equipment for such procedures [145]. As a result, most cases of TSCIs in these settings are managed conservatively. Conservative management requires bed rest for between 6 and 12 weeks, as healing of the skeletal injury before commencing ambulation is awaited.

Conservative management of TSCI exposes the individual to the risk of pressure ulcers and the dysfunction of systems such as respiratory, urinary and musculoskeletal. These systems remain healthy and perform better in the upright position and with weight bearing and mobility. As a result, incidents of pressure ulcers, respiratory infections, UTIs, kidney failure, deep vein thrombosis and contracture are not uncommon in these settings [23, 70, 149]. In the two hospital-based studies in this thesis, pressure ulcers and UTI were some of the most commonly registered complications. Promoting surgical management following TSCIs in rural LIC would reduce bedrest related complications and shorten hospital stays. Prolonged LOS has a broader array of consequences, including lost working days for those who could go back to employment in a wheelchair. Furthermore, in rural Tanzania, the family feels obliged to visit the person with a TSCI for the whole period of hospitalization. In doing so, the family members incur financial costs (bus fare, buying food and drinks for the injured person) while missing work days as well. If the injured person is a breadwinner, a

prolonged hospital stay leads to a major socioeconomic crisis to the family that affects all the dependents.

Quality of Life after TSCIs in rural LIC

As in many other studies [150], persons with TSCIs in this setting registered a relatively lower QoL compared to the average scores for normal subjects, as shown below.

Table 6: Comparison of domain mean scores of QoL of the current study with globally recommended normal values

Domains	Physical	Psychological	Social relationships	Environment
Mean <i>well</i> by WHOQoL Group [151]	15.4	14.8	14.8	14.1
Mean <i>ill</i> by WHOQoL Group [151]	13.1	13.7	14.0	13.8
Mean <i>TSCI in rural Kilimanjaro</i> (current study)	11.48	12.76	12.62	9.59

Rural areas of LIC are known for hardships in accessing and affording information, health service and employment, even for able-bodied persons, as compared to townships. Obviously for a person with a TSCI in a wheelchair, the conditions are even harder, as their mobility device may not be able to access many environments. Lacking healthcare and rehabilitation services, health information, appropriate pressure care and mobility devices contributes largely to secondary health complications [149]. The rural poor economy, an inaccessible environment and unattended secondary health complications account for the relatively reduced life expectancy for a person with a TSCI in a low-income country as compared to those in high-income countries [61, 149].

Most rural areas of the LIC are likely to have a high prevalence of SCI-related complications due to various factors. For example, the lack of appropriate pressure management tools such as mattresses, pillows and cushions in hospitals and at home adds to the risk of pressure ulcers. The unavailability and/or unaffordability of uridomes forces persons with TSCIs into using unclean procedures for bladder management, leading to UTIs. Efforts to make bladder

care tools available and affordable in rural areas would reduce the prevalence of UTI and future consequences such as nephritis.

Challenges of preventing falls from height in rural areas of developing countries

Climbing trees is a typical socioeconomic activity for rural inhabitants in many rural settings of low-income regions. One of the most common reasons for climbing is to prune tree branches for firewood and/or for making charcoal. Firewood is the only cooking fuel for most families in rural settings where electricity and gas are either unavailable or unaffordable. Another reason is to search for fruit, which can be sold for family income or can be used for consumption. For example, in Tanzania, coconuts and fruits such as mangoes, avocados and guava are picked by the climber from trees without any tool for this task. The fruit is either hand-picked or the branches are shaken to release them. In doing so, the person may lose his grip or the branch might break, leading to a fall. In mountainous areas such as the Kilimanjaro region, trees are very tall, above four meters high.

Reducing the incidence of TSCIs means to establish strategies for either preventing people from falling from trees or reducing the need to climb trees. This requires safe, alternative income-generating activities that are acceptable to the people. On the other hand, designing safety tools for a tree climber or a head loader would require that the user is interested and accepts the proposed solution. For this to happen, intensive education will be needed to make it possible.

Methodological considerations

In the retrospective study, data was collected from patients' folders retrospectively for a period of five years (2010-2014). This was an important and useful approach to take for a place where no studies had been published on TSCI. Using this approach allowed for one would to determine what future studies should address. For example, the retrospective study encouraged the design of study II, which looked at incidence and clinical outcomes (especially pressure ulcers) prospectively. The retrospective study had its shortcomings. First, the patient folders of some cases reported in the ward admission book could not be obtained in health records archives. Secondly, some patients' folders were either unreadable (bad handwriting) or lacked information that was necessary for the study. These two factors resulted in a lack of information for 76 cases (26%), which made most of the findings inconclusive. These shortcomings could be overcome in the prospective study.

The prospective study was a one-year, hospital-based prospective data collection. This design was crucial to verifying or refining some of the findings in the first retrospective study (such as the common cause of injury and incidence) due to the missing cases. It was also a powerful approach for following up on persons with TSCIs from admission to discharge, observing the occurrence and disappearance of health complications, such as pressure ulcers and UTIs, as well as death. Still, clinical complications that were of more of symptoms than a visible sign could be noted in time, as these required lab tests to confirm. For example, fever could indicate infection in the urinary tract, the respiratory system or on the pressure ulcer. At the same time, disappearance of the fever does not necessarily mean that the infection has cleared. The cause of death was also not clear for most participants. Most were labeled as respiratory failure, septicemia and multiple organ failure, but with question marks. This was due to a lack of a thorough investigation being done prior to or after death.

The questionnaire study data was collected in the rural communities of the Kilimanjaro region where participants were identified by snowballing [4, 152]. This sampling procedure was necessary, as very few person with TSCIs in this region could be identified through hospital and other organization registries [4, 5]. This was a useful approach, as there are no addresses or street names in this area, because in African rural settings it is the people who know where other people are. Village and political leaders also helped in the identification of persons with TSCIs in their areas. However, it could be that newly injured persons whose conditions were not yet known to many people were missed during the identification. Another shortcoming to this approach is that we were directed to

persons with strokes, brain tumors and TB of the spine, as people believed these too were cases of TSCI.

This tool (WHOQoL-BREF) was considered appropriate for the aim of the study, as we intended to find out which areas of life were most affected for this population. The questionnaire was also extensive, as it assessed 26 items that affect sick and healthy individuals. Although the questionnaire is supposed to be self-administered, the questions were read to the majority of the participants and, once they responded, the researcher filled in the questionnaire. This was important, as many participants read and wrote with difficulty due to the impaired function of their upper limbs (tetraplegia) or because of illiteracy. Furthermore, there were a few questions in the questionnaire that, under normal circumstances, most people would answer the same. For example, question number 12 asks, "Have you enough money to meet your needs?" It is known that even rich people usually declare that they do not have "enough" money. So the answer for this question would have been more or less the same for all.

Qualitative study: This study analyzed 10 selected interviews with persons with TSCIs who were known to have lived the longest in the community. This analysis was not a classical constructivist approach, as data was collected from all 10 participants and analyzed at the end. A classical constructivist approach requires that in-depth interviews be conducted by starting from a very broad perspective before subsequently narrowing the focus and refining inquiry based on emerging concepts. Identification of the emerging concepts that require further elaboration in subsequent interviews is achieved through simultaneous data collection and analysis [153].

Even though the approach was not of classical constructivist approach, summarizing each case and writing reflection notes after each interview could be regarded as a "simultaneous data collection and analysis". The difference is that the previous analysis did not inform on what should be explored more in the next interview. This means that each participant had to tell a life story, not necessarily based on the areas that mattered to those who were interviewed first. After all of the interviews were conducted, the researcher ensured that data was approached with a more open mind (broad view). Open coding allowed for the formation of codes whose multi-stage synthesis provided categories that formed the results for the study.

Like any qualitative interview study, results for paper IV cannot be generalized to the population of persons with TSCIs in Kilimanjaro or Tanzania. Nonetheless, the identified coping resources in this study could be used as key components for recognizing and facilitating their utilization when rehabilitating a person with TSCI in any resource-constrained areas. However, QoL may change with changes

in socioeconomic life over time, and so the same results may not hold true at all times.

Trustworthiness

Credibility

In quantitative research, internal validity is crucial in proving that the results are true and that the tool that was used is appropriate for assessing or measuring the variable in discussion [154, 155]. Synonymously, there should be efforts in qualitative research to demonstrate that the presented results are a true reflection of the lived experiences of the people from whom data was collected. This strategy is referred to as credibility [129, 156-158]. In-depth, one-on-one interviews, writing summary notes and reflections for each interviewee before leaving the home, and open coding were done to ensure that results were representative of the participant. Below is an example of a summary and reflection notes that were written soon after one of the interviews:

Example of Summary:

P4 has gone through a lot in life. Since he fell down from a tree his life has changed completely. He did not know that he would live for more than a year but somehow he did. He stayed in the hospital for more than a year because he had pressure ulcers. In the village he couldn't go anywhere because the roads are very bad. He moved to another village not very far from town where the roads are better. He started a salt business but thieves stole his capital one night. He couldn't go to the village because he feels his family is not supportive, and while there, he cannot earn for himself. At least in this new village he does not pay rent because the landlord is his aunt. He propels his wheelchair daily, begging in the street. He still earns a living in this way. He is worried; he has a new pressure ulcer on the sitting bone. His wheelchair is also broken. He feels that soon he won't be able to go to the road to beg anymore. Life will be impossible, just like in the village.

Reflection:

This is one of the most tear-jerking scenarios. It was difficult to locate him, as he had gone begging on our appointed day! He looks so worried, wasted and very unhappy. His torn clothes, dirty exposed urine bag and catheter, weary wheelchair and cushion are evident of poor economic status. He has left his family because he does not feel loved there and the environment is inaccessible. We see why one needs a family and accessible environment to survive. Once again we learn that these people are continuously worried about health complications such as pressure ulcers. We should not forget; Environment + family + Wheelchair + health and income.

Credibility is also achieved by other strategies including triangulation, prolonged engagement with informants, persistent observation and member check [157].

Triangulation

Triangulation is the application of more than one procedure or persons in acquiring data or results for the study [158]. Firstly, interviews went hand in hand with context observations. The distance to the house, the types of roads, homes, socioeconomic context and mobility devices were described as part of case summaries. Further triangulation was achieved during coding of the results. The principal investigator consulted with his supervisors (co-authors) at each synthesis stage. For a theme to be endorsed, it had to be agreed upon by the principal and co-investigators. In the same manner, the model that was developed from the results was reviewed and amended several times by all investigators before being endorsed.

Observation and prolonged engagement with informants

A long time spent in the field with participants enables the researcher to understand the dynamics of the community. At this state, the researcher can better relate the narrated experiences with observable context [157]. In this study, the interview took between 15 and 20 minutes, and the environment in which life experiences occur were observed and documented. Moreover, the principal investigator was born and brought up in these settings, so he is not a stranger to the culture and socioeconomic situation of most of the participants.

There was also a prolonged engagement with the collected data that occurred simultaneously with the literature review. For example, in phase 4, it took a long time to capture the relationship between the categories, even after looking over the memos, reflective notes and case summaries. A prolonged literature review was carried out to find theories that could explain what was being conveyed by the results at that time. At first we viewed the results as “coping strategies”, but with time we found that they were more akin to coping “resources”, as described in the book by Lazarus and Folkman on stress appraisal and coping [159]. After identification of the categories as “coping resources”, further analysis followed in which we looked for an over-arching theme that seemed to describe most or all of what we had observed. It was later discovered that acceptance was the most important theme. It was noted that persons with TSCIs should first accept that the condition is irreversible. Secondly, there must be acceptance of the available resources. Thirdly, the person should be accepted by the people (social support) and the environment (accessibility, economy, social services). Through this realization, we perceived that acceptance was the core category that holds most of the remaining resources together.

Transferability and deep description

Transferability refers to the effort made by the researcher to ensure that findings could be more or less replicated in other settings if participants of similar characteristics were enrolled [157]. This is normally done by rich description of the context, sampling and inquiry procedure. The study is described in detail from the recruitment of study participants, accessing the field, the interview and the analytical steps. The community in which the interviewees live (Kilimanjaro region) is also described to help the reader associate the socioeconomic and physical environment with the results. The principal investigator is a native of the setting where the interviews took place, and so he has a lived experience of the environment and the culture of the interviewees. The interview scenario is described, including the interviewers' observations concerning the life situation and socioeconomic status of the interviewed participants.

Member check

There is a known danger of qualitative analysis being driven by personal understanding and experiences rather than facts of the lived experiences of the interviewed persons [158, 160]. To avoid this, a form of member checking should be involved so that the conceptualization of the experiences is not done and confirmed by one person [157, 161]. Member checking was ensured by having the summary of the interview read to the interviewee for approval or amendment. Furthermore, the researcher had to set aside time after every interview and discuss with the research assistant to come to agreement on the case summary and reflections. Finally, data analysis involved three of the authors at each stage. Agreement had to be reached for the codes, categories and overarching theme to be endorsed. In this way, we believe that member checking was consistently fulfilled.

Implications for public health and rehabilitation service delivery

This thesis contains four of the few studies on TSCI to be carried out in rural areas of Tanzania, a low-income country. It provides useful information on the uniqueness of the occurrence of trauma and TSCI in these areas, consequences of the resulting disability, the availability of medical and rehabilitation services, and the community life of persons with disabilities.

Knowledge that most TSCIs in these areas are due to falls (particularly from trees) and RTAs is of public health importance. Injury prevention can now be focused on falls from a height and RTAs as the leading causes of such injuries. Focused prevention strategies are cost effective and are likely to yield results in time. This thesis has at least estimated the incidence and mortality rate for the studied years. In public health, setting a baseline for the occurrence of incidents and mortality is crucial in determining the direction in terms of increase, decrease or remaining the same.

Clinically, this thesis maybe a foundation for rehabilitation strategies, taking into account the level of injury, neurological completeness and clinical complications. Clinicians are now informed of these baselines so that they may know where to focus rehabilitation strategies and resources. This is even more important with the scanty resources (manpower and equipment) in rural LIC. Knowing the severity of injury in terms of level and neurological status also gives a clue to one's needs. Complete injuries are also at a higher risk for pressure ulcers, so they need closer care. Again, unlike paraplegics, who might be independent, for tetraplegia a caretaker may be needed. Clinicians who know that they have more persons with tetraplegia ought to prepare to train caretakers on various issues pertaining to this condition.

Quality of life is the utmost goal in the rehabilitation of a health condition. Community rehabilitation clinicians and therapists for persons to know what to do and where to focus in order to achieve this goal. This thesis presents resources that rehabilitation personnel have to address to facilitate QoL for such individuals. Improved independence, functional ability and, ultimately, QoL is positive and inspiring to any community-based rehabilitation personnel.

Implications for future research, health care and prevention

This thesis addresses three main areas of TSCI in rural Kilimanjaro: occurrence, clinical outcomes and life in the community. Not having addresses, coupled with under-developed patient record systems, makes epidemiological surveys in developing settings difficult. We recommend that hospitals in low-income countries such as KCMC improve their patients' recordkeeping to enable reliable and easy retrieval during research. The emerging use of cell phones could be used to keep track of patients for easy follow-up and give participants access to future community-based surveys. Furthermore, it would be of importance to have a trauma registry in large hospitals such as KCMC, not only for TSCI but for all other types of trauma. In this way, the trend, mechanism and outcomes of such traumatic incidents could be evaluated with time.

There is a need to raise awareness of occurrence of TSCI[162] among people living in areas where climbing trees and other risk-taking is a common practice. Awareness campaigns ought to make people perceive risks and their susceptibility to trauma and SCI. For example, the health belief model has been used and has proven to be useful in reducing domestic trauma by creating a perception of risk [163]. When people perceive that they are at risk, they find cues for taking action to alleviate or avoid the threat. A model that incorporates physical environment, culture and technology has been proposed to reduce low falls [164]. Such a model could be looked at and tested for its applicability to Tanzanian rural settings

While developing a spinal cord injury management system is costly and may take time for a developing country like Tanzania, an interim solution for safe evacuation and transportation of trauma patients ought to be considered [34]. Layperson trauma training has proven to be one of the possible and successful strategies for promoting safety in handling trauma patients in resource-constrained areas [165]. In Tanzania, this education could be compulsory to all public and private vehicle drivers, traffic police officers, bus workers (conductors) and senior school children. However, it is important for the governments in these regions to establish or enhance trauma information and management systems for the early detection and safe transportation of injured persons to the hospital.

Further studies are recommended to analyze the mechanism and precipitating factors for falls and RTAs in rural settings. For example, it is beyond the scope of this thesis to ascertain the reason for an individual to fall from a tree. With this information missing, it is difficult to plan on how to keep tree climbers safe once

they are up in the trees. We also hypothesize that there is a significant lower prevalence in the region compared to the observed incidence. We therefore recommend a cohort study to confirm or refute this assumption. If this hypothesis holds true due to post discharge mortality, causes of death can be determined retrospectively (verbal autopsy) or longitudinally (cohort). The incidence of TSCI in Kilimanjaro region is estimated at more than 38 new cases per a million population based on the major tertiary hospital admissions.

Conclusions

This thesis aimed at investigating traumatic spinal cord injuries, TSCI in one rural setting, the Kilimanjaro region in Tanzania, in terms of occurrence, clinical outcomes and life situation after discharge from hospital. The thesis consist of four studies, two in a hospital setting and two in the society.

- The majority of TSCI in rural Kilimanjaro are due to falls especially from trees, mostly injuring the neck.
- The incidence rate of TSCI in Kilimanjaro region is estimated to be more than 38 per one million population, based on admission to Kilimanjaro Christian Medical Center during one year
- There are hardly any emergency services for evacuation and transportation of an injured person. The majority is thus handled by lay persons til they reach the first health facility
- Medical complications during hospital stay, especially pressure sores and urinary tract infections, are alarmingly high.
- In hospital death is high, up to one fourth of those admitted to Kilimanjaro Christian Medical Center annually
- After discharge from the hospital, persons with TSCI faces inaccessibility problems in the society, which accounts for low quality of life
- Living with TSCI is facilitated by internal and external coping resources, thus leading to acceptance of the life situation.

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Appendix

Appendix I: Management of traumatic spinal cord injury at the Kilimanjaro Christian Medical Center. Context for studies I and II

REHABILITATION STAGES	STAGE I Intensive Care	STAGE II Immobilization (6 – 12 weeks of complete bed rest)	STAGE III Intensive Physiotherapy	STAGE IV Self-care program and discharge plans
Location of intervention	General ward or ICU	General ward or Orthopedic Rehabilitation Center (ORU)	ORU + Physio & Occupational therapy gym	ORU + Occupational therapy venue
Priorities of interventions	Respiratory care as necessary + I.V Fluids as necessary + Initial neurological assessment + Skin care + Bladder and bowel care + Joints mobilization	Respiratory care + Skin care + Follow up neurological assessment + Bladder and bowel care	Mobility + Balance and posture + Self-care + Recreational activities	Self-care + Discharge arrangements + Home visit + Independence training + Caretaker training as necessary + Carrier discussions
Key intervention professionals	Orthopedic surgeon + Neurologist + Nurse + Physiotherapist + Urologist	Orthopedic surgeon + Neurologist + Nurse + Physiotherapist + Urologist	Physiotherapist + Occupational therapist + Nurses	Occupational therapist + Social worker + Mobility device technologist
Professionals needed if necessary	Occupational therapist + Counselor + Mobility aid technologist	Occupational therapist + Counselor + Mobility aid technologist	Neurologist + Orthopedic surgeon + Urologist + Counselor	Physiotherapist + Neurologist + Orthopedic surgeon + Urologist + Counselor