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Faculty of Community and Health Sciences

RESEARCH REPORT

Title: Epidemiology of and challenges experienced by individuals surviving a traumatic spinal cord injury with community reintegration in Tanzania

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Abstract

A traumatic spinal cord injury (TSCI) often occurs unexpectedly and causes considerable disability. This condition requires specialized care that is delivered in a time sensitive manner. Data on the incidence, causes, mortality and injury characteristics of TSCI are important for gauging demand for health care and social support services. Unfortunately data on the incidence and causes, as well as functioning such as participation and integration into society, of TSCI are sparse in developing countries such as Tanzania. The overall aim of this study is to determine the incidence, causes, mortality and injury characteristics of TSCI, and to explore the challenges experienced with community reintegration after injury in Tanzania. Both quantitative and qualitative research paradigms were used. The quantitative phase of the study was conducted at Kilimanjaro Christian Medical Centre (KCMC), a referral and teaching hospital in northern Tanzania. The study population was all patients admitted to KCMC with a TSCI from 1 January 2011 to 31 December 2015 (five year period). Quantitative data were collected retrospectively using a data extraction sheet designed by the International Spinal Cord Society which consisted of the following sections: participants' characteristics (for example age, gender, duration of hospital stay, causes of injury and vertebral injuries) and injury characteristics (location of injury and completeness of injury). Differences between groups (stratified by year) was analysed using both descriptive and inferential statistics. The population for the qualitative phase was based on those included in the quantitative phase. Purposive sampling was used to select adults (over the age of 18 years) with TSCI who were managed at KCMC. Qualitative data were collected by means of individual, semi-structured interviews, and lasted until theoretical saturation was achieved. Thematic analysis was used to derive themes (categories) explaining the latent perceptions of community reintegration and its influences. Permission and ethics clearance were obtained from Senate Research Committee at the University of the Western Cape (UWC) South Africa, the

ministry of Health and Social Welfare in Tanzania, Medical director of KCMC, and Head of Medical Records and Physiotherapy department of KCMC. The study was conducted according to the ethics practices pertaining to the study of human subjects as specified by the Faculty of Community and Health Sciences Research Ethics Committee of the UWC. The results of this study indicated that 224 cases of TSCI were recorded over the five-year period. In terms of uncovering the epidemiology, the incidence of TSCI in Kilimanjaro was found to be increasing yearly, which was estimated at 45.7 per million population in 2011, and 50.4 per million population in 2015. Concerning causes of injury, the leading cause of injury was falls from a height which account for 45.54%, followed by motor vehicle accidents at 36.16%, and assault at 13.84%. Concerning mortality, the in-hospital, acute mortality rate was also found to be increasing yearly, which account for 17.9% of deaths over the five years period. Also, pressure ulcers, as secondary complication, was the leading secondary medical complication during acute care. The qualitative component of the thesis explored challenges with community reintegration after TSCI. The properties (categories) of challenges were conceptualized as 1) social support, 2) social injustice, 3) socio-economic challenges, 4) personal factors as barriers, 5) environmental barriers, and 6) inaccessible and unaffordable health and rehabilitation services. The general sense was that people with TSCI in a region of Tanzania were often excluded from community life and societal roles due to personal and environmental factors. In conclusion, the findings of this study provide useful information in terms of primary and secondary prevention aims of TSCI in Tanzania. Furthermore, this study provides the basis to study the health care system and its processes in order to evaluate its alignment with international management guidelines, with the aim of strengthening management plans for injured individuals in Tanzania.

DECLARATION

I declare that "Challenges experienced with community reintegration after sustaining a traumatic spinal cord injury in Northern Tanzania" is my own work that has not been submitted for any degree or examination at any other University and that all the sources used or quoted have been indicated or acknowledged by means of complete references.



Prof JS Phillips November 2018

DEDICATION AND ACKNOWLEDGEMENT

Firstly, all thanks God the Almighty, through whom I am able to do all things even the ones thought impossible. I am grateful to St. Francis Referral Hospital for giving me a chance to further my knowledge. In conjunction with them, I am equally full of gratitude to Capuchin Friar minor as a sole of funding for my tuition fees, living costs in South Africa and all other involved flight costs. My academic achievements are erected on the firm teachings and instructions from the lecturers in the Physiotherapy department of the University of the Western Cape, the visiting lecturers from other universities and from other departments within the university. I also acknowledge the continuous commitment by the whole facilitating and coordinating staff that always made sure that my academic needs are being addressed and attended to. To all of them I render my gratitude beyond measure. Special thanks to my thesis supervisor Professor Julie Phillips and Co supervisor Dr. Conran Joseph. They were always been there for me, even when I popped into her office without prior appointment. Many thanks also go to Mr. Haleluya Moshi for his continuous support and guidance particularly in accessing the field and data collection. I dedicate this thesis to my Mother and Capuchin brothers of Tanzanian province, many thanks to you mum and my brothers.

ABBREVIATIONS

AD: Autonomic dysreflexia

AIS: American Spinal Injury Association Impairment Scale

ASIA: American Spinal Injury Association

DPOs: Disabled people's organization

DVT: Deep vein thrombosis

ISCoS: International Spinal Cord Society

KCMC: Kilimanjaro Christian Medical Center

MTA: Motor traffic accident

PGT: Peer group trainee

PU: Pressure ulcers

SCI: Spinal cord injury

TSCI: Traumatic spinal cord injury

UTI: Urinary tract infection

WHO: World Health Organization

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TABLE OF CONTENTS

TITLE PAGE	ii
ABSTRACT	iii
DECLARATON	v
DEDICATION AND ACKNOWLEDGEMENT	vi
ABREVIATIONS	vii
CHAPTER 1	
1 INTRODUCTION	1
1.1 BACKGOUND	
1.2 PROBLEM STATEMENT	4
1.3 RESEARCH QUESTION	5
1.4 AIM OF THE STUDY	
1.5 OBJECTIVES	5
1.6 SIGNIFICANCE OF THE STUDY	6
1.7 DEFINITIONS	.6
1.8 OUTLINE OF THE THESIS	8
CHAPTER 2	
LITERATURE REVIEW	10
2. 1 INTRODUCTION	10
2.2 THE INCIDENCE AND MORTALITY OF SPINAL CORD INJURIES	. 10
2.3 CAUSES OF SPINAL CORD INJURIES	12
2.4 MANAGEMENT OF SPINAL CORD INJURIES	14
2.5 COMMUNITY REINTERGRATION	17

2.6 THEORETICAL FRAMEWORK OF THE STUDY	19	
CHAPTER 3		
METHODOLOGY	21	
3 INTRODUCTION	21	
3.1RESEARCH SETTING	21	
3.2 RESEARCH DESIGN	22	
3.3 METHOD OF DATA COLLECTION	22	
3.3.1 QUANTITATIVE PHASE	23	
3.3.2 QUALITTIVE PHASE.	25	
3.4 ETHICS	29	
CHAPTER 4 4.1 INTRODUCTION	30	
4.2 QUANTITATIVE RESEARCH FINDINGS	30	
4.2.1 Incidence of TSCI at KCMC in Tanzania		
4.2.2 Etiology and level of lesion of TSCI in Kilimanjaro		
4.2.3 Mortality rate of TSCI in Kilimanjaro		
4.2.4 Demographic and clinical characteristics of the cohort from 2011-2015		
4.2.5 Demographic and clinical characteristics of persons according to years		
4.2.6 Secondary complications per years		
4.3 QUALITATIVE RESEARCH FINDINGS		
4.3.1 Introduction.		
4.3.2 Factors influencing reintegration into community life		
4.4 SLIMMARY OF THE CHAPTER		

CHAPTER 5

DISCUSSION	49
5.1 INTRODUCTION	49
5.2 EPIDEMIOLOGY OF TRAUMATIC SPINAL CORD INJURIES KIL TANZANIA	IMANJARO, 49
5.3CHALLENGES EXPERIENCED WITH COMMUNITY REI INDIVIDUALS SURVIVING A TRAUMATIC SPINAL	NTEGRATION BY CORD INJURY 54
5.4 SUMMARY OF THE CHAPTER	57
CHAPTER 6 SUMMARY, CONCLUSION, AND	
RECOMMENDATIONS	58
6.1 INTRODUCTIONUNIVERSITY of the	58
6.2 SUMMARY	58
6.3 CONCLUSION	60
6.4 LIMITATIONS	61
6.5 RECOMMENDATIONS	62
REFFERENCES	64

APPENDICES

APPENDICES

Appendix 1 interview questions in English

Appendix 2 interview questions in Kiswahili

Appendix 3 information sheet English

Appendix 4 information sheet Kiswahili

Appendix 5 consent form in English

Appendix 6 consent form Kiswahili

Appendix 7 translator letter

Appendix 7 ethics clearance TZ

Appendix 8 ethics clearance ZA



CHAPTER ONE

INTRODUCTION

1.1 Introduction

In this chapter, traumatic spinal cord injury as a condition is highlighted with emphasis on period prevalence, physiological, psychological and socio-economic consequences for the individual, the family and the community. Furthermore, the global burden of this condition is highlighted, with specific reference to Africa, especially Tanzania. The chapter further highlights the aim of the current study, the specific objectives as well as the problem statement and significance of this study.

1.2 Background to the study

The incidence and prevalence of disability due to Traumatic Spinal Cord Injury (TSCI) is increasing globally affecting both males and females (Lukersmith, 2013; Migliorini, New & Tongwe, 2009). Studies conducted almost a decade ago revealed that the incidence for TCSI globally was estimated to be 23 cases per million, per year (Lee, Ceippa, Fitzharris & Wing 2011). The estimation was reported for each region with the highest estimation in North America (40 per million), Sub- Saharan Africa-Central (29 per million), Asia-Central (25 per million) and Latin America-Southern (25 per million). It was then further reported that an estimated 133 226 incident cases of TSCI were due to accidents and violence (Lee, et al., 2011). The situation therefore needs to be addressed globally as the estimated global traumatic spinal cord injury incidence is as high as 40 to 80 new cases per million (Lukersmith, 2013). As the number of individuals sustaining a TSCI increases, the medical and rehabilitation costs will also increase due to the long term disabilities. After sustaining a spinal cord injury, the damage

could either cause complete or incomplete neurological impairment which requires long term rehabilitation and medical attention (Ackery, Tator, & Krassioukov, 2004).

Even though it has been reported in various previous studies that motor traffic accidents (MTA) are the most common causes of TSCI (Stokes, 2004) other causes due to the socioeconomic context such as those seen in developing countries are also reported. For example in Zimbabwe the leading cause of TSCI is self-harm and violence (61%); and in Pakistan and Asia falling is the main cause by 68% and 61% respectively (International Spinal Cord Society, 2011). When examining the causes of TSCI, it is evident that the proportion of TSCI from land transport is decreasing or stable in developed countries but increasing in developing countries due to trends in transport mode (transition to motorized transport), poor infrastructure and regulatory challenges (Lee, et al., 2011). These authors further reported that TSCI from low falls in the elderly are increasing in developed countries with ageing population while low falls in developing countries are as a result of heavy loads being carried on the head by young people. Furthermore, high falls, commonly from trees, balconies, flat roofs and construction sites are also reported in developing countries (Lee et al., 2011).

Spinal cord injury is an insult to the spinal cord either by trauma or through a disease process which carries with it major physical dysfunctions rendering the person immobile, with loss of sensation below the level of injury and an inability to control bowel and bladder functions among further physiological symptoms. These physical impairments depend on the level and extent of injury. The higher the location of the injury in the spinal column, the more severe is the physiological and functional impairments (Dawodu, 2008; Stokes, 2004). The individual suffers from a sequence of interconnected psychological, social and economic problems which

extend its effects from the individual or personal to the immediate family, friends, relatives and community at large (Middleton, 2004). For example, the inability to move lower and or upper limbs may hinder the person to do self-care. This makes such an individual dependent on family members for activities of daily living. The fact that he cannot get to his work place and thus cannot work has a negative impact on the economy of both the family and the community where he/she lives. Wyndaele and Wyndaele (2006) highlighted that the knowledge of incidence and prevalence of spinal cord injury is important because of their high personal, biophysiological impact, their high socio- economic consequences, short term as well as long-term plan of management and rehabilitation. Data on the prevalence of SCI are important for gauging demand for health care and social support, and to assess the impact of the secondary prevention measures, unfortunately data on the prevalence of SCI are sparse (Bickenbach et al., 2011). Any type of SCI is typically characterized by a sudden loss of voluntary muscle strength, sensation and autonomic functions below the level of injury which will vary depending on the neurological level of injury and the extent of impairment (Kirshblum et al., 2011). UNIVERSITY of the

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Studies have been done to examine the issue of community reintegration after sustaining a spinal cord injury and those undertaken in Canada and South Korea (Boschen et al, 2003; Song, 2005), found that these individuals had to undergo significant adjustments after SCI. A number of factors are raised including education, involvement in productive activity, and social and leisure participation influence community reintegration. Community reintegration is defined as 'resuming age/gender/and culturally appropriate roles/statuses/activities, including independence or interdependence in decision making, and productive behaviors performed as part of multi- varied relationships with family, friends, and others in natural community settings (De Wolf, et al., 2011). According to a study done in India, individuals with a spinal cord injury

after rehabilitation, were having a wide range of variation with regards to participation in the community; leading to a decline in community reintegration in the areas such as occupation and social integration as examples (Sekaran et al., 2010). It is thus clear that when an individual suffers a SCI, challenges and changes are faced by the individual, the family and even the community regardless of their socio-economic level. However, the physical and social circumstances that individuals experience, as well as coping mechanisms, vary substantially around the world, depending on their cultural backgrounds too (Saravanan et al., 2001). Strong relationships with friends and family members, social support and peer support have been described to have a substantial impact on adapting to the new situation after sustaining a traumatic spinal cord injury (Joseph at al., 2016; Monden at al., 2014).

Moreover, inaccessibility, financial constraints and stigma towards people with disability also play a role in limiting integration back into society in both well-resourced and poorly resourced countries (WHO& International Spinal Cord Society, 2013; Burn & O'connell 2012). In poorly resources countries, the risk of poverty and dependency on the family might become barriers to participation in the society and can be exacerbated by devaluing attitudes (Weerts & Wyndaele, 2011; Babamohamadi, Negarandeh, & Dehgan-Nayeri, 2011). Stigma might also be aggravated by cultural beliefs that disabilities derive from a curse or as a punishment for sin, occasionally leading to families hiding their disabled family member out of shame (Rathore, New, & Iftikhar, 2011). Although most of the studies are conducted in developed countries, few have been done in developing countries like Tanzania.

1.2 PROBLEM STATEMENT

Based on my working experience in Tanzania, I have observed a number of accidents leading to traumatic spinal cord injury (TSCI). Despite the fact that many studies have reported on the

incidence of TSCI and the challenges experienced with community reintegration after sustaining a TSCI globally, few reports have been published in developing countries and specifically Tanzania. It is therefore important to establish the current situation of TSCI in Tanzania which could lead to the appropriate preventive measures.

1.3 RESEARCH QUESTION

What is the incidence and causes of traumatic spinal cord injuries at KCMC, Tanzania and what are the challenges experienced with community reintegration by individuals surviving a traumatic spinal cord injury after discharge from hospital?



The overall aim of this study is to determine the epidemiology of TSCI, and to explore the challenges experienced with community reintegration by individuals surviving a traumatic spinal cord injury in Kilimanjaro, Tanzania.

1.5 SPECIFIC OBJECTIVES

- 1. To determine the annual incidence of TSCI in Kilimanjaro over a five-year period.
- 2. To determine the leading causes of TSCI in Kilimanjaro over a five-year period.
- 3. To determine the mortality rate during the initial acute and rehabilitation period.
- 4. To determine the injury characteristics and outcomes following TSCI.
- 5. To explore the challenges experienced with community reintegration by individuals surviving a traumatic spinal cord injury.

1.6 SIGNIFICANCE OF THE STUDY

The current status of SCI in Tanzania is not clearly understood, and it is in this regard that the researcher would want to establish the extent of TSCI and its contributing factors. The outcome of the study could lead to community awareness program of how to prevent identified factors leading to TSCI, improvement of the health care system in terms of rehabilitation and community involvement in the long term management of TSCI patients. The current study will add to the national findings of disability studies, specifically addressing issues related to TSCI. The findings could further assist policy makers in refining and implementing laws that could address the issues related to the prevention and management of TSCI. It is an opportunity for the persons with TSCI in the selected region to raise their voices on behalf of others on issues that are of importance to this group that can be seen as socially and economically disadvantaged.

1.7 DEFINITIONS

ASIA Impairment Scale (American Spinal Injury Association, 2002):

ASIA Impairment Scale	Description
(AIS) category	
AIS-A	Sensory and motor, i.e. no sensory or motor function in the sacral
	segments
AIS –B	Sensory but not motor function is preserved, sensory function is
	preserved in the sacral segment

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AIS-C: Incomplete injury with some sensory and motor function below

the level of injury with more than half the key muscles having a

power less than grade 3

AIS-D: Incomplete injury with motor function is partially preserved

below the neurological level, with more than half the key muscles

having a power of to grade 3 or greater than grade 3.

AIS E: Full sensory and motor function having normal function of muscle

grade 5

Community reintegration: Defined as acquiring, resuming, age/gender, culture and appropriate roles, statuses including, independence, interdependence, in decision making and in productive behaviors which is carried out as part of relationship with family friends, and community at large in natural community settings, therefore in rehabilitation in SCI is the key issue to make sure the participation of a person is full addressed in order to meet the necessary needs in the community (Sekaran et al., 2010).

Disability: is a complex term that refers to impairments in body functions and structures, limitations in activity resulting from such impairments and restrictions into participation in life either due to extrinsic or intrinsic factors (The World Health organization, 2002).

Family: as used in this study refers to father, mother and children as well as any relative living permanently in the same house.

Paraplegia: paralysis of lower extremities and part of the trunk following injury to the spinal cord at any level below level of nerve root C8 (Disability World, 2007).

Quadriplegia: paralysis of both upper and lower extremities following injury to the spinal cord at any level above nerve root C8 (Disability World, 2007).

Rehabilitation: In this context, the term refers psychosocial components such as "a range of social, educational, occupational, behavioral, and cognitive interventions for increasing the role performance of persons with serious and persistent mental illness and enhancing their recovery" (Barton, 1999, p 526) physical component which involves therapeutic attempts to deal with physical dysfunction or disease process, whose outcome is measure by the restored body function (Selected Therapy Services, 2011) and environment which covers both physical environment such as roads and home and environment which encompasses community behavior and actions around person with spinal cord injury approach. The process deals with such factors with an attempt to restore disabled person to the highest possible functional point, participation and independence (WHO, 2002).

Spinal cord injury: A temporally or permanent deficit in sensory motor and bladder and bowel function which occurs as a result of pathology or traumatic lesion of neural elements in the spinal canal. SCI causes varying degree of loss of motor, sensory function below the level of the injury depending on the extent of the injury (Hampton & Marshall, 2000).

Traumatic spinal cord injury: A spinal cord injury caused by external trauma, typically both high and low velocity mechanisms like sport, fall from a height, or transport related.

1.8 OUTLINE OF THE THESIS

Chapter one provides a brief introduction to the study outlining the extent of traumatic spinal cord injuries globally with specific reference to Tanzania and community reintegration. In

addition, the problem statement, research questions, aims and objectives of the study are also provided.

The **second chapter** provides a review of relevant literature with an overview of the incidence of spinal cord injuries, its causes and management. In addition, the aspect of community reintegration is also reviewed. The chapter ends with an outline of the theoretical framework of the study.

Chapter three describes the methods used to reach the objectives of the study. The chapter outlines the setting where the research took place, the study design, the methods used for both quantitative and qualitative data, and the data analysis used for both data sets. The chapter ends with an outline of the ethics considered in the study.

Chapter Four provides the results for both phases of the study. Firstly, the chapter presents the quantitative results describing the incidence of TSCI at KCMC in Tanzania, the demographic and clinical characteristics of the cohort, as well as the secondry complications of the cohort. The results are summarized in tables and illustrated by means of figures. In the second part of the chapter, the results of the analysis of the interviews are provided. Themes are illustrated by means of selected verbatim quotes.

Chapter Five presents an integrated discussion of the findings of the two phases of the study and compares the findings with the salient literature.

Chapter Six provides the summary, conclusion and recommendations based on the findings of the study.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter is a review of literature pertaining to spinal cord injuries, the incidence and causes thereof. The impact of spinal cord injury to the individual, family and community at large is highlighted in various studies. Finally, the theoretical framework of the study is provided.

2.2 THE INCIDENCE AND MORTALITY OF SPINAL CORD INJURIES

Spinal cord injury (SCI) is a devastating event causing significant burden to the individuals, their family and community. A spinal cord injury results from damage to the spinal cord, leading to neurological impairment, affecting motor, sensory and autonomic function (American Spinal Injury Association, 2006). Based on the etiology, SCIs can be divided into two main groups: traumatic spinal cord injuries (TSCI) and non-traumatic spinal cord injuries (NTSCI) (WHO, 2013). Stokes (2007) stated that the spinal cord injury resulting from trauma accounts for approximately 84% of cases and due to disease process approximately 16%, affecting more males than females by the ratio of 5:1. Persons with paraplegia have damage to their thoracic, lumbar or sacral spinal cord and tetraplegia occurs with damage to the cervical spinal cord (WHO & International Spinal Cord Society, 2013). Despite the immense health care and personal costs associated with those surviving a SCI, there was a surprising paucity of data regarding the incidence (number of new cases of SCI that occur over a period of time) and prevalence (number of people living with SCI at a point in time) globally (Noonan et al., 2012).

Researchers stressed that that research on the incidence and prevalence of SCI is very important because of its high personal, bio-psychological impact together with their significant short and long-term high socio-economic consequences (Wyndaele & Wyndaele, 2006). The global estimate of annual incidences ranges from 13 to 53 per million persons with a mean of 23 per million, even though a wide dispersion, ranging from 3.6 in Canada to 195 in Ireland has been reported (Jazayeri et al., 2015). Moreover, the studies conducted in the Southern part of the Africa region reported ranges from 21 to 29 cases per million population of SCI more than 5 years ago (Lee et, at., 2011). A more recent study conducted in a metropolitan region in South Africa reported an incidence of 76 cases per million persons (Joseph et, al., 2015). In Botswana a prospective hospital based study reported an annual incidence rate of 13 per million (Löfvenmark et al., 2015). No prospective data are available for Tanzania, but a five-year retrospective, hospital-based study from north- east Tanzania reported the annual incidence for at 26 persons per million (Moshi, Sundelin, Sahlen, & Sörlin, 2017).

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As from as early as 1700 BC until World War II, spinal cord injury was viewed as a fatal, untreatable and hopeless condition, which will always lead to complete dysfunction and death. One of the earliest scientists (whose name is not known) suggested that one should not bother to treat the condition (Dawodu, 2008). Thus, historically a high mortality rate used to be associated with a spinal cord injury (Lukersmith, 2013). However, in more developed, higher income countries, TSCI are not viewed as the end of a productive life any more. This is due to the development of medicine, the improved response to emergencies and the effective health and rehabilitation interventions. This is however not the case for lower income countries where TSCI are still viewed as a terminal condition (Lukersmith, 2013). It is well documented that spinal cord injuries not only are devastating but it also mainly affects the young and healthy individuals. TSCI therefore does not only create huge physical and emotional cost but because

of the age group affected, also a huge financial burden to a society (Cieza et al., 2010). The study done in Lagos Nigeria revealed a total of 468 cases of spinal cord injury over a 15-year period, of which 66.2% were aged 40 years and below and 70.1% were males with a male to female ratio of 2.34:1 (Obalum, Giwa, Adekoya-Cole, & Enweluzo, 2009). A traumatic spinal cord injury is a life - transforming condition of a sudden onset that can have devastating consequences" (Stokes, 2007,). These 'consequences' are short lived or permanent changes in normal motor, sensory or autonomic functions.

The majority of studies on SCI are conducted in the high income countries mainly America, Europe and Australia. Many authors have addressed the issue of scarcity of epidemiological, clinical, and qualitative data in the past from low income countries which are constrained in resources (Jazayer, et al., 2015; Holfman, Primack, Keusch, & Hrynkow, 2005. There was thus a huge gap of knowledge with regards to spinal cord injuries in the developing context and a need for research in this field. Information on the incidence and prevalence of SCI is critical for developing prevention-based strategies, health care planning including rehabilitation, and directing future research. The past few years have however seen more studies being conducted in the Southern African region, which is promising (Moshi et al., 2017; Joseph et, al., 2015; Löfvenmark et al., 2015).

2.3 CAUSES OF SPINAL CORD INJURY

Damage to the spinal cord may result from trauma (84%) or disease process (16%), affecting more males than females by the ratio of 5:1(Stokes, 2007). The causes of spinal cord injuries vary from region to region. Jagdish and Maharaj (1994) reported the causes of SCI in Fiji were

traumatic (53.6%) and non-traumatic (46.4%). These authors reported the highest percentage of TSCI to be caused by falls (38.7%) and motor vehicle accidents (25.3%) and sports (20%) (Jagdish & Maharaj, 1994). According to World Health Organization (2013), the main cause of TSCI are motor traffic accidents, followed by falls and violence while sport related accidents account for less than 10% (Nwadinigwe, Iloabuch, & Nwabuda; Ibbrahim et, al., 2013). Although motor traffic accidents have decreased in many high income countries due to implemented traffic safety regulations, the United States still reports high rates compared with similar contexts (Devivo, 2012). Africa as whole is a victim of traumatic spinal cord injury due to the poor economy, risky transportation systems and comparatively poor infrastructure (Jungu, 2006) even though epidemiological studies are very scarce (International Spinal Cord Society, 2011).

In Sub-Saharan Africa, motor traffic accidents accounts for approximately 70%, followed by a variation of causes dependent on the nature of the country such as high rate of assault, fall from trees or collapsing tunnels (Igun, Obekpa, Ugwu, &Nwadiaro 1999; Draulans et, al., 2011). In many underdeveloped countries those countries with resources constrained, the growing middle-class population lead to increasing number of vehicles on the roads. Due to insufficient reinforcement of traffic safety legislation the transport related injuries are expected to continue to increase in many of these countries (Rahimi-Movaghar et, al., 2013; Draulans, Kiekens, Roels, & Peers, 2011). A study done in Lagos, Nigeria reported that road traffic accidents accounted for (77.4%) of cases (Obalum et al., 2009) with a large majority (91.9%) of these injuries classified as complete traumatic spinal cord injuries according to the ASIA classification. Obalum et al., (2009) further reported that the most frequent complication seen was bedsores, with a mortality of 17.5% were reported (Obalum et al., 2009). Lee et al. (2011) reported that land transport accidents account for 90% of deaths in low and middle income

countries. This is the highest cause of death for the age group between 15-29 years; these causes of high mortality rate can be due to poor infrastructures, non-standard vehicles and poverty in the developing countries (Lee, Cripps, Fitzharris &Wing, 2011). In two studies done in the capital city of Tanzania, it was found that MTA was the leading cause of spinal cord injury (Bunde, 2007; Museru, Leshabari & Mbembati, 2002). However, infrastructure and socioeconomic activities in the city are very different from those in the rural areas and therefore causes of spinal cord injury in the rural Tanzania would be expected to be different from those found in the cities and more developed countries. According to these studies TSCI can be a major problem to the developing countries as the health system is inadequate to meet the needs of care of the patients in all stages from acute to rehabilitation, therefore there is a need to determine the cause and the way of preventing it.

2.4 MANAGEMENT OF TSCI

Levins, Redenbach and Dyck (2004) stated that traumatic spinal cord injuries are associated with the risk of developing secondary complications and life threatening conditions like "deep vein thrombosis, urinary tract infections, pressure ulcers, chronic pain, respiratory tract complications and others. Proper care, including medical and rehabilitation services are therefore essential for preventing and managing those conditions. TSCI may render individuals dependent on others for all activities of daily living, like washing, eating for the rest of her/his life, leading to depression which may affect their overall health (World Health Organization Spinal cord injury fact sheet, 2013). Lukersmith (2013) alerted that individuals with a TSCI tend to live longer in developed countries where medical and rehabilitation services are advanced as opposed to those in developing countries. The study done in Lagos Nigeria

revealed, that the most frequently seen complication was bedsores (59.9%) (Obalum et al., 2009).

In the low income resource-countries and where systematic SCI-care is lacking interventions are often challenged by for example inconsistent availability of adequate resources or absence of neurosurgeons, which can often lead to long delays in the surgical management of TSCI. Meanwhile, spine immobilization needs to be maintained by using collars, braces and log-rolling i.e. maintaining the alignment of the spine while rolling the patient to the side; which is necessary to relieve pressure and maintain hygiene. Log-rolling is a staff demanding activity and requires knowledge and training to be performed correctly (Idowu et al., 2011). These authors further stated that this can be challenged by limited knowledge and over-occupancy of the hospital wards (Idowu et al., 2011). Anthony (2012) stated that the challenges faced by TSCI patients differs between high- and low resource nation in that the provision of comprehensive care in low- resource environments are different to high-resource environments. He further asserts that in many-low income resources regions it is rare for an individual with an acute TSCI to be immobilized in the field and transported by trained personnel by the use of ambulance, resulting in an unstable spine, which can lead to further neurological compromise (Antony, 2012).

The National Institute of Medical of Neurological Disorders and Stroke (2011) reported that due to the advancement in emergency services, equipment and hospital services together with the advancement in research and rehabilitation services, secondary damage to the individuals sustaining TSCI and the accompanying complications are minimized. This leads to the increase in life expectancy for persons with spinal cord injury (National Institute of Medical of

Neurological Disorders and Stroke, 2011). However, this life expectancy depends on the socioeconomic environment and other physical factors such as the extent of the disability (Burt, 2004). Furthermore, the management for patients with TSCI varies from minimal available heath care to highly specialized management according to Wuermser et al. (2007). Optimal management should start at the site of the accident with proper stabilization and transport by professionals, followed by prompt emergency attention, within 24-hour availability of x-ray, computerized tomography or Magnetic Resonance Imaging (MRI), and surgery, well-staffed acute care units, and specialized rehabilitation (Parent et al., 2011). Not only that but, provision of appropriate technical aids, home modifications, and access to personal assistance are crucial to optimize functional outcomes. However, these recommendations are often not incorporated in many low income resources countries, especially tural areas, which most likely affect the long –term functional outcomes, participation in society, and the changes of survival. Early transfer of a casualty to a trauma or spinal centres has shown to decrease secondary complications, improve outcomes, psychosocial adjustment, and survival (Parent et al., 2011).

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In addition, after the acute phase, early transfers to specialized centres have shown to reduce cost, length of stay, secondary complications, and mortality (World Health Organization & International Spinal Cord Society, 2013; Parent et al., 2011). Other studies reported that, specialized SCI rehabilitation by trained multi-professional teams, including physiatrists, nurses, physio- and occupational therapists, social workers, rehab coaches as well as often urologists, plastic surgeons, and dieticians are required to address the multitude of issues that arise after an injury (Chhabra, 2015). Well-staffed and well-equipped SCI-units are established in many countries to serve this patient group but these services are often lacking in resource-constrained settings which results in significantly lower chances of returning to a full and productive life. In this case, patients are often admitted to general wards with a low nurse to

patient ratio and where special equipment such as pressure relief mattresses is none existent. When no SCI rehabilitation unit is in operation, the objectives for SCI management are often not according to the recommendations, and the prognosis and expected functional outcomes are low. Limited knowledge among the staff might also contribute to poor functional outcomes, high rate of complications and high mortality rates (Chhabra, 2015).

2.5 COMMUNITY REINTEGRATION

According to Mothabeng, Eksteen, and Westaway (2012), ccommunity reintegration has become the focus and ultimate goal of rehabilitation for people living with disabilities including individuals with a TSCI. It has also been an important objective and aim of public policy and legislation (Mothabeng et al., 2012). Extensive effort has gone into the development of a comprehensive and consensual definition of community reintegration with several authors agreeing that community reintegration is a multi-dimensional concept that includes common features or idea such as: residential setting, an appropriate social network, community activities and accepting responsibilities as an equal member of the society, productive activities such as employment, education and voluntary work as well as interactive relationships with family members, friends and the larger communities (Parvaneh & Cocks, 2012; Yasui & Berven, 2009; Ware et al.; 2007; Dijkers, 1998). One of the definitions relevant for the SCI population asserts that "community reintegration is resuming age, gender, and culturally appropriate roles/status/activities, including independence/interdependence in decision making, and productive behaviours performed as part of multi-varied relationships with family, friends and others in natural community setting (Dijkers, 1998). The term "participation" is also often used to capture this construct and is broadly defined by WHO as involvement in life situation (WHO, 2001).

The aim of rehabilitation for persons with spinal cord injury (SCI) is to help them adjust to life after SCI by equipping them and their families with the skills and resources required for living in the community (Suddeck, et al., 2009). According to Sekaran et al. (2011) individuals with spinal cord injury experience a wide variation of participation in the community after rehabilitation, some would lead to a decline in community reintegration in areas such as occupational, social integration and others. Another study reported that community reintegration differs for those who are supported by family and attend regular follow up visits to the rehabilitation center after rehabilitation Samuelkamaleshkumar, et al., 2010). Boschen et al (2003) found that individuals with a traumatic spinal cord injury had to undergo significant adjustments after SCI, which were influenced by various factors such as education, involvement in productive activity, and social and leisure participation. In many parts of the southern African region, the challenges facing the people with spinal cord injury and their families are considerable and can be aggravated by poverty, ignorance and unequal distribution of available resources. The rural, and even the urban environment is often harsh, with hilly, rough roads, and sand terrain which is unfriendly for wheel chair users. Equipment to support individuals with a traumatic spinal cord injury, if available at all, is usually supplied through chart donations and is not customized to the patients need (Oderud, 2016).

The physical environment of the selected area, in the Kilimanjaro region is characterized by dusty and uneven roads which are not friendly for wheelchair users (HEM Trust Fund, Tanzania, 2011, The United Republic of Tanzania, 1998). The inability to freely or without assistance move within the home and away from home inevitably hinders the individual from economic interactions leading to isolation and dependency in various aspects of life. These aspects include meeting friends, relatives, and attending social gatherings or move from one place to the other (Murphy, Middleton, Quirk, Wolf & Cameron, 2011; Newman, 2010; Levins,

Redenbach & Dyck, 2004), All of these would have adverse effects on the individual's community reintegration. There is therefore a need to explore the challenges individuals with a traumatic spinal cord injury experience in developing countries and Tanzania specifically.

2.6 THEORETICAL FRAMEWORK OF THE STUDY

The functional outcomes of individuals with a SCI are important when one wants to understand the reintegration of these individuals back into their respective communities. The International Classification of Function (ICF) defines rehabilitation as all measures necessary to maximise physical and psychological health including social, economic and vocational aspects and that the person and his/her opinion plays and important role in determining outcomes (WHO, 2001). The International Classification of Functioning, Disability and Health (ICF) was approved in the fifty-fourth World Health Assembly (WHO, 2001) in an effort to understand and measure key elements of health and disability.

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The ICF groups different domains for a person in a given health condition in two main parts, i.e. Functioning/disability and contextual factors. The main components of the ICF include impairments of body structure and function; activity limitations; participation restrictions; and environmental factors. The health condition (a disease or disorder) may impact functioning in relation to the body, at the level of activities, and at the level of participation in society. Body function and structure refer to the anatomical and physiological functioning of individuals. Activity and participation refers to a task or action and person's ability to execute the task or action in a life situation. Contextual factors (Environmental and Personal) refer to physical, social and attitudinal environment in which people live and conduct their lives (WHO, 2001).

Using the ICF's framework of the environmental factors will determine how physical, social, and attitudinal environment affect community reintegration of individuals with a TSCI.

2.7 SUMMARY OF THE CHAPTER

This chapter provided a broad overview of the literature pertaining to spinal cord injuries, including the incidence, causes and management thereof. In addition, the theoretical framework of the study was outlined.



CHAPTER 3

METHODOLOGY

3.0 INTRODUCTION

This chapter describes the methodology used in this study. The research setting is described, along with the inclusion criteria, data collection instruments and procedures, as well as steps taken to ensure methodological rigor. Ethical considerations are also discussed.

3.1. RESEARCH SETTING

This study was conducted at Kilimanjaro Christian Medical Centre, (KCMC) which is a referral and teaching hospital. It is situated in Moshi town in the Kilimanjaro region of northern Tanzania. Tanzania is situated in East Africa (www.tanzania.go.tz). The referral hospital was established in 1971, serving over 11 million people in the northern, eastern and central zone of Tanzania. It is one of four consultant hospitals in Tanzania and the only hospital with a rehabilitation center for spinal cord injury patients in Tanzania, and it typically accommodates 500-800 in-patients. It has 630 official beds, 90 canvas, 40 baby incubations, 1852 students, 1300 staff, and there is a daily attendance of 80 to 100 patients who are referred from different places including nearby countries. The hospital has 22 clinical departments and 11 hospital supporting departments like surgery, medicine, obstetrics and gynecology, pediatrics, radiology, ear- nose —throat (E.N.T), physiotherapy, occupational therapy, rehabilitation medicine and medical records (www.kcmc.ac.tz).

3.2. RESEARCH DESIGN

Both quantitative and qualitative methodologies were used in this study (Östlund, et al., 2011). A descriptive, retrospective design was employed for the quantitative methodology. Quantitative research is a means for testing objectives and theories by examining the relationship among variables (Polit and Hungler, 2013). The main concerns of the quantitative paradigm are that measurement is reliable, valid, and generalizable in its clear prediction of cause and effect (Cassell & Symon, 1994). In answering research objectives one to four, for the description of epidemiological features, a hospital-based register was used to define the incidence cohort.

In addressing the qualitative research objective (number 5) regarding challenges with community reintegration, qualitative description (QD) was used as operative methodological approach. Qualitative research, as with QD, is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore social human problems and phenomena (Croswell, 1998). In QD, the aim is to better understand the perceptions and experiences attached to a particular phenomenon, such as how persons with SCI experience community reintegration. QD is also useful in developing a conceptual basis of a phenomenon.

3.3 METHOD OF DATA COLLECTION

The data collection instruments and procedures are outlined separately for the qualitative and quantitative phases of the study.

3.3.1 Quantitative phase

Study population and sampling

The source population was those patients with a TSCI that were admitted to KCMC from 1 January 2011 to 31 December 2015. A convenient, non-probability sampling method, involving all subjects based on availability (Carter et al., 2011), was used to form the study sample. An inclusive sampling strategy was used. The study included all adult (≥18 years) patients with confirmed traumatic spinal cord injury. Excluded patients were those with non-traumatic spinal cord injury and those who died within the first week of injury. Annually, up to 55 patients with TSCI; therefore, approximately 220 case files were available for review.

Research instruments

Data for this phase was collected with a data extraction sheet. The data extraction form was based on the International Spinal Cord Injury Data Set (ISCOS). The ISCOS data set, designed by the International Spinal Cord Society, consists of three sections. Section A request for demographic data such as age and gender; the second section captures medical and neurological data such as admission date, injury date, type and level of injury sensory and motor level; and the third section captures management data such as assistance with ventilation and spinal surgery. In addition, information on the nature of secondary complications, such as pressure ulcers (PU), pneumonia, urinary tract infections (UTI), deep vein thrombosis (DVT), spasticity, and autonomic dysreflexia (AD) were collection from the medical records.

Reliability and validity of the instrument

Test-retest reliability study of the ISCOS was done by Whiteneck et al (2012) and an internal consistency coefficient of 0.89 to 0.94 was reported. Inter-rater reliability was determined by the researcher and research assistants collecting data from the first 30 files and compare their findings (Joanna Briggs Institute, 2014; Heffner, 2011).

Procedure

Data were retrospectively collected from patients' folders after ethical clearance was obtained from the University of the Western Cape Senate Research Ethics Committee and NIMR from Tanzania, which was granted on 15 March 2017. The CEO of KCMC further provided the necessary permission to conduct the study. The researcher highlighted the aims and objectives to the Head of the medical record department at KCMC through an information sheet.

Steps: After receiving the ethics clearance and permission from the respective authorities, the researcher and research assistant, along with the internal supervisor, set a meeting with the chief nurse of the Surgical Department of Rehabilitation of Spinal Cord Injury to seek the admission of all patients with TSCI between January 2011 to December 2015. A list of eligible patients was compiled. This list was then submitted to the medical records department for use by the researcher and research assistant. All files were screened and included only if all data variables were completed. Medical records with incomplete information concerning diagnosis and demographic characteristics were excluded from the study.

Data analysis

Data were captured and analysed using the Statistical Package for Social Sciences (SPSS) version 24.0. Participants' characteristics (for example age, gender, duration of hospital stay, causes of injury and vertebral injuries) and injury characteristics (location of injury and completeness of injury) were analysed descriptively. Continuous variables are expressed as means with standard deviation and median with range. Categorical variables are expressed as number of cases and percentage. Differences between sub-groups were analysed using Chisquare- and Fischer's exact test, and student t-tests. The annual incidence was calculated by the number of TSCI cases (numerator) divided by the number of persons (denominator) in the catchment area for that particular year. Since census data are only available for 2012, the total number of persons at risk in 2011, as well as for 2013 to 2015, were either multiplied by 0.9686 or 1.0314 to account for the annual population growth of 3.14% in Tanzania. Significance level was set at p-value <0.05.

3.3.2 Qualitative phase

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Population and sampling

According to the Kilimanjaro Association for spinally injured individuals, Kilimanjaro region is estimated to have between 300 and 500 persons with spinal cord injury and the Moshi district has more than 100 persons with spinal cord injury (Nyamubi, 2010).

The population consisted of all individuals who were included in the quantitative phase. Purposive sampling was used to select only above 18 years old TSCI patients at KCMC. To start off with, 10 individuals were approached, based on their injury level to ensure that individuals with both cervical and thoracic/lumbar lesions are included. Data collection continued until theoretical saturation occurred, which was after 15 individual face-to-face

interviews. This was done for the study to benefit from the diversity of participants based on resources, cultural issues and socioeconomic within the same community as experienced by different persons with SCI. A semi-structured interview was conducted at a convenient venue and time with those selected and willing to participate in the study. All interviews were conducted in the comfort of the participants' home. The interview started with a broad question and then probes were used to explore community reintegration and factors influencing it (Fischler, 2014). Each interview lasted about 45-60 minutes.

Procedure of information gathering

The first step was to obtain ethical clearance from The University of the Western Cape Senate Research Ethics Committee (Appendix 8). Thereafter, permission to conduct the study was sought from the Tanzania National Institute of Medical Research Ethics Committee (Appendix 7) to perform the study in the specified area. The interview guide, consent and information sheets were translated from English into participants' appropriate language (Kiswahili) by the researcher then back-translated by a professional translator, a retired professor from the University of Dar es salaam. The translated copy of the interview guide was subjected to piloting in which they were given to one person with spinal cord injury (not included in this study) to read and see if the questions were understandable. No corrections were needed. The purposively selected participants, from medical records as from phase 1, were visited in their homes prior to data collection, with the aim of explaining this phase of the study, familiarizing them with ethical rules, and requesting their participation. This visit was done together with the research assistant for her to be familiar with the environment and the study itself. The participants were requested to sign the consent forms after understanding and agreeing to participate in the study. All visited participants agreed to participate in the study and some signed the consent forms on the first visit (preliminary visit) while most opted to sign on the second visit (interview day). The researcher and participant planned for the interview visit (date, time, and place i.e. at work or at home) that would be convenient to the participant but within the time frame of the data collection period.

All participants had a way of being communicated to before the interview day (by personal cell phone). All participants received reminder calls two days before the interview day to make sure that they were available and prepared. On the appointed date the interview was conducted with the participants in their natural environment (homes).

Trustworthiness of data

Trustworthiness refers to how true and rigorous the data is (Heffner, 2011). To ensure trustworthiness of the qualitative data the following criteria was considered:

i. Credibility

There are different ways of checking the credibility of the collected data (Creswell, 2008). The researcher used member checking and peer debriefing sessions. This is done with engaging of other peers or superiors who are familiar with the explored research problem to give feedback on the summarized data (Lincoln & Guba, 2011). Notes were taken during the process to check whether the researcher and the supervisor have the same understanding of the findings (Shenton, 2004). To ensure credibility, the researcher and the supervisor generate themes independently which were then compared (Creswell, 2008). Also, participants were given the summary of the transcripts to confirm the accuracy and clarity of the information (Creswell, 2008; Shenton 2004).

ii. Confirmability

Confirmability was ensured by having transparency of methods and to demonstrate the neutrality of the interpretations (Lincoln & Guba, 1985). A confirmability audit trial will be

possible by providing an audit trial consisting of raw data, analysis notes, reconstruction and synthesis products, research's' process notes, personal and preliminary developmental information.

iii Transferability

To assess the transferability of the findings, methods employed in data collection, data analysis and interpretation were properly described. In addition, several of data analysis documents are available which gives others researchers the ability to transfer the findings of this study to other research projects.

iv Dependability

To address the dependability, the research design and its implementation, the operation details of data gathering and reflective appraisal of the thesis were reported in details (Shenton, 2004).

Data analysis

The recorded interviews were transcribed verbatim for analysis. The analysis of the interviews starts with the transcription of the information from the audiotape recordings to produce manuscripts. A comparison was made with the notes taken during discussion to verify the accuracy. Transcripts were read through several times by the researcher, with the emphasis on the emergence of the themes. Furthermore, grouping of the themes into broader categories was done in order to reduce the number of themes or small categories (i.e. very similar categories will be subsumed to come up with one). However, the researcher emphasized the searching of categories that have internal convergence and external divergence which means that the categories must be internally consistent but distinct from one another (Marshall, & Rossman, 2014). After the derivation of themes, an independent researcher, the supervisor, read through the transcripts and generate themes in order to ensure credibility (validity) and dependability (reliability) of the produced themes.

3.4 ETHICS

The study received ethical clearance from the UWC Senate Research Committee. The request to conduct the study was submitted to the National Institute of Medical Research (NIMR) in Tanzania for the same purpose, and ministry of health and social welfare, Medical director of KCMC, head of medical record and Physiotherapy department of KCMC for permission. The study began after receiving a final clearance letter from KCMC. Before giving written consent form, participants (including Medical director, head of medical records and Physiotherapy departments) were informed about the aim and objectives of the study, issues of confidentiality were described to them, and they were further informed that their participation in this research is completely voluntary and that they may withdraw from the study at any time without any consequences (all information will be contained in an information sheet). To ensure anonymity, names of patients were not included. Instead, numbers and identification codes were used. Only the researcher had access to identification codes. For the maximum possible protection of participants' identity during the publishing of results, in the future, pseudonyms will be used. Participants were informed that there are minimal risks associated with this research study, in that sensitive issue will be discussed and if they feel emotionally unwell, an appropriate referral to an expert for will be made. Furthermore, the researcher explained the benefit of the study, in that no direct individual benefits exists but the results may help the hospital and other health professional understand the process of care of SCI patients. The relevant institution and participants of this study will be informed of the study outcomes when the final reports are available.

CHAPTER 4

RESULTS

4.1 INTRODUCTION

The chapter contains results from the quantitative and qualitative research questions which were gathered and analyzed separately. The quantitative research objectives are answered first, followed by the results from the thematic analyses which address the last, 5th, objective. Results are displayed in text and tables.

4.2 QUANTITATIVE RESEARCH FINDINGS

4.2.1 Incidence of TSCI at KCMC in Tanzania

The total number of adults with TSCI in this Hospital for 5 years was 224, while the total population according to the national census of 2012 in the region of Kilimanjaro was 164 0087, with 793 140 males and 84 6947 females. There were 40 new cases of TSCI in Kilimanjaro in 2011. The total population in the defined catchment area in 2012 was 1640 087. Of these, 903 688 (44.9%) persons were under the age of 18, and were thus excluded from those at risk. Therefore, the incidence rate of TSCI was 55.1 (40/ 818 404 persons) per million persons. In order to account for population growth, for 2011, the population figures for 2012 was multiplied by 0.9686 for the year 2011 and by 1.0314 for the years 2013 to 2015, accounting for a population growth of 3.14% yearly. Consequently, the incidence rates of TSCI in the Kilimanjaro region were as follow: there was an increase in the number of TSCI cases every year, leading to a steady increase in the incidence rate between 2011 and 2015. Furthermore, the male-specific incidence ranged from 75.6 to 93.2 per million per year, where the highest increase was in 2013. Contrary, the incidence among females range from 10.4 to 18.1 per

million population, with the highest incidence found in 2014. Table 4.1 presents the overall and gender-specific incidence rates over the five year period.

Table 4.1. Crude and gender-specific incidence of TSCI from 2011 to 2015 in KCMC in Kilimanjaro region.

Years	2011	2012	2013	2014	2015
Number of cases	40	41	47	46	50
Population at risk	875 312	903 688	932 064	961 331	991 517
Incidence per million	45.7	45.3	50.4	47.8	50.4
Male-specific incidence	75.6 (423297)	80.1 (437 020)	93.2 (450 743)	79.5 (464 896)	85.5 (479 494)
Female-specific incidence	17.7 (452015)	10.7 (422 627)	10.4 (481 321)	18.1 (496 434)	17.6 (512 022)

4.2.2 Etiology and level of lesion of TSCI in Kilimanjaro

The major cause of injury was falls, which account for 45.54% of injuries, followed by transport, at 36.16%, while assault being the least common cause of injury at 13.84%. Cervical level lesions were more common (111 out of 224), followed by thoracic (71 out of 224) and lumbar/ sacral (40 out of 224) as outlined in Table 4.2.

Table 4.2 Etiology of TSCI

Variables	number	%
Sport	0	0
Assault	10	4.46
Transport	81	36.16
Fall	102	45.54
Others	31	13.84

4.2.3 Mortality rate of TSCI in Kilimanjaro

The in-hospital mortality rate was increasing yearly where the highest rate was in 2014 and the lowest in 2011 as outlined in Table 4.3. Importantly, there was no statistical difference in mortality rates across the years of observation.

Table 4.3 Mortality rate of TSCI in KCMC

	2011-2015	2011	2012	2013	2014	2015	p values
Mortality							0.387
Death	40	6	8	9	9	8	
Total	224	40	41	47	46	50	
%	17.9	15	19.5	19.1	19.6	16	

4.2.4 Demographic and clinical characteristic of the cohort from 2011-2015.

In total, 224 patients' files were included in this study, where male were more affected than female, accounting for 84% and 16% respectively. Overall, the mean age at injury was approximately 38 years. There were 52 patients with associated injuries. Moreover, the majority of patients were treated conservatively and only one had surgery. Table 4.4 illustrates pertinent demographic and injury characteristics of included patients.

Table 4.4 Participants' characteristics (N =224)

Variables	Total 2011-2015				
Age					
Mean (SD)	38.17	16.7			
Median (IQR)	37	18-92			
Etiology (n and %)					
Sport	0	0			
Assault	10	4.46			
Transport	81	36.16			
Fall	102	45.54			
Others	31	13.84			
Level of injury (n & %)					
C1-C4	42	18.75			
C5-C8	69	30.80			
T1-T12	71	31.70			
L1-S5	<mark>4</mark> 0	17.86			
Associated injury (n & %)					
Yes	UNIV 52RSI	ΓY of 23.21			
No	WESTI72RN	CA 176.79			
Vertebral injury (n & %)					
Yes	31	13.90			
No	193	86.10			
Spine surgery (n & %)					
Yes	1	0.45			
No	223	99.55			
Secondary complications (n &	& %)				
Yes	79	35.27			
No	145	64.73			
Discharges (n & %)					
Home	172	76.79			

Other hospital	7	3.13
Self-discharge	5	2.23
Death	40	17.85

Abbreviations: SD= Standard deviation; IQR= Interquartile range.

4.2.5 Demographic and clinical characteristic of persons according to years

The following table (Table 4.5) illustrates injury profiles by year. The leading cause of injury was falls in general, with the highest in 2015, which accounted for 26 patients, following by 2011, affecting 22 patients, while the least was in 2012. Concerning level of injury, the cervical spine was most commonly affected. Concerning completeness of injury, complete injuries were found in 113 patients (out of 224), with the highest proportion seen in 2012. Out of the 111 incomplete injuries over the five year period, most were seen in 2013. Furthermore, almost all patients were treated conservatively, with only one patient receiving surgical intervention. Statistically significant differences were found for level of injury (as per the international recommendation for categorizing it) and vertebral injuries across the five year period. Table 4.5 illustrates pertinent demographic and injury characteristics of patients over the five year period.

Table 4.5 Core demographic and injury characteristics of patients per year (N=224)

Total	2011- 2015	2011	2012	2013	2014	2015	P-value
Gender	Total	40	40	47	46	50	0.661
Male	188	32	35	42	37	41	
Female	36	8	5	5	9	9	
Age mean	38.17	37.4	37.4	37.7	41.52	37.08	
							0.174
Etiology							
Assault	10	1	2	1	1	5	
Transport	81	15	17	15	18	16	
Fall	102	22	15	20	19	26	
Others	31	2	7	11	8	3	
		THE		00-00-	9		
Level of injury							0.010
C1-C4	42	10	5 WED 6	5	10	12	
C5-C8	69	6UNI	V ₁₈ R S		20	12	
T1-T12	71	12 E S	12 K	N ₂₃ CA	12	12	
L1-S5	40	10	6	6	4	14	
Completeness							
Complete	113	21	26	17	24	25	0.137
Incomplete	111	17	15	30	22	25	
Total	222	38	41	47	46	50	
Discharge							
Home	172	29	30	38	35	40	0.387
Other hospital	7	3	3	0	1	0	

Self-discharge	5	2	0	0	1	2	
Death	40	6	8	9	9	8	
Total	224	40	41	47	46	50	
Ventilation on discharge							0.550
No	222	39	41	47	46	49	0.000
Yes	2	1	0	0	0	1	
Total	224	40	41	47	46	50	
Spine surgery							
No	223	40	41	47	46	49	0.479
Yes	1	0	0	0	0	1	
Total		40	41	47	46	50	
Vertebral inj.		لسلم			Щ,		
No	193	36	V ³⁹ ERS	46 _{V of}	44 the	27	0.000
Yes	31		TERM			23	
Total	224	40	41	47	46	50	

^{*}The distribution of cases across the different variables were calculated using 2011 to 2015 data

4.2.6 Secondary complications per years

Out of 224 patients over the five year period, 79 of them were having at least one secondary complication during acute hospitalization. Pressure ulcers was the leading complication, accounting for 51 cases, followed by pulmonary complications in 12 cases. Deep vein thrombosis was the least common complication and was only detected in 2 patients. The only statistically significant difference in complications across the years was seen for pressure

ulcers. Table 4.6 illustrates the prevalence of secondary complications over the five year period.

Table 4.6 Secondary complications per year

Secondary complication	2011-2015	2011	2012	2013	2014	2015	P value
Complication							0.152
Yes:	79	18	14	21	11	35	
No:	145	22	27	26	35	15	
PU							0.020
Yes	51	8	6	17	5	15	
No	173	32	35	30	41	35	
PC					T		0.339
Yes	12	3	3	0	4	2	
No	212	UNIV	VERS	1TY 03	42 f the	48	
UTI		WES	TER	N CA	PE		0.184
Yes	6	3	1	2	0	0	
No	218	37	40	45	46	50	
DVT							0.468
Yes	2	1	1	0	0	0	
No	222	39	40	47	46	50	
Spasticity							0.534
Yes	11	4	2	2	2	1	
No	213	36	39	45	44	49	

Constipation							0.463
Yes	4	1	1	2	0	0	
No	220	39	40	45	46	50	
AD							0.716
Yes	3	1	0	1	1	0	
No	221	39	41	46	45	50	

Abbreviations: PU= Pressure ulcer; PC= Pulmonary complications; UTI= Urinary tract infection; DVT= Deep vein thrombosis; AD= Autonomic dysreflexia.

4.3 Qualitative research findings

4.3.1 Introduction

The qualitative phase involved six (6) persons with TSCI who were rehabilitated at the Kilimanjaro Christian Medical Centre (KCMC) referral hospital, and then discharged into the community with their disability. The aim was to explore the challenges with reintegration into their communities following rehabilitation, as per objective five. The six persons included were diverse, including: one educated young man, a non-educated adult from a poor family, a woman who is married, a married man, and a young woman who is unmarried. All of them were living back in the community for about 10 to 19 years. Furthermore, five (5) persons had paraplegia and one tetraplegia, with causes as follows: fall from a height (2), sliding (one), road accident (two) and one had a banana tree fall on him. The mean age of the six persons at the time of the injury was 34.2 years. Table 4.7 illustrates demographic and injury characteristics of the included persons.

Table 4.7 Demographic and injury characteristics of participants n = 6

Participants	Sex	Age	Cause of injury	Classification of SCI	Education	Injury duration
						(Years)
P1	M	49	A banana tree fell on him	T12 compete	Primary 7	10
P2	F	44	Transport	T2 complete	Primary 7	10
P3	M	37	Land slide mineral	T5 complete	No schooling	11
P4	M	32	Fall	T12/L1 complete	University	19
P5	F	32	Transport	T3 complete	Primary 7	15
P6	M	34	Fall	T1 complete	Primary 7	14

4.3.2 Factors influencing reintegration into community life

The overarching theme was factors, primarily challenges, influencing community reintegration after TSCI. The categories of influencing factors were 1) social support, 2) social injustice, 3) socio-economic challenges, 4) personal factors as barriers, 5) environmental barriers, and 6) Inaccessible and unaffordable health and rehabilitation services.

4.3.2.1 Social support

The majority of the participants showed that they had social support from either a wife or husband, and those who were unmarried had support from a friend or Disabled People's Organizations (DPOs). The DPOs are doing a great deal for persons with SCI in Kilimanjaro as they assist the injured in building a house, assist them in getting a wheelchair, sustained them with food and psychological support by visiting them in the hospital and their homes. However, the reliability/sustainability of support is a big challenge for the injured. Specifically,

financial support is often not secured which forces the injured to continue with small businesses such as selling vegetables and bananas to sustain their living.

The peer group training plays a big role in this group as they visit them in hospital after the injury, whilst informing them on what to expect and how to go about solving problems with functioning. Furthermore, spousal support was seen as life-saving in this context, where participant one - a father of two children and farmer said:

"Without my wife I could have died very early since my wife takes care of me and the children; she woke up in the morning and took the vegetables to the market so that we could get food and sustain the family and send the children to school" [P1]

Similarly, participant 2, a woman with 5 children (a farmer and hard working woman supported by her husband, who lives in village with hills surrounding her said:

"Without Mr. Zacharias I was helpless. He helped me a lot when he visited me in the hospital and here in my home and provide me with much support: he brought me sugar and food; at the beginning he give me psychological support; sometimes he assisted me with money for buying my catheter and transport to the hospital. My husband helped in pushing my wheel chair, taking care of the family, finding means of living by selling bananas and going to work, so that we could get money to send me to the hospital when I am sick, especially from urinary tract infection, and for sending the children to school." [P2]

The ones who had no wife had great support from his friends who helped him in daily living. Participant 6, a man of 34 years, who fell from a tree, has now been living with SCI for 14

years. He had no job, no wife or children, and so was assisted by a friend in all daily living said:

"I was only able to get support from my friend and my girlfriend who came to cook for me and assist me in pushing my wheel chair. As you can see I cannot move by myself; sometimes it is difficult, because they do not live here with me all the time; when I have a problem I call one of my friends, and he would come to assist me; they help me a lot."

[P6]

4.3.2.2 Social injustice

The majority of the participants felt social injustice in some way in their lives. The majority had difficulty with accessing societal services such as transport. They commented that the bus conductors refuse to take them with their wheelchairs. This makes it difficult for them to find means of travelling from one place to another, especially when going to the hospital or visit a relative. Also, they said that they needed to pay double fare for bus for themselves and the wheel chair. Participant 5, who is an active young person of 32 years, a tailor, a peer group trainer for SCI patients said:

"I cannot travel with my wheelchair from one place to another in a mini bus or a bus.

They refuse and tell me to pay double fare; sometimes they even refuse because of my disability." [P5]

The majority have difficulties to secure a job for which they have been trained; while the others had difficulty because they had no qualifications for any employment as they were not trained or they did not have a chance to attend vocational training or secondary school. Some felt

discriminated against: when they go looking for a job the community talk behind them, saying, "They are looking for a job yet they know they are disabled people, there are enough people who are not disabled. They should leave the post to be filled by "normal persons". Even the employer looks down at them. One participant who was trained, and had a good education from university, also faced the problem of getting a job, as he said:

"No one wants to give us a job I am a university graduate. When I went for an interview, they told me I had passed. But because of my disability condition they found it difficult to employ me, because, if they did, the office environment would need to be changed a bit so that my wheel chair can move about, and modification in the toilet which they find difficult to do. So they told me: sorry the position had been taken by another person as we had only one opportunity." [P4]

A few also had difficulties getting support from the community. They said the community discriminated against them due to their disability, especially in solving problems with accommodation as people in Tanzania often rent a place to stay. The owners are often reluctant to rent out their places to people with disabilities. A few of the participants had difficulty securing accommodation, as one said:

"It is difficult to rent a room or a house, because the owner said I should do modification of the doors and toilet by myself and when I want to move to some other house I should bring his house back to the condition in which it was before. It is difficult to live when the cost is increasing as many people discriminate against me. Many house owners wondered where I would get money for the rent." [P5]

Another societal problem is the lack of knowledge of SCI in the community as it has been said by majority of the participants, which make the relative refuse to assist them in cooking providing them with necessary living materials, look them down, refuse to push their wheel chair. All of these lead to systemic isolation and lack of community reintegration. The majority were humiliated by the community, as they are perceived as people with a bad smell due to urine leakage.

4.3.2.3 Socio-economic challenges

The majority reported to struggle to get food and daily needs for living, due to poverty. Others said they have major challenges not having a proper toilet as they did not have money to do modification or to build a proper toilet. A young man of 34 years old who sustained his injury after a fall said:

"Sometimes I had no food, because there was no money to buy it. I would eat only once a day because I should budget properly the small food I have. I am poor up to now; I haven't got a toilet; so I go to the banana field to relieve myself." [P6]

All of the participants had a common problem with catheters being very expensive and make them suffer much since they were afraid to change them accordingly as they cannot get it easily. Also, wheelchair repairs and the material for repairs were found to be very expensive. One participant said:

"I searched for the front tire for so long but could not find one in the town; so they told me to go to Kenya. I decided to improvise; I made a wooden tire. The problem is poverty. That is why I cannot order a proper tire from abroad." [P1]

Most of them find it difficult to get a job according to their level of education, as they have no qualifications and education. They felt that having employment would have helped them manage the living cost for their family and themselves. Also, the majority found it difficult to get a loan from the bank or groups which deal with money since banks are afraid to give them a loan since they do not have a steady income. One participant said:

"I am a university graduate; but when I went for an interview they told me you pass but they did not employ me due to disability they had finding it difficult to change their offices and toilet so that I can be comfortable to work, or they give me difficult conditions which at the end I say thank you, as they told me we will call you but at the end no calling." [P4]

Few of the participants said they have no money to sustain life; others had no bed, only a mattress which they received from the DPO. Also the majority had a problem to reach the hospital when they get sick for problems like UTI, and they do not have the finances for laboratory tests. One participant said:

"When I am sick sometimes I give my husband my urine and send to the laboratory as we have no money to send me to the hospital, as I need a transport to hire the taxi which is very expensive I find it difficult sometimes I said better to die"[P2].

4.3.2.4 Individual factors as a barrier (intrinsic factors)

The majority of the participants have struggled to accept what has happened, while some thought that it was a punishment from God. They thought about their lives as they were told in

the hospital they will not walk again. Some participants were also thinking of doing the extreme by committing suicide.

"Better to die rather than remain with this condition for the rest of my live...it is difficult to go back to normal life." [P3]

Some of the participants, especially the unmarried, felt low and demotivated, since no relatives visited them as they did prior to having the SCI. Some of the participants were not members of the disability association due to poverty, as one participant said:

"I would like to join the association but I have no money and the place they meet is very far it is not easy to reach with a wheel chair, yet the member fee is also a problem."

[P3]

The majority of the participants only completed primary school education, received no vocational training, or have any employment. Consequently, they find themselves struggling with life, as one participant said:

"If I was educated I would try to find a job. But I do not have even a certificate. That means that, if I were to get a job, it would be one which I would hate." [P3]

Forming social and intimate relationships after injury was difficult for the participants since they were afraid to approach anyone to seek friendship; One participant indicated that she wants to get married but is afraid to approach any man. She said: "I am afraid to approach a man to be my boyfriend, because of my condition as a disabled person; what would he think of me?" [P5]

4.3.2.5 Environmental barriers

The physical environment (home and away from home), meaning home and its surroundings, was found to impose major challenges to community reintegration. All of the respondents found it difficult to have a user-friendly road, which led to problems with propelling their wheelchair. Also, all participants could not get to where they wanted and needed to be due to the inaccessibility of roads and the community setting. One participant said:

"look I am living between the hills no road from my house to the main road in all directions. If I want to go the hospital I need two men to carry me on his back up to the main road, then I can hire a taxi to town or hospital, not only this the other side there is wooden bridge not easy for the person to use while carrying a heavy load, I use the wheel chair from my room to the toilet and move around my home only as you see it is not possible to move outside the home." [P1]

Another participant said:

"The road in the village is very bad with rivers, stones hills mud during rainy season, and rough road so it was not easy to go to school with a wheel chair until my parents and teachers decide to transfer me to town so that I can continue with my studies. I move from my home and rent a room because in the village the road was not friendly for me and no people to help me push my wheel chair or carry me when I fell to propel it" [P4]

Due to bad roads the majority cannot visit the friends or attend any ceremony function in the community, it is not possible to attend social gathering like going to the church or village meeting, leading to the exclusion of people with TSCI from important life events. One participant said:

"I cannot visit my friends and even the friends are not visiting me as they were doing before I got this problem they said he is a disabled has nothing to offer this cut me from the outside world". [P1]

4.3.2.6 Inaccessible and unaffordable health and rehabilitation services

The majority of the respondents report that the health facilities are far from their homes and when they attend, services are found to be very expensive. Also, all health and rehabilitation services are paid services, including workshops for repair and maintenance of assistive devices. Another issue is the fact that NPO's are only situated in bigger town, leaving injured persons in rural areas with no assistance or support from them when needed. One participant said:

"The dispensaries are too far to reach by wheel chair. The nearest one is more than 6 km from home, and the community nurse we have here is unable to change my catheter. So I have to go to the health center. There I can also have the urine checked for urinary tract infections and get treated. But it is expensive." [P2]

The majority experienced a problem in the community for not having rehabilitation teams to visit them. Physiotherapists or occupational therapists were found needed in the community to further the rehabilitation of the injured people. Some had difficulty with wounds dressing, especially when treating pressure ulcers. One participant said:

"When I got pressure ulcer it is difficult to dress in the village or nearby hospital as they charge me expensively which I don't have but when I go to a big hospital like KCMC they assist me nicely." [P3]

All insist to have rehabilitation team in the community so as they can assist them with selfmanagement advice on exercise, diet, and lifestyle modification. One participant said:

"I need rehabilitation workers to visit me so that they can help me in different ways like insisting my relative to take part in looking after me and give instructions on exercise, sometimes they are the one offer me some food, and soap for washing my clothes". [P6]

4.4 SUMMARY OF THE CHAPTER

This chapter discussed the incidence, aetiology, in-hospital mortality, and injury characteristics of traumatic spinal cord injury in a region of Tanzania. The incidence rates were found to increase over the five-year period, and the leading cause of injury was found to be falls. Those sustaining a TSCI are generally younger males. We further found that deaths do occur early on after injury, according to the in-hospital mortality rates. Also, participants are almost exclusively managed conservatively.

The qualitative component of the thesis explored challenges with community reintegration after TSCI. The properties (categories) of challenges were conceptualized as 1) social support, 2) social injustice, 3) socio-economic challenges, 4) personal factors as barriers, 5) environmental barriers, and 6) Inaccessible and unaffordable health and rehabilitation services. The general sense is that people with TSCI in a region of Tanzania are often excluded from community life and societal roles due to personal and environmental factors.

CHAPTER 5

DISCUSSION

5.1 INTRODUCTION

This chapter provides a discussion of the results of the objectives stated in chapter one. The results of both the quantitative and qualitative components are provided. The overall aim of this study was to determine the epidemiology of TSCI, and to explore the challenges experienced with community reintegration by individuals surviving a traumatic spinal cord injury in Kilimanjaro, Tanzania. The findings of these two phases are thus presented and compared with salient literature.



The incidence rates for the Kilimjaro region in Tanzania was found to be 45.7 per million in 2011. Thereafter a steady increase in incidence was observed from 2011 (45.7 per million) to 2015 (50.4 per million). These incidence rates are higher than the global incidence rate of 23 cases per million as reported by Lee et al. (2014). The rates are however comparable to those in China (60.6 per million) (Li et al., 2011) and Canada (42.4 per million (Kattail, Furlan, & Fehlings, 2009). On a closer glance at the African continent, the incidence rates in the Kilimanjaro region differs significantly to the studies on the continent. Löfvenmark et al. (2015) reported an incidence of 13 per million population in Botswana while Joseph et al. (2015) reported an incidence rate of 75.6 per million in a region in South Africa. Comparisons with the incidence of traumatic spinal cord injuries in other countries in Africa are difficult as there is a lack of current information with regards to the epidemiology of these injuries.

On closer examination of the gender-specific rates in this region, the male-specific incidence ranged from 75.6 to 93.2 per million per year, where the highest increase was in 2013. Contrary, the incidence among females range from 10.4 to 18.1 per million population, with the highest incidence found in 2014. This trend was similar to that reported by Joseph et al. (2015) in South Africa where the male-specific incidence was also significantly higher than for that of females. Similarly, Sabre et al. (2012) also reported a higher incidence for males when compared to women. In addition, the mean age of those that sustained a TSCI ranged from 37.4 (2011) to 41.52 (2014). In this study the higher incidence of males being affected is possibly due to the activities that they are involved in to ensure household income such as climbing trees which are frequently seen in certain parts of Tanzania. Joseph et al. (2015) noted that a great need exists to identify the factors that place males at a higher risk for traumatic spinal cord injuries. This is of great importance as the average age of those with a TSCI in this study was approximately 38 years which is a very active and productive age group, which means failure to lead a productive life at this age would have extensive socioeconomic consequences, to the WESTERN CAPE person, family and community as well.

The majority of the traumatic spinal cord injuries were caused by falls from a height (45.54%) followed by transport (36.16%). The cause of injury could be seen as a reflection of the major socioeconomic circumstances in this part of Tanzania. The most common activities in this region is related to agriculture, necessitating frequent climbing of trees for leaves for animal feed, fruits and firewood for domestic use. Falling from heights has also been found to be the leading cause in other studies conducted in the developing contexts such as India (Gupta, Solomon & Raja, 2008; Singh, Sharma, Mittal & Sharma, 2003). In a more recent study

conducted in India, 54% of the TSCI were caused by a fall from a height (Singh, Shrivastva & Dulani, 2011). This may be the pattern of etiology in rural, poverty stricken and less developed areas. These results indicate that the etiology of traumatic spinal cord injury is related to socioeconomic activities as well as infrastructure of a particular setting (Ackery, Tator & Krassioukov, 2006) requiring proper targeting of risky area and activities in taking preventive measures. Vanneste (2001) argued that 95% of disabilities in the sub-Saharan African countries are poverty related and therefore the risky "economic" activities could be the result of many injuries.

The proportion of TSCI resulting from land transport, i.e. four wheel vehicles, is stable or on the decrease in developed countries, but on the increase in developing countries according to the global map report. The increase in transport related accidents in developing countries is due to poor infrastructure, many non-standard vehicles, poor regulation and enforcement due to cost and lack of resources and poor safety culture, while developed countries have safer cars, better roads design, and alternative means of transport like railways (Lee et al., 2014). Prevention efforts of traumatic spinal cord injuries in countries such as Tanzania should therefore include implementation of better or stricter enforcement of traffic laws, roadworthy vehicles and an improvement of the road infrastructure.

Mortality

The mortality rate in this study was 17.85% with the majority of deaths occurring in the acute phase. The exact cause of injury however was not indicated in the patient folders and this is an area that should be researched further. Lee et al. (2014) stated that our ability to care for people

with SCI is reflected in survival statistics: the survival rate at 1 and 10 years after injury, and the life expectancy compared with the normal population. In this category it shows the developing countries have the highest 1-year mortality rates compared with the developed countries, the particularly Sub-Saharan Africa are the countries which suffer most. Rathore et al. (2007) reported no deaths in their study and attributed that to safe and efficient rescue techniques at the scene of accident, therefore preventing deaths in the acute phase.

Secondary complications

Seven groups of secondary complications were reported on in this study, i.e. pressure sores, pulmonary complications, UTI, DVT, muscle spasms, constipation, and autonomic reflexia. Pressure sores were the major secondary complication, accounting for 22.7% of all complications and pulmonary complications 5.4%. Vasiliadis (2012) stated that urinary tract infections followed by pressure ulcers and upper respiratory tract infections are the most common complication for those individuals with tetraplegia.

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In developing countries pressure sores are the major cause of morbidity and mortality for patients with traumatic spinal cord injury as shown in a study done in Pakistan, where 39.7% of the patients suffered pressure sores at rehabilitation admission (Burns & O'Connell, 2012). It has well known that if an individual who has sustained a TSCI receives optimal services within the first 72 hours, ideally being directly transferred to a specialized spinal treatment center, secondary complications are reduced drastically. At KCMC a specialized spinal unit was only operational from 2014 and also the only one in the country. Therefore, the patients admitted before that would most likely suffer from secondary complications. Lee et al. (2014) reported that delayed admissions of over 1000 TSCI patients to specialist centers in Italy and the United Kingdom resulted in pressure sores, heterotopic ossifications and urinary

complications in addition to longer hospital stay. It would therefore be recommended that in addition to specialized care, personnel such as emergency service workers that are first on the scene of an accident, be properly trained with regards to handling, etc.

Hospital stay

The length of hospital stay in this study ranged from 1 to 374 days (mean = 64.97). Length of hospital stay varies between complete and incomplete injury and from according to the area of injury (cervical vs thoracic vs lumbar region). In addition, Vasiliadis (2012) reported that length of hospital stay also varies between countries depending on the country's admission system and could range between 30.9 and 539 days. Li et al. (2011) reported a length of hospital stay ranging from 1 - 136 days with a mean stay of 18 days. These researchers attributed the short hospital stay to the financial crisis and lack of rehabilitation facilities in that particular area.

The length of stay in hospital in this study differs significantly from that reported in a study in Sweden (Joseph et al., 2017). These researchers attributed this difference to the early surgical management of individuals with a TSCI therefore resulting in better neurological recovery and shortening the hospital stay and cost to the person and community. The management of TSCI in KCMC was mainly conservatively and done in the general word prior to 2014 while in Stockholm, Sweden 77% of all traumatic spinal cord injuries was managed with surgery within 48 hours of injury as recommended in the acute clinical profile guidelines for spinal cord injury (Wing, 2008). In addition, the majority of poorly-resourced countries the management of traumatic spinal cord injury is done in the general surgical wards due to the lack of specialist care such as neurosurgeons and orthopedic surgeons.

5.3 CHALLENGES EXPERIENCED WITH COMMUNITY

REINTEGRATION BY INDIVIDUALS SURVIVING A TRAUMATIC

SPINAL CORD INJURY

Mothabeng (2012) viewed community reintegration as one of the most critical goals of rehabilitation of an individual with a traumatic spinal cord injury and therefore disability. Researchers such as Samuelkamaleshkumar et al. (2010) and Pang et al. (2007) have expressed concerns over the challenges individuals with physical disabilities experience with community reintegration. Some of these challenges include mobility, social integration and economic self-sufficiency.

In-depth interviews were conducted with individuals with a traumatic spinal cord injury to explore the challenges they might face in regard to community reintegration. Below follows a discussion of these challenges.

The majority of the participants pointed out that they had social support. Their support was offered from their significant other (i.e. wife or husband), friends or Disabled People's Organizations (DPOs): "Without my wife I could have died very early since my wife takes care of me and the children; she woke up in the morning and took the vegetables to the market so that we could get food and sustain the family and send the children to school". Receiving support greatly assists those with TSCI to cope with their new situation although the DPOs are not always consistent. They can assist individuals in the towns but not in the villages. A study conducted in India reported similar findings, i.e. social support from family members assisting individuals with a TSCI to cope with the new environment, the majority of the participants in the Indian study found support of great help (Samuelkamaleshkumar et al., 2010). In another study, it was reported that community reintegration declined when family members and friends

do not visit individuals in hospital during their acute phase, while those who were visited had better outcomes (Sekaran et al., 2010). In addition to family members, the support of others such as health care professionals, peers, and colleagues were also important to assist TSCI clients adopt to their new lifestyle (Newman 2010).

The majority of participants in this study expressed that they felt social injustice and/or discrimination in some way in their lives. They reported difficulties with transport such as bus conductors refusing to take them with their wheelchairs, making it difficult to find means of traveling from one place to another. These types of concerns are similar to those expressed by participants in Cape Town, South Africa who reported difficulties with mini-bus taxis (Joseph et al., 2016). Similarly, to participants in the South African study, those in this study found it difficult to obtain decent jobs (Joseph et al., 2016). Jackson et al. (2006) highlighted that many participants in the United States of America had jobs before their injuries but found it difficult to find jobs after they sustained a TSCI. These researchers also reported that it was difficult to return to old jobs as some of the workplaces were inaccessible with a wheelchair. These are all issues that should be taken up by policy makers and/or government to ensure that people with disabilities are treated fairly in terms of public services and employment.

Participants in this study reported difficulties obtaining food and meeting their daily needs of living due to poverty. Not having decent or any employment further aggravated their situation and the lack of government assistance and cultural perceptions of the disabled as useless made it even worse. This is in total contradiction to a study in the Netherlands which showed that a high percentage of individuals with a spinal cord injury return to their work due to the policies pertaining to disability (Schönherr et al., 2004). The Dutch legislation regarding work for the

disabled is complex and very different from those in other countries, and the few individuals that could not return to work in the Netherlands after sustaining a traumatic spinal cord injury was due to difficulties such as the distance and nature of work.

Individuals in this study reported difficulties with wheelchair repairs. This in turn affects their active and effective participation in the community and therefore technical aids are of utmost importance. In addition, despite the importance of wheelchairs for individuals with a TSCI, it is not readily available or no information is readily available with regards to where it can be sourced from. In the developed context individuals also reported experiencing difficulties with regards to wheelchairs, however in that context issues such as expensive motorized wheelchairs were highlighted (Teo et al., 2011; Suddick & Neill, 2009). Therefore, in both the developing and developed context people with disabilities fail to effectively participate in their respective communities although more so in the poorer-resourced countries.

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A number of individuals struggled with intrinsic factors to reintegrate fully in their respective communities. Some of the participants viewed sustaining a traumatic spinal cord injury as punishment from God. These internal struggles are so intense that some participants reported suicidal feelings. These are similar to those reported by Joseph et al. (2016) in South Africa. These researchers reported that survivors of a spinal cord injury felt alone and not able to participate in the community as before. Jackson et al. (2006) reported similar findings in the USA. Kendall, Ungerer and Dorset (2003) however warned that decreased community participation could lead to depression, anxiety, family conflicts, difficult social adjustment and ineffective coping skills.

Difficulties with health services were expressed by many of the participants. Most of the challenges experienced were related to the distance of health services and the expensive nature thereof. Issues as basic as catheters were only available in big hospitals, which in turn means that individuals need the necessary financial means to travel to the city. Many researchers in developing countries have highlighted challenges with regards to accessibility of health services (Teo et al., 2011; Song 2005; Newman 2010).

5.4 SUMMARY OF THE CHAPTER

This chapter discussed the results of both the quantitative and qualitative findings of the study.

The next chapter provides a summary and conclusion to the study.

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CHAPTER 6

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

This chapter provides a summary and conclusion of the study. In addition, recommendations based on the findings are provided.

6.2 Summary

Based on the working experience of the researcher in Tanzania, a number of accidents leading to traumatic spinal cord injury (TSCI) have been observed. However, many studies have reported on the incidence and challenges experienced with community reintegration after sustained SCI across the world with little being published in developing countries such as Tanzania. This therefore led to the research question: "What is the epidemiology of traumatic spinal cord injuries at KCMC, Tanzania, and what are the challenges experienced with community reintegration by individuals surviving a traumatic spinal cord injury after discharge from hospital?"

The overall aim of this study was thus to determine the epidemiology of TSCI, and to explore the challenges experienced with community reintegration by individuals surviving this devastating injury in Kilimanjaro, Tanzania. This study was conducted at Kilimanjaro Christian Medical Centre, (KCMC) which is a referral and teaching hospital situated in Moshi town in the Kilimanjaro region of northern Tanzania. Both quantitative and qualitative methodologies were used in this study. A descriptive, retrospective design was employed to

determine some epidemiologic aspects of TSCI in Tanzania. In addressing the first four objectives for the description of epidemiological features, a hospital-based register was used to define the incidence cohort. The source population was all patients with a TSCI that were admitted to KCMC from 1 January 2011 to 31 December 2015. Approximately 220 case files were available for review. Data were collected with a data extraction sheet. The data extraction form was based on the International Spinal Cord Injury Data Set (ISCOS).

For the qualitative phase, purposive sampling was used to select adults, above 18 years old, who have sustained a TSCI, have been managed at KCMC, and have returned home following acute management of their injuries. Ten individuals were initially approached based on their injury level, to ensure that individuals with both cervical and thoracic/lumbar lesions are included. All semi-structured interviews were conducted in the comfort of the participants' home. The interview started with a broad question and then probes were used to explore community reintegration and factors influencing it (Fischler, 2014). Each interview lasted about 45-60 minutes.

The findings suggest that the incidence rates of TSCI were found to increase over the five-year period, and the leading cause of injury, over the five year period, was found to be falls. Those sustaining a TSCI were generally younger males. Also, participants were almost exclusively managed conservatively, an aspect in total contrast to acute clinical practice management guidelines for SCI. We further found that deaths do occur early on after injury, according to the in-hospital mortality rates. The qualitative component of the thesis explored challenges with community reintegration after TSCI. The properties (categories) of challenges were conceptualized as 1) social support, 2) social injustice, 3) socio-economic challenges, 4) personal factors as barriers, 5) environmental barriers, and 6) Inaccessible and unaffordable

health and rehabilitation services. Overall, people with TSCI in a region of Tanzania perceived themselves as excluded from community life and societal roles, mainly due to personal and environmental factors.

6.3 Conclusion

Spinal cord injury is a medically complex and live-disrupting condition, requiring specialized care provided along the entire lifespan following injury. In order to provide suggestions to policymakers, as well as to increase our awareness of this devastating condition, it is important to study the epidemiology of injury and associated challenges in functioning. The incidence rates of TSCI in KCMC were increasing yearly, which was 47.8 per million population in 2014 and 50.4 per million population in 2015. Furthermore, men were mostly affected, at 83.86%, compared to females. The mean age of injury onset was 38 years, when persons were mostly employable. Furthermore, the majority had secondary complications during their acute hospital stay, where pressure ulcers were the most common.

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Concerning challenges with community reintegration, the majority of the participants depended on close family and friends for assistance in terms of functioning, with no reliable social support provided by health and social services in Tanzania. Most of the barriers to community reintegration were extrinsic (social and physical environment), and participants needed to develop skills to self-manage their condition and finding ways to overcome challenges. However, due to the dominance of the barriers, most of the participants indicated that their reintegration into their respective communities were sub-optimal. Barriers which made them feel like they were not part of the community were as follow: social injustice with

regard to not being able to access public transport, unfriendly environment for wheelchair users or partially provided social support, unavailability and or affordability of health services, and difficulty securing a job.

6.4 Limitations

- Some of the medical files were not found in the medical record department, as
 recorded in the admission book. This led to missing data. These cases were in fact not
 considered in this study, which might have led to an underestimation of the incidence
 rate and other epidemiologic assumptions.
- We further found that some of the names and diagnosis differed between the
 recordings in the admission book and official medical record. The accuracy of data
 could not be confirmed in a few cases. The cases were thus deleted from the study
 cohort to prevent a potential misclassification of cases.
- The retrospective hospital-design used in this study is considered a methodological
 weakness since we might have missed (unaccounted) those with milder SCIs which
 did not require acute hospitalization or those who died at the accident scene or within
 the first few days post-injury. All these uncertainties may influence the true burden
 associated with a TSCI.
- Another limitation relates to the lack of using a valid and reliable clinical assessment for SCI diagnosis, for example the American Spinal Injury Association Impairment Scale (ASIA). This would have contributed to a more sound assessment of sensory and motor levels affected and sparred.
- The sample for the quantitative phase has being selected from only one referral hospital in the northern part of Tanzania; thus the representativeness of this sample to

- the larger population with TSCI in Tanzania cannot be assumed. Further nationwide studies are required to determine the epidemiology of TSCI in Tanzania.
- This qualitative study only included six participants which were purposefully selected, therefore the results may not represent the condition of lives of most persons with spinal cord injury in this setting and this calls for a study including a more heterogeneous group.

6.5 Recommendations

- The major causes of traumatic spinal cord injury in this study are found to be falling from heights, which shows a link between socioeconomic activities and the cause, as the majority show that they were either looking for fire wood, food for their domestic animals which they keep inside the house. Preventive measures should prioritize this prominent cause; meaning that policymakers and primary campaigns should target safety by educating citizens on avoiding climbing trees as much as possible.
- ➤ Since almost 20% of the injured individuals die during their acute hospital stay, it seems necessary to determine the nature and quality of acute care in order to assess whether it meets international standards. This information could thus be used to advocate for policy reform and implementation of best practice interventions.
- Family is found to be the basic foundation of psychological stability and socioeconomic solutions to participants, as derived from the qualitative phase. With this in mind, it is necessary that the relationship between the injured person, family and friends is maintained from early on in order to facilitate a smooth transition from the hospital to home and community life. This can be done by educating the community, starting with the family, on pathophysiology of spinal cord injury, its

psychology, levels of assistance and importance inclusion into the community. Any planned income generating activity should involve the family and community as a whole.

- In this study, all parents who had young children reported a constant psychological and economical struggle to cater for their needs. Rehabilitation service providers are challenged by these results to look further and consider enabling parents with TSCI to cater for their young children by providing more comprehensive services. The Ministry of Social Welfare has to have a plan to the disadvantaged children and such plan should be made known to the beneficiaries.
- Wheelchair is clearly identified in qualitative study as the foremost important necessity by all participants. However majority of participants had broken wheelchairs and it was difficult to get the spare parts in the country. These findings call for efforts to be made by providing an appropriate wheelchair as one of the basic necessities needed to improve participants' reintegration into community.

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APPENDICES

Appendex 1: interview questions in English



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THE INTERVIEW QUESTION

C C	Demographic information:	
Name:	Ago (vogrs)	Say Docidential
Address Family	THE STATE OF THE S	
Cause of the injury		
THE BROAD QUESTION	JNIVERSITY of the	
As a victim of traumatic spinal car		

As a victim of traumatic spinal card injury, what challenging experiences have you faced during community reintegration after rehabilitation?

LEADING QUESTIONS

- i. How has the injury influenced your life?
- ii. Tell me the negative effects.
- iii. What did you do before the injury that you cannot do now?
- iv. Why?
- v. Why?
- vi. Why
- vii. Is the environment partly or wholly to blame for this?

APPENDIX 2: interview questions in Kiswahili



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SWALI LA USAILI

Jina:	Umri
(miaka)Jinsia	Anwani ya
makazi	FamiliaMuda
tangu kuumia Kili	chosababisha kuumia
SWALI KWA UPANA WA	KE
	UNIVERSITY of the

Ukiwa mhanga aliyevunjika uti wa mgongo, uniambie ni changamoto zipi umekumbana nazo wakati wa kurudi kwenye jumuiya yako baada ya tiba?

MASWALI YA KUONGOZA USAILI

- i. Je, kuvunjika huku kumeathiri kwa namna gani maisha yako?
- ii. Nitajie athari hasi.
- iii. Je, ni yapi uliweza kufanya kabla ya kuvunjika, ambayo huwezi kufanya sasa?
- iv. Kwa nini?
- v. Na sababu nyingine?
- vi. Na nyingine tena?
- vii. Je, pengine na mazingira yalikuwa na athari kidogo au kubwa kwa maisha yako ya sasa?



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Revised: December 2015

INFORMATION SHEET

Project Title: Challenges experiences by individuals surviving a traumatic spinal cord injury with community reintegration in Tanzania

What is this study about?

This is a research project being conducted by Joseph D. Swai at the University of the Western Cape. We are inviting you to participate in this research project because you senate higher degree of UWC, ministry of health and social well fare in Tanzania, Medical director of KCMC. As you are the key persons to give the permission of conducting the study, and provide with the necessary information needed for my study. The purpose of this research project is to determine the period prevalence of TSCI and to explore the challenges experienced by individuals with community reintegration after sustaining TSCI in Tanzania.

What will I be asked to do if I agree to participate?

You will be asked to a broad question and then probe further to enable the researcher to concentrate in the research objectives which will take about 45 to 60 minute of interview to each participant. For quantitative part I will use those patients who were admitted from January 2011 to December 2015 with traumatic spinal cord injury approximately 220 case file available will be used from medical record department which will collected by the use of data extraction sheet from International Spinal Cord Injury Data Set (ISCOS). The study will be in Kilimanjaro Christian Medical Centre in Tanzania.

Would my participation in this study be kept confidential?

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity, for the interview the names will not be used at all only code will be used in this study.

To ensure your confidentiality, the data will be kept in locked cabinet and using and using identification codes only on data forms, and using password to protect the files in the computer.

If we write a report or article about this research project, your identity will be protected.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.

What are the risks of this research?

There may be some risks from participating in this research study.

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

The benefits to you include the outcome of this study will bring awareness to the community on how to prevent the identified factors lead to SCI, improve health care system in terms of rehabilitation and long term management of SCI in the community, the policy makers can also benefit by putting in plan the lows and help the government in planning.

or

This research is not designed to help you personally, but the results may help the investigator learn more about Challenges experienced with community reintegration after sustaining traumatic spinal cord injury in Tanzania. We hope that, in the future, other people might benefit from this study through improved understanding of real the Challenges experienced with community reintegration.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by *Josoph Didas Swai* at the University of the Western Cape. If you have any questions about the research study itself, please contact __Joseph Didas Swai at: University of Western Cape [+255753370432 or +255683195375, and e-mail swaij@ymail.com]

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

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This research has been approved by the University of the Western Cape's Research Ethics Committee. (REFERENCE NUMBER: *HS 16/5/42, and from Tanzania NIMR/HQ/R.8a/Vol.1X/2494.*)

UNIVERSITY of the WESTERN CAPE



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Private Bag X 17, Bellville 7535, South Africa *Tel:* +27 65474307 **E-mail:** swaij@ymail.com

Iliohakikiwa: December 2015

FOMU YA MAELEZO

Mradi huu wa utafiti unaitwaje: changamoto zitokanazo na kurudi katika jumuiya baada ya tiba kwa mtanzania aliyefunyika uti wa mgongo.

Mradi huu wa utafiti unamhusu nani?

Utafiti huu utafanywa na Joseph D.Swai katika chuo kikuu cha Western Cape cha South Africa.Tunawalika kushiriki katika utafiti huu kwa sababu Bodi ya Elimu Ya Juu ya Chuo Kikuu cha Western Cape, Wizara ya Afya na usiwi wa jamii watoto na wazee ya Tanzania, Mkurugenzi wa Afya wa KCMC. Kama watu muhimu sana wa kunipa ruhusa katika utafiti huu na kupata taarifa muhumu za utafiti huu kwa ajili ya utafiti huu. Sababu ya kufanya utafiti huu ni kuangalia idadi ya wagonjwa waliovunjika uti wa mgongo kwa ajali na changamoto wanazopata warudipo katika jamii baada ya tiba.

Ni maswali gani nitaulizwa kama mshiriki wa utafiti huu?

Utaulizwa swali kuu la msingi na kufafanuliwa maswali ambayo yatamsaidia mtafiti aweze kufikia malengo ya utafiti huu,maswaali hayo yatachukua muda wa dakika 45 mpaka dakika 60 kwa kila mshiriki. Kwa upimaji nitatumia wagonjwa waliolazwa katika hospitali kutoka Januari 2011 mpaka Desemba 2015 kwa ugonjwa wa kuvunjika uti wa mgongo, kwa mkadirio nitatumia mafaili 220 ya wagonjwa ambao walipata tatizo kama hilo. Nitatumia fomu ya kimataifa ya kukusanya

habari za kuvunjika uti wa mgongo (ISCOS).utafiti huu utafanyika katika hospitali ya Kilimanjaro Christian Medical Centre ya Tanzania (KCMC).

Je ushiriki wangu utakuwa wa siri katika utafiti huu kama nikitoa taarifa?.

Mtafiti atahakikisha anaficha utambulisho wako na majibu yako pia, mshiriki hataandiwa jina lake. Hiyo yote nikufanya mshiriki asijulikane kama yeye ndiye aliyetoa hizo taarifa, kwa hiyo kwa mshiriki jina halitatumika katika kujaza taarifa hizo na kanuni ndizo zitatumika katika utafiti huu. Kuwa na uhakika kwamba kutakuwa na usiri wa taarifa zako, taarifa zote zitahifadhiwa kwenye kabati ambalo linafungwa kwa usalama wa taarifa zake, na kabati hilo litafunguliwa kwa kutumia kitambulisho cha kanuni na zile ambazo zipo kwenye tarakilishi(komputa) zitafungwa kwa kutumia namba za siri.

Kwakufuata mahitaji ya kisheria ya bodi ya viwango muhimu tutaweka wazi mtu au taasisi kwa taarifa zote zinazohusu unyanyasaji wa watoto au ukiukwaji wa haki za binadamu.

Nini hatari au madhara ya utafiti huu?

Kunaweza kukawa na madhara yanayotokana na kushiriki katika utafiti huu.

Tutajitahidi kupunguza hatari ambazo zinaweza zikatokea katika jamii hasa kimahusiano kati ya mtu na mtu. Tutatoa msaada kwa wale ambao watashiriki kutoa majibu katika uatfiti huu. Tutawaandaa kisakoloji wakati utafiti ukiendelea. Tutatumia miongozo mbalimbali wakati uatafiti ukiwa unaendelea ili kumsaidi mshiriki anayetoa taarifa.Mpango utakuwepo kwa atakaye umia kwa kumpeleka kwa mtaalamu atakaye msaidia.

Nini umuhimu wa kufanya uafiti huu?.

Umuhimu wa huu utafiti ni kuleta uelewa kwenye jamii jinsi ya kuzuia sababu ambazo zina sababisha kuvunjika kwa uti wa mgongo (SCI) katika jamii na watunga sera pia itawasaidia kutunga sheria na kusaidi serikali kupanga mpango mkakati kuzuia kuvunjika kwa uti wa mgongo (SCI).

Utafiti huu haujaandaliwa kukusaidia wewe mwenyewe lakini matokeo ya utafiti huu yatakusaidia kujifunza na kujua changamoto ambazo zinaikumba jamii baada ya kupatwa na madhara ya kuvunjika uti wa mgongo hapa Tanzania. Tunaamini kwamba kizazi kijacho kitafaidika na utafiti

huu kwa kuuboresha zaidi au kuutumia kama mwongozo wa tafiti zingine zinazohusu changamoto wapatazo watu waliovunjika uti wa mgongo warudipo katika jamii baada ya tiba.

Je naweza kuhusika katika utafiti huu na kujiondoa kushiriki wakati wowote?.

Kushiriki katika uatfiti huu ni hiari yako mwenyewe unaweza ukaamu kushiriki au kutoshiriki katika uatafiti huu. Unaweza kuacha kushiriki katika utafiti huu muda wowote bila kipingamizi chochote.kama ukiamua kushiriki au kutoshiriki hakuna adhabu yoyote ambayo iatatolewa juu yako au kupoteza haki yoyote ambayo ulikuwa umeahidiwa.

Itakuwa je kama kuna maswali natakakuuliza?.

Utafiti huu unafanywa na Joseph Didas Swai katika Chuo Kikuu Cha Western Cape.kama kuna maswali yoyote kuhusu utafiti huu wasiliana naye kwa:-Joseph Didas Swai, Chuo Kikuu Cha Western Cape,+255753370432/+255683195375,e-mail:swaij@yahoo.com.

Kama ninamaswali ya kuuliza kutokana na mradi huu wa utafiti, na haki zako kama mshiriki wa utafiti au unataka kutoa taarifa juu ya matatizo uliokumbana nayo wakati wa utafiti, tafadhali wasiliana na wahusika wafuatao:

Dr Nondwe Mlenzana
Head of Department: Physiotherapy
University of the Western Cape
Private Bag X17
Bellville 7535
nmlenzana@uwc.ac.za

Prof José Frantz
Dean of the Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
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Website:www.nmr.or.tz

Utafiti huu umekubaliwa na chuo kikuu cha Western Cape,na baraza la madili la utafiti (number ya kukubaliwa ni HS 16/5/42, and from Tanzania NIMR/HQ/R.8a/Vol.1X/2494.)



Appendix 5: Consent form



UNIVERSITY OF THE WESTERN CAPE

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CONSENT FORM

Title of Research Project: Challenges experienced by individuals surviving a traumatic spinal cord injury with community reintegration in

Tanzania.

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name
Participant's signature
Date

Appendix 6Fomu ya kukubali



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa *Tel:* +27 65474307 mob: +255753370432 E-mail: swaij@ymail.com

Fomu ya Kukubali

Mradi huu wa Utafiti unaitwa: Changamoto zinazotokana na kurudi katika
Jumuiya baada ya tiba kwa Mtanzania
aliyevunjika uti wa mgongo

Nimeelezwa kuhusu utafiti huu kwa lugha rahisi ambayo naielewa. Maswali yangu kuhusu hayo niliyoelezwa yamejibiwa. Ninaelewa kushiriki kwangu kunahusu nini, nami nakubali kushiriki kwa matakwa yangu yaliliyo huru kabisa bila shuruti yo yote. Naelewa ya kuwa hakuna atakayefahamishwa jina langu. Naelewa pia kwamba naweza kujitoa katika utafiti huu wakati wo wote bila kutoa sababu yo yote na bila hofu yo yote kuhusu kufanyiwa lo lote baya kwa kujitoa, wala kunyimwa maslahi yangu.

WESTERN CAPE

Jina la Mshiriki Sahihi ya Mshiriki Tarehe

Appendix 7 Translator letter

Br Prof Josaphat Baran Maghway

Padre Pio Programme

P O Box 76312

Dar es Salaa, Tanzania

2017-09-01

TIN No. 118 725 077

Br Joseph Didas Swai P O Box 131Ifakara

Tanzania

To whom it may Concern

Re: Document Translation English-Kiswahili-English: for questioner for interviews for research on, Challenges experiences with community re-integration after sustaining a traumatic spinal cord injury in Tanzania.

Regarding the above mentioned subject, we confirm that we have translated in English-Kiswahili-English documents related to the above research, submitted to us by the researcher Joseph Swai. We wish to further confirm that since the translations were professionally done, they therefore maintain the true meaning and sense of the original language from which they were translated.

Very sincerely

WESTERN CAPE

Br Prof J B Maghway

For PPP



THE UNITED REPUBLIC OF TANZANIA



National Institute for Medical Research Ministry of Health, Community 3 Barack Obama Drive Development, Gender, Elderly & Children P.O. Box 9653 6 Samora Machel Avenue P.O. Box 9083 11101 Dar es Salaam Tel: 255 22 2121400 11478 Dar es Salaam Fax: 255 22 2121360 Tel: 255 22 2120262-7 Fax: 255 22 2110986 E-mail: headquarters@nimr.or.tz NIMR/HQ/R.8a/Vol. IX/2494 16th May 2017 Joseph Didas Swai Western Cape University in South Africa Faculty of Community and Health Sciences South Africa C/o Haleluya I. Moshi Othorpaedic Rehabilitation Unit for Spinal Cord Injury Kilimanajro Christian Medicl Center P.O. Box 3010 MOSHI CLEARANCE CERTIFICATE FOR CONDUCTING

MEDICAL RESEARCH IN TANZANIA This is to certify that the research entitled: Challenges experienced by individuals surviving a traumatic spinal cord injury with community reintegration in Tanzania (Swei J. et al) whose local investigator is Haleluya I. Moshi of KCMC Moshi has been granted ethical clearance to be conducted in Tanzania.

The principal investigator of the study must ensure that the following conditions are fulfilled:

- 1. A progress report is submitted to the Ministry of Health, Community Development, Gender, Elderly & Children, the National Institute for Medical Research, Regional and District Medical Officers after every six months.
- Permission to publish the results is obtained from the National Institute for Medical Research.
- Copies of final publications are made available to the Ministry of Health, Community Development, Gender, Elderly & Children and the National Institute for Medical Research.
- Any researcher, who contravenes or fails to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine as per NIMR Act No. 23 of 1979, PART III Section 10(2).
- 5. Site: K.C.M.C Hospital in Kilimanjaro region.

Approval is valid for one year: 16th May 2017 to 15th May 2018.

Name: Prof. Yunus Daud Mgaya

Signature CHAIRPERSON

MEDICAL RESEARCH COORDINATING COMMITTEE

RMO of Kilimanjaro regions DMO/DED of Moshi

Name: Prof. Muhammad Bakari Kambi

Signature CHIEF MEDICAL OFFICER MINISTRY OF HEALTH, COMMUNITY DEVELOPMENT, GENDER, ELDERLY & CHILDREN

Appendix 9 Ethics clearance



OFFICE OF THE DIRECTOR: RESEARCH RESEARCH AND INNOVATION DIVISION

Private Bag X17, Bellville 7535 South Africa T: +27 21 959 2988/2948 F: +27 21 959 3170 E: research-ethics@uwc.ac.za

15 March 2017

Mr JD Swai
Physiotherapy
Faculty of Community and Health Sciences

Ethics Reference Number: HS16/5/42

Project Title: Challenges experiences by individuals surviving a traumatic

spinal cord injury with community reintegration in Tanzania.

Approval Period: 14 March 2017 - 14 March 2018

I hereby certify that the Humanities and Social Science Research Ethics Committee of the University of the Western Cape approved the methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval. Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

pres

Ms Patricia Josias Research Ethics Committee Officer University of the Western Cape

PROVISIONAL REC NUMBER - 130416-049

FROM HOPE TO ACTION THROUGH KNOWLEDGE