

EXPLORATION OF THE MOST VALUED CONSTRUCTS OF QUALITY OF LIFE
AMONG PERSONS LIVING WITH SPINAL CORD INJURY IN A TANZANIA RURAL
AREA.

BY

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KEYWORDS

Persons living with spinal cord injury

Constructs of quality of life

Rural area

Tanzania

Facilitators

Barriers



ABSTRACT

A spinal cord injury causes a major impact on the life of individuals who experience it. From the impact of the accident or disease causing spinal cord damage, one is left immobile, insensitive to touch and dysfunction of the urinal and anal organs, which in turn leaves bowel, bladder and sexual functions in jeopardy. These impairments and activity limitations restrict or exclude the individual from participation in everyday social interaction. There is also a perceived stigma from society, depending on the response from the surrounding physical and social environment. The aim of the current study was to explore the most valued constructs of quality of life among persons with spinal cord injury in a Tanzania rural area. The study objectives were to deduce the participants' own understanding of quality of life and exploration of its constructs in all domains of life namely physical, social, economic and environmental with consideration to the barriers and facilitators. A qualitative study design is employed in which a sample of 15 persons with spinal cord injury living in three selected districts of the rural Kilimanjaro region, were purposefully selected. Environmental observations and semi structured interviews were conducted in the home of each participant. Transcriptions were done verbatim before translation from Kiswahili (national language) to English by the researcher then back translated by two professional translators (Appendix M, page 145). The whole translated sample was compiled, proof read by the researcher several times; and major pre-determined themes were assembled by content analysis, parallel to a generation of sub themes to form the results part of this study. The findings of the current study showed that the most valued facilitators of Quality of life are support from family and friends, having faith in God, socioeconomic connections, income generating activities and an accessible home and environment.

Barriers to quality of life were inaccessible environments, unreliable social support, and lack of empowerment, negative psychological traits such as anger, fear and worries that resulted from negative community actions, beliefs and attitudes (social environment). Such findings generate a package of intrinsic issues of concern from persons with spinal cord injury which adds to the body of knowledge pertaining to quality of life and spinal cord injury. The results from the current study indicate that persons with SCI in the selected rural area are partially satisfied with their current life due to various psychosocial, economic and environmental barriers. This dissatisfaction could be used as one of the major indications of poorly perceived quality of life .

The researcher recommends that a comprehensive rehabilitation program should assess and take account of subjective needs from the client's perspective to achieve better quality of life. Due to a known fact that the infrastructure of the rural area is complex, with a number of physical barriers, which further affects participation of persons with spinal cord injury in their communities, resolute social and political actions are necessary to rectify such environments to make it accessible for all.



DEDICATION AND ACKNOWLEDGEMENT

Firstly, all thanks and glory be to God the Almighty, creator of all that is seen and unseen, author and sustainer of life, through whom I am able to do all things even the ones thought impossible.

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ABBREVIATIONS

CBR	Community Based Rehabilitation
FOP	Friends of Para
ICF	International Classification of Functioning
KASI	Kilimanjaro Association of the Spinally Injured
KCMC	Kilimanjaro Christian Medical Centre
SCI	Spinal cord injury
MTA	Motor Traffic Accident
WHO	World Health Organisation
UWC	University of the Western Cape
QoL	Quality of life
ADLs	Activities of Daily Living



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DECLARATION

I declare that “Exploration of the most valued constructs of quality of life among persons living with spinal cord injury in a Tanzania rural area” 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.

.....

HALELUYA IMANUELI MOSHI



Signature.....

UNIVERSITY of the WESTERN CAPE
May 2012

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CHAPTER 1

1. INTRODUCTION

In this chapter, Spinal cord injury as a condition is highlighted with its physiological, psychological and socioeconomic consequences on the individual person, family and community. Further, highlights are given on the global burden of this condition narrowing it down to Africa, anticipated consequences to Tanzania and rural areas in particular. The already known epidemiology, rehabilitation and need for this study on this condition are also included. This chapter also contains the aim of the current study, the broad objective and specific objectives as well as the description of the significance of this study in various aspects.

1.1 Background

In the most recent findings, two million people in the World have spinal cord injuries (SCI), 82% of them being male. The major cause worldwide is motor traffic accidents and it is a second leading cause of paralysis in the United States which accounts for 23% of all paralysis cases, next to stroke (Paralysis Resource Centre, 2011; Spinal cord injury Information Network Spinal cord injury Centre National Spinal cord injury Association Resource Center, 2011). The global epidemiological data might even be overwhelming if there were more comprehensive and inclusive statistics involving even the less resourced and inaccessible regions such as rural Africa. The majority of the epidemiological information is reported from well-resourced and accessible environments and there is very few study results found in the literature pertaining to epidemiological data on SCI in Africa and particularly in the rural areas.

Although study results obtained by Wyndaele and Wyndaele (2006) had not enough statistical data to generalize world prevalence, it was significant to find that the incidence of SCI was between 10.4 and 83 per million of the world population per year. Even though there is still scarcity of epidemiological data on spinal cord injury for Africa and Tanzania in particular, disability is still a socioeconomic challenge in the sub-Saharan countries where prevalence of about 95% is believed to be poverty related and that 10% of the population of sub-Saharan countries has one form of disability or another (World Health Organisation, 2010; Vanneste, 2001).

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 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 lives.

Despite the world's scientific efforts to restore or replace damaged spinal nerves, to date, chronic spinal cord injury leaves no promise for further functional recovery and so the utmost rehabilitation goal is to ensure the highest quality of life (QoL) possible. Being an overwhelming health problem as it is, SCI requires long term or lifetime rehabilitation and there is evidence that the life span for persons with spinal cord injury is getting extended parallel to the advancement in medical and rehabilitation services (Hallin, Sullivan & Kreuter, 2000). This further necessitates more studies in the area of QoL as lived in the community and whether anything can be done to improve it.

Quality of life is a complex phenomenon which has been defined in many ways. However there has never been a consensus about one definition that among researchers. It is a construct that accounts for the individual's physical and socioeconomic feeling of satisfaction, subjectively and objectively. It also encompasses the feeling of being a valuable person based on what the person is and or has and reflects a general sense of happiness and satisfaction with life and environment in which the individual lives (Flynn, Berry & Heintz, 2002; Wade, 1995; Renwick, Brown & Nagler, 1996). QoL is assessed from four broad domains which are physical health, psychological, social and environmental (Marcel *et al.*, 1998; The WHO QoL Group, 1998). It has been found that constructs of QoL among persons with disabilities such as spinal cord injury are closely linked to their state of well-being (Putzke, Richards, Hicken & DeVivo, 2002;

Patrickka, Kinnea, Engelberga & Pearlmanb, 2000; Hampton, 2004; Rick Hansen Institute, 2011), Other constructs of QoL are cultural values (Monk & Wee, 2008), proper living standards (Murphy, Middleton, Quirk, Wolf & Cameron, 2011; Newman, 2010), economic sufficiency, appropriate accommodation (Seekins *et al.*, 2011; Lysack, Komanecky, Kabel, Cross & Neufeld, 2007), as well as cultural and historical background, as well as environmental conditions . Therefore, the major challenge faced is the building of harmonious relationships with these areas of life in spite of much limitation in functional abilities (Magenuk, 2007). Persons from different cultural and socioeconomic environments and state of health, tend to differ in the way they value certain aspects of life. These factors need to be considered when providing any service to persons with special needs such as with spinal cord injury (Rosenbaum, 2004).

In some studies it has been shown that the way the individual associates and lives with people has been compromised, leading to perceived exclusion and stigma in society (Babamohamad, 2011, Monk & Wee, 2008). It is this detachment from society that contributes to most persons with SCI becoming dependent on others in meeting the demands for their daily needs. It largely accounts for the possible dissatisfaction with life, which leads to the perceived poor QoL (Berkowitz, O'Leary, Kruse & Harvey, 1998; Potgieter & Gadisa Khan, 2005). Furthermore, Neufeldt & Albright, 1998; Tasiemski, Nielsen & Wilski, 2010; Martin, Cherian, John, Tharion & Bhattacharjee, 2010; Migliorini & Tonge, 2009) highlight the utmost need for persons with SCI to be connected to the family for support and they say that life is almost impossible without this social connection. This is even truer for rural dwellers that when in very difficult situations depend on human support for solution of problems at personal and community level.

Accessibility of the physical environment, infrastructure and communication has been found to be another determinant of achievement of socioeconomic stability and QoL for persons with SCI (Haglund, 2010; Hallin, Sullivan & Kreuter, 2000). This is a major concern in less developed countries. Various studies have reported that the inaccessible environment adds hardship to the lives of persons with SCI and consequently negatively affects their QoL (Babamohamad, 2011; Sekaran *et al.*, 2010; Monk & Wee, 2008). One would expect these hardships to be of an even greater intensity for persons with spinal cord injury in rural Africa, particularly in Tanzania, which is characterized by very poor economy and social services and inaccessibility of environments as compared with those in more developed countries. Persons with disability such

as SCI have been identified by the national social protection network (NSPN) in Tanzania as one of the vulnerable groups when it comes to social security and human rights issues. This vulnerability is more intense in the rural areas due to an increase in physical environmental barriers, restricted access to information, low socioeconomic status, customs, taboos and values which may consequently lead to stigmatization (Ministry of Finance and Education affairs, 2010). Harriss-White (1996) identified loss of income, additional costs resulting from the disability and marginalization or exclusion from services and/or social and community activities as three factors that put disabled people or families in the worst of conditions. These are some of the typical characteristics of the Tanzanian rural areas. In order to help individuals to face such challenges successfully, it may be necessary for one to review the life lived by persons with disability such as SCI in such vulnerable rural environments. It is also stressed that in the process of re-integrating persons with spinal cord injury back to productive life in the community there should be a reassessment of possible physical, socioeconomic and cultural barriers such as inaccessible environment, poor communication systems and false beliefs about disability, which is a pre-requisite for stigma (International Labor Organisation, 2009). It is for this reason that this study also involved exploration of possible barriers and facilitators of QoL.

It is estimated that Tanzania has a disabled population of more than 3 million and prevalence of 7.8, of which 56% are living in the rural areas below the poverty line and unable to afford rehabilitation services which are either absent, scarce or unreliable (Tanzania Bureau of Statistics, 2009; Kuijis, 2010). Even though it is found in various studies that MTA are the most common causes of traumatic SCI (Stokes, 2004; Bunde, 2007) one should expect other leading causes such as socioeconomic factors in regions with less traffic such as rural areas of developing countries such as Tanzania. For example in Zimbabwe the leading cause is self-harm and violence by 61%; in Pakistan and Asia falling is the main cause by 68% and 61% respectively (International Spinal Cord Society, 2011).

After discharge from the hospital, the majority of Tanzanian persons with SCI stay in the rural areas with their families as there are no permanent inpatient rehabilitation centers in the country (Tanzania Bureau of Statistics, 2009; International Labor Organisation, 2009). Currently, Comprehensive Community Based Rehabilitation Tanzania (CCBRT) runs rehabilitation weeks in some areas in which persons with SCI attend with their caretakers. In these programs the SCI

person learns to live independently and productive in spite of their condition, from fellows with the same type of disability (Kaijis, 2010).

Due to findings that challenges differ between geographical settings as well as between social groups (Kortte & Gilbert, 2010; Ackery, Tator & Krassioukov, 2004) the researcher raised the question, “What are the most valued constructs of QoL to persons living with spinal cord injury in rural areas such as in Tanzania?” It is expected that an answer to this question will provide a foundation for proper holistic rehabilitation of persons with SCI in the rural areas as their most important concerns would now be identified and successfully incorporated in the rehabilitation plan. The researcher is of the opinion that few studies have been done in Africa and non in rural Tanzania on the QoL of persons with spinal cord injury particularly in the identified region.

It could therefore be questioned as to whether therapists in the country have been attending to persons with Spinal cord injury with or without evidence based way of addressing their fundamental subjective needs. Therefore this study attempts to fill in the gap between rehabilitation services provided and the valued subjective concerns of the service beneficiaries.

1.2 Problem Statement

Spinal cord injury is an overwhelming health problem which requires long term rehabilitation. There is evidence that the life span of persons with spinal cord injury is getting extended parallel to advancement in medical and rehabilitation services (Hallin, Sullivan & Kreuter, 2000). This necessitates more studies in the area of QoL lived in the community and whether anything can be done to improve it.

In Tanzania, persons with spinal cord injury stay in their families as there are no inpatient rehabilitation centers in the country. Most of the Tanzanians live in the rural area (Tanzania Bureau of Statistics, 2009) and this applies to most of the persons with spinal cord injury. Being with SCI in the rural areas where infrastructure is very poor (Harriss-White, 1996) and without well-structured social support, it is a big challenge for one to lead an independent and productive life. Even though there is scarcity of studies pertaining QoL of this group in rural Tanzania, the visible and documented life conditions in rural areas would kindle an expectation that persons with SCI in such areas would have poor QoL. According to the researcher, only few studies have been done in Africa and non in Tanzania on the QoL of persons with spinal cord injury in rural

areas. It could therefore be questioned as to whether therapists in the country have been attending to the needs of persons with spinal cord injury.

1.3 Research question

What do people with spinal cord injury living in the rural area (Tanzania) consider as the most important for the quality of their lives?

1.4 Aim of the study

To explore the most valued constructs of QoL among persons with spinal cord injury in the rural Tanzania.

1.5 Objectives

The objectives of the study were to:

- deduce participants' primary understanding (conceptualization) of QoL
- explore participants' most valued physical constructs of QoL.
- explore the most valued constructs from participants' perspective within the psychological domain.
- explore participant's most valued constructs of QoL from participants' perspective within the psychological domain
- explore participants' most valued environmental and social constructs of QoL
- explore the barriers and facilitators for the participants towards improvement of their QoL

1.6 Significance of the study

This is a very important study to the region and the country of Tanzania at large as it aims at generating a package of intrinsic concerns to be dealt with when therapists and other stake holders are providing rehabilitation services to persons with spinal cord injury in the rural areas. The outcome is expected to improve rehabilitation outcomes as subjective concerns of persons with spinal cord injury will have been addressed to a certain degree.

The current study will add to the National findings of disability studies, specifically addressing issues related to spinal cord injury. It is an opportunity for the persons with spinal cord injury, in the selected region to raise their voices on behalf of others on the things that matter most for them as this group is socially and economically disadvantaged.

Having worked as a physiotherapist in a hospital which provides services to clients in the rural area, the researcher was involved in home visits at various occasions and saw a need to evaluate the life lived in such settings. It is also the intention of the researcher to find areas of concern to the individuals themselves as suggested by the World Health Organisation (2004) in order to get the therapists to a position of prioritizing the scarce rehabilitation services available.

1.7 Definition of terms

Spinal cord injury: is an insult to the spinal cord either traumatically or by disease process which interferes with functions such as mobility of the limbs, control of bladder and bowel and reproduction depending on the level and extent of destruction of the spinal nerves.

Quality of life: WHO defines Quality of life as an individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment (WHO, 1997).

Appropriate Wheelchair: is one that meets the user's needs and environmental conditions; provides proper fit and postural support; is safe and durable; is available in the country; and can be obtained, maintained and serviced in the country at an affordable cost (The World Health organisation, 2008).

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 organisation, 2002).

Rural area: is a multidimensional term which in African context refers to areas with very limited social services, uncivilized, unindustrialized and keeping some of the oldest virtues of ancient life such as communism (Wampler, 2000).

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). See appendix A., page 122.

Quadriplegia: paralysis of both upper and lower extremities following injury to the spinal cord at any level above nerve root C8 (Disability World, 2007). See appendix A, page 122.

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

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 social environment which encompasses community behavior and actions around person with spinal cord 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)

Spina bifida: is a congenital neurological condition characterized by disclosure of the spinal column most commonly at the lumbar leading into paralysis of lower limbs (paraplegia), bladder and bowel dysfunction (Center for Spina Bifida at Gillette Children’s Specialty Healthcare, 2005).

1.8 Overview of chapters

Chapter one introduced spinal cord injury as a condition, its consequences to individual person, family, community and global impact. It also introduces the concept of quality of life and rehabilitation in relation to spinal cord injury. A highlight is given on the state of Tanzania as far as spinal cord injury in the rural areas and rehabilitation services are concerned, gaps identified from the literature and hence the rationale for this study.

Chapter two focuses on literature review on spinal cord injury, its etiology, incidence and prevalence, its impact on the individual's life and community to a wider extent. The concept of quality of life is reviewed under the major domains of life namely physical, economic, social, psychological and environmental in relation to disability due to spinal cord injury. Literature is also reviewed on instruments used to measure quality of life and identification of barriers and facilitators to quality of life as highlighted by literature.

In chapter three the methodology of the study is explained starting from the research setting, design, population and sampling, trustworthiness, procedures of data collection, analysis and compilation of results. Ethical issues are also highlighted in this chapter

Chapter four presents results from the study. It contains the demographic findings, social and geographical information of the participants, conceptualization of QoL by the participants and constructs of QoL in the major domains of life namely social, physical, psychological, economic and environmental. These are presented with sub themes under each category. Barriers and facilitators for quality of life are included.

Chapter five discusses various themes as found in results namely demographic information of the participants, conceptualization of quality of life by participants, social, physical, psychological, economic and environmental constructs of QoL relating the current findings to literature.

Chapter six is a summary of what is contained in this thesis, conclusions as gathered by the researcher from the findings as well as recommendation on where and how these findings can be applied.

CHAPTER 2

2. LITERATURE REVIEW

2.1 Introduction

This chapter is a review of various literatures on spinal cord injury and quality of life. A highlight is given on spinal cord as a condition, its immediate consequences and historical background, etiological, incidence and prevalence in the global perspective and subsequent levels. The impact of spinal cord injury to the individual, family and community at large is highlighted as found in various studies. The concept of QoL and its relationship with rehabilitation of spinal cord injury is also studied and some major domains of assessment of QoL are reviewed.

2.2 Introduction to Spinal cord injury

“spinal cord injury is a life - transforming condition of a sudden onset that can have devastating consequences” (Stokes, 2007, p. 126). These ‘consequences’ are short lived or permanent changes in normal motor, sensory or autonomic functions. As from 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).

Following the advancement in emergency equipment and hospital services together with advancement in research as well as rehabilitation services, secondary damage and the accompanying complications are minimized leading to 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 socioeconomic and other prognosis related physical factors such as the extent of disability (Burt, 2004).

2.3 Etiology, incidence and prevalence 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). A recent mixed method study in Tshwane Metropolitan area in South Africa (N=160) in which snowballing sampling was used, gave same male female ration of 5:1 (Mothabeng, 2011). Traumatic causes (MTA) and domestic/industrial accidents are the leading causes in most of the developed countries followed

by other causes such as sports and self-harm/criminal assault (Burt, 2004; Stokes, 2007). The world epidemiological map compiled by International Spinal Cord Society (2011) presents regions where MTA are the leading cause such as in Romania (72%), central Europe (57%) and Greece (51%). However there are etiological differences from place to place depending on the physical and social environment as well as socioeconomic status in a particular area (Ackery, Tator & Krassioukov, 2004; Burt, 2004). For example a study which was done by Hart and Williams in 1994, found that assaults, especially gunshots and stab injuries were the leading cause of spinal cord injury in South Africa while the worldwide leading cause was known to be MTA (Ackery, Tator & Krassioukov, 2004). This is an indication that etiology of spinal cord injury changes with differences in culture and social economic status. A very recent study in rural India, with a sample of 212 persons with SCI for four consecutive years (Singh, Shrivastva & Dulani, 2011) has identified that improvement in infrastructure and use of motor vehicles increases chances that more spinal cord injuries will result from MTA. In the same study in a rural area, most of the SCI are resulting from falling from heights (about 55% of all cases). More evident of possible epidemiological changes with time and activities, are current studies in South Africa which show that assaults is the leading cause of spinal cord injury (61%) followed by MTA (30%) according to the International Spinal Cord Society (2011). From the same source, it is indicated that in the combined sub-Saharan region MTA is the leading cause by 40% followed by assaults of 38% which is a difference of 2% only. It is suggested that this region has a high crime rate and is a dominant cause of SCI. However, findings may differ from place to place within the same country. An example contradicting assaults as the leading cause of SCI in South Africa on this year is found in a big study (N=160) in the Tshwane metropolitan which indicates that 71% of SCI resulted from MTA (Mothabeng, 2011).

Africa as whole is a victim of traumatic spinal cord injury due to her poor economy, risky transportation systems and comparatively poor infrastructure (Jungu, 2006; Calvo, 1998) even though epidemiological studies are very scarce (International Spinal Cord Society, 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.

There are several findings suggesting that spinal cord injury (SCI) is still a big global challenge. Wyndaele & Wyndaele (2006) reported that worldwide incidence of SCI lies between 10.4 and 83 per million inhabitants per year. According to the National Spinal cord injury Statistical Center of America (2010), SCI is estimated to have an incidence of approximately 40 cases per 1,000,000 per population in the U. S. or approximately 12,000 new cases each year. Up to the end of last year it was estimated that there are 4,259 new cases of SCI in Canada with estimated 85,556 persons living with spinal cord injury (Farry, Hansen & Baxter, 2010).

Figures on the incidence and prevalence of spinal cord injury in Africa are limited but in few available studies the problem is addressed by terms which suggest the incidence of spinal cord injury is also high. For example in Zimbabwe it is addressed as “of high prevalence” (Levy et al., 1998), in Nigeria “there is rising number of cases and devastating outcome of such injuries” (Obalum et al., 2009) and out of the population of South Africa it is estimated that at least 400 – 500 South Africans sustain a spinal cord injury every year (Quadriplegic Association of South Africa, 2010; Hart & Williams, 1994). It has been found by Ackery, Tator & Krassioukov (2006) that similar geographical and economical settings tend to have similar incidence and etiological features and this suggests that incidence of Spinal cord injury in Tanzania rural areas could be the same as elsewhere in rural Africa.

2.4 The Impact of spinal cord injury to the individual’s life, family and community

Depending on location of the injury in the spinal column, one may have some muscle power and or sensation in lower limbs (paraplegia) or both upper and lower limbs (quadriplegia) with the trunk included (Stokes, 2004). It is found that One-third of persons with SCI worldwide have tetraplegia and 50% to have a complete lesions (National Spinal cord injury Statistical Center of America, 1999; Wyndaele & Wyndaele, 2006).

Following loss of sensation and dysfunction of the reproductive and recto anal organs, there could be inability to control bladder and bowel as well as sexual dysfunction which have a big impact on the social life of the individual (Stokes, 2007). The impact includes stigma attached to incontinence and sexual dysfunction, particularly among men in the African context (Monk & Wee, 2008). Further, this condition predisposes the individual to various secondary medical complications throughout life such as urinary tract infections, continuous complex pain,, kidney stones, muscle spasm, pressure sores from sitting in one position for too long without a correct

pressure cushion and wide and rapid fluctuations in body temperature (Stokes,)2004). These may interfere with health and well-being, social activity, productive occupation and have an adverse effect on the individual's QoL (Middleton et al., 2004; Stokes, 2007). Secondary social difficulties following spinal cord injury are such as inability to return to work, economic dependence and low level of participation in the community which will eventually reduce the level of satisfaction with life and general QoL (Krause & Reed, 2009; Cullen & Hills, 2007; O'stera°ker & Levi, 2005; Cassini et al., 2009; Scho°nherr et al., 2005; Putzke, Richards & Dowler, 2000).

In a survey involving agricultural workers with SCI in five consecutive years in one part of Australia, it was found that returning to work increased from 41% to 61% within this period (Young, Strasser & Murphy, 2004). Although Tanzania rural areas has agricultural activities as the major socioeconomic activity, the Australian findings wouldn't represent this setting due to differences in the type of agricultural activities involved, availability of agricultural tools which are wheelchair user friendly and the difference in general infrastructure. Furthermore, this study did not explore the satisfaction of the individuals with the work they were involved in hence these findings cannot directly assume that quality of life was enhanced by return to work.

Various negative psychological components have been found among persons with spinal cord injury such as fear, worry, anger, psychological distress and depression (Sanchez, Perez & Vila,2004; Wollaars, Post, van Asbeck & Brand, 2007) and these are reported to have a negative impact on the individuals quality of life (Que, Siddall & Cousins, 2007; Vall, Costa, Santos & Costa, 2011).

The rehabilitation to persons with SCI is found to be very costing as it extends from the individual person to family, relatives and caretakers (Kathryn, Mark & Judith, 2005; Johnson, Gerhart, Mccray, Menconi & Whiteneck, 1998) and eventually sums up to negatively affecting the economy of the community at large. For example SCI was reported to cost the American government around \$4 billion per year (Berkowitz, O'Leary, Kruse & Harvey, 1998). An example of a person with high quadriplegia (C1- C4) sustaining injury at 25 years old would have spent more than 1.9 million US dollars for health care and living expenses by the time he is 50 years old. The cost estimated is expected to lower with the lowering of level of injury (The National SCI Statistical Center, 2010). When this cost has to be incurred by individuals from less

resourced and disadvantaged areas such as rural Tanzania, the socioeconomic burden would be expected to be even heavier and unbearable to the individual and family particularly due to inability to afford, and access necessary socioeconomic services (Hagglund & Clay, 2010) in comparison with their counterparts in more resourced and accessible geographical settings.

The physical environment in the Kilimanjaro rural areas are characterized by dusty and uneven roads which are not wheelchair user friendly (The United Republic of Tanzania, 1998; HEM Trust Fund, Tanzania, 2011). Inability to freely move within home and away from home inevitably hinders the individual from socioeconomic interactions leading to isolation and dependency in various aspects of life (Murphy, Middleton, Quirk, Wolf & Cameron, 2011; Newman, 2010; Levins, Redenbach & Dyck, 2004), a state which would have adverse effects on the individual's QoL.

2.5 Conceptualization of QoL

Historically the concept of QoL (QoL) started gaining momentum in the 1960's in the American political realm in which the politician's use of the term intended to mean that they were interested in the total well-being of the people who they were leading. The widespread use of this term called for studies on this phenomenon in which the only areas considered in the early studies were economic and later social factors to evaluate the QoL of the general population (Renwick, Brown & Nagler, 1996). The problem with the social and economic factors considered in the earlier studies was that it neglected subjective factors such as anxiety, anger, aches and pains, malaise and dissatisfaction which substantially would have an effect on the individual's quality of life (Ross & Van Willigen, 1991; Renwick, Brown & Nagler, 1996). The first conceptualization and application left a gap between objective and subjective constructs of QoL which called for development of a more comprehensive model in which both intrinsic and extrinsic factors would be in cooperated.

To date debates and studies continues with the aim of getting the most inclusive, extensive and comprehensive model which best describes components of QoL (Stun, Chatterji, Bickenbach, Kostanjsek & Schneider, 2003; The WHO Quality of Life Group, 1998). One of the most recent works in this regard is a proposed new model of QoL that would cover both subjective and objective domains done at the University Of Wales College Of Medicine (Felce & Perry, 2011).

Although there is still lack of consensus about the definition of QoL, one of the most comprehensive definitions describes it as “the individual’s response to the congruence (or lack of it) between expectations and achievements, as experienced within a time perspective” (Duggan, Lysack, Dijkers & Jeji, 2002, p. 114). In line with this definition, (Renwick, Brown and Nagler, 1996; Chappell & Wirz, 2003; Felce & Perry, 1995; Flynn, Berry & Heintz, 2002) suggests that QoL should be assessed in four major domains which are physical well-being, material well-being, social well-being, development & activity, and emotionally well-being which means that rehabilitation outcomes will need to be measured not only in terms of physical functioning and independence but also in terms achieved and perceived QoL. In addition to these four domains, the World Health Organisation in the process of developing an international and cross cultural tool to measure QoL added environmental factors as another domain which should be encompasses both social and physical environments (World Health Organisation, 2011).

2.6 Barriers and facilitators to QoL

Facilitators to quality of life are conditions and or things, which enable the individual to lead a desired life. Based on the revised definition of health and the International Classification of Functioning, Disability and Health (ICF) of WHO, (WHO, 2011; Weigl, Cieza, Kostanjsek & Stucki, 2007; WHO, 2002), these barriers and facilitators should be explored as from personal (intrinsic) factors and environmental (extrinsic) factors under all four domains of life namely physical, psychological, economic and environmental (social and physical environment). The following are highlights on the relationship that exists between these domains and QoL for persons with SCI.

2.6.1 Physical well-being and QoL

Although factors such as culture, religion, environment, education and finance which can also affect QoL may be beyond the scope of health care, in its broadened definition by the World Health Organisation, health remains one of the biggest determinants of QoL which has both objective and subjective components (Stun, Chatterji, Bickenbach, Kostanjsek & Schneider, 2003; The WHO QoL Group, 1998). Physical well-being cover areas such as “health, personal safety, fitness and mobility” (Renwick, Brown & Nagler, 1996 p. 53). Good health, sound functional ability and absence of disease are been reported as facilitators of QoL (Putzke, Richards, Hicken & DeVivo, 2002; Patrickka, Kinnea, Engelberga & Pearlmanb, 2000; Cassini,

2009; Hampton, 2004; Rick Hansen Institute, 2011). On the contrary, health complications, low level of physical functional ability and pain are found to negatively affect the individual's quality of life (Kortte et al., 2010; Matheis, Tulsy & Matheis, 2006). Spinal cord injury is characterized by various physical dysfunctions mainly limiting mobility and this may be accompanied by various complications such as urinal and sexual related dysfunctions, spasms and pressure sores (Stokes, 2004) and these could have adverse effect on the quality of life lived by the individual (Amatachaya, Wannapakhe, Arrayawichanon, Sitarathiwat & Wattanapun, 2011). A two year follow up of 46 persons with spinal cord injury by Anke, Stenehjem and Stanghelle (1995) showed that 70% experienced one type of pain or another at their chronic stage. This pain was said to cause psychological distress as well as low QoL.

From as far back as 1980's the state of functioning of the individual has been considered not only as a personal concern but also a family and community issue. This means inability to live independently and providing for one self and dependents and puts one at risk of developing depression, poor health and QoL (Wells et al., 1989). There has been evidence from studies involving the old age groups suggesting that age and the state of physical well-being determines to a big extent the perceived QoL which could suggest that people at different functional levels perceive and value their physicality differently (Tseng & Wang, 2001; Li, Fisher, Harmer, McAuley & Wilson, 2003; Noro & Aro, 1996). Following the same results, populations of the aged have shown that many perceive poor QoL; possibly because with increase in age there is decrease in activity level hence an increase in dependence (Pentland, McColl & Rosenthal, 1995; Kemp, & Ettelson, 2001). This suggests that even though all persons with SCI may have same pathophysiology older persons with SCI would be more vulnerable to financial insecurity and perception of low QoL as compared to their young and more active counterparts (Elisabeth, Gunnar, Palmi & Bucht. Older persons in this category might need to have their socioeconomic needs more extensively taken into account. In other words to old people spinal cord injury is an added restriction to their already restricted level of functional ability. However, it has been found in studies involving persons with SCI at different levels of functional ability elsewhere that there was no significant difference in the way they rated their QoL (Dijkers, 1997; Siösteen, Lundqvist, Blomstrand, Sullivan & Sullivan, 1990; Osterthun, Post & van Asbeck, 2009) which suggest that there are other psychological and socioeconomic factors that add up for the individual's perceived QoL, besides functional ability and physical health. This is to say that the

health condition by itself cannot be used to determine QoL of an individual but that some other intrinsic and extrinsic factors need to be considered.

2.6.2 Psychological or emotional well-being and QoL

Emotion is defined as the ability of understanding the inner feeling and being able to use and control such feeling for good outcome. It is the outcome of interaction between the individual's internal world with the external surroundings from which behavior is produced and includes perceived control of life, experienced sense of coherent, endorsed positive factors such as hope and purpose in life, feelings of self-worth such as self-efficacy and self-esteem, positive affect, and reported cognitions (Vissers et al, 2008).

Among many other studies in support of the association that exists between psychological components and QoL is a study which was done in Sri Lanka showing that among other factors which had effect on the QoL of individuals with SCI was self-esteem and that the subjective needs outweigh the objective needs (Chappell & Wirz, 2003). Despite the fact that this study had a small sample of 20 participants, its strength and applicability is from the fact that it employed both qualitative and quantitative methods and conducted on persons whose socioeconomic status are more or less the same as those of a third world setting. One can also argue that when individuals are economically deprived, they tend to value social support more than their inner feeling and may value the extrinsic factor as opposed to the intrinsic ones. However this finding was only supported by the subjective findings possibly because the sample was too small for the statistical evidence of the quantitative data. Craig, Tran, Lovas and Middleton (2008) compared 33 persons with SCI injury with a control group of able bodied persons and found that at least 20% of persons with SCI had negative psychological traits serious enough to lead into psychiatric disorder. Negative psychological traits such as tension, depression, anger and confusion sums up into depressive mood.

Although emotional disturbance for one suffering major physical loss such as in spinal cord injury cannot be avoided, the perceived intensity of the effect depends on the individual's background and coping strategies (Pollard & Kennedy, 2007; Kennedy, Duff, Evans & Beedie, 2003; Kennedy, Lude, Elfström & Smithson, 2011). This can create big variation on the way different individuals behave emotionally under particular condition and will determine the perceived QoL. van Leeuwen, Post, van Asbeck, van der Woude, de Groot and Lindeman,

(2010) report that social support relates with psychological distress whereby majority of the socially supported individuals (though not exclusively) are at low risk of psychological problems.

2.6.3 Socioeconomic factors and QoL

Competence, independence and control over environment and situations play a role in determining the QoL especially among individuals with physical disabilities. This includes productivity, job, housework and education just to mention a few (Kathryn, Mark, & Judith, 2003; Renwick, Brown & Nagler, 1996; Kennedy, Lude & Taylor, 2006). Restriction in involvement in productive occupation and unemployment are found to be contributing factors to poverty, lack of education and facilities which finally affect the QoL of individual's with SCI (DeVivo & Richards, 1992; Kennedy, Lude & Taylor, 2006; Cullen & Hills, 2007). Many of the persons with SCI have shown eagerness to get involved in further education and or income generating activities at their functional level (Kathryn, Mark & Judith, 2003) but socioeconomic and environmental barriers have proved to be the obstacle (Burns, Boyd, Hill & Hough, 2010) which results in dependency to close relatives and friends. Extent of SCI can go as far as affecting not only the employment of the individual but may also affect that of the spouse who might have to turn into being a caretaker instead of the bread winner. An example is reported in findings by Kathryn, Mark & Judith (2005) in a study in which 46 caretakers where the productivity status, satisfaction with community integration, and quality of life as outcome measures were used. The majority of the caretakers of persons with SCI reported a decrease in their economic productivity which further describes the extent of the effects of SCI from individual to the rest of the family and community at large.

Although Africa and Tanzania in particular may have fertile land and small scale self-employed jobs, the environment and socioeconomic factors are not conducive for the individuals to exercise their remaining potentials (Moshiro et al., 2005). Sarris and Karfakis (2006) describe Tanzania rural as a region where even able bodied persons strives economically due to barriers particularly those related to physical environment and general infrastructure. If such situation is as described for able bodied individuals one can expect tougher economic situations to persons with disabilities such as spinal cord injury.

2.6.4 Social well-being and quality of life

One of the key aims of rehabilitation of a person with chronic condition and disability like SCI is to facilitate participation and re integration into the community. This is clearly stated in the WHO mode of functioning disability and health (Üstün, Chatterji, Bickenbach, Kostanjsek & Schneider, 2003). Successful participation by individual with disability into normal life has an enormous contribution to QoL (Scelza et al., 2007). QoL of persons with SCI has been found to be affected by good interpersonal relationships, by being accepted and supported, by the manner in which one is treated by family, spouse, relatives and friends and their feeling of belonging to the community in which they live (Post & van Leeuwen, 2010; van Leeuwen, Post, van Asbeck, van der Woude, de Groot & Lindeman, 2010). Availability of social support is known to reduce chances of anxiety and depression amongst persons with SCI hence facilitating adjustability to the new way of living (Chappell & Wirz, 2003).

For example, in a 2 year study of 100 participants employing both qualitative and quantitative methods of inquiry by Kathryn, Mark, & Judith (2003), the main facilitator for enhancing QoL that was identified was social and peer support. Satisfactory relationships and the support provided are therefore some of the major areas to be assessed when QoL has to be explored. These are best assessed qualitatively. Even though community behavior was not significantly found to affect QoL of persons with SCI the availability of support from family and close friends especially in difficult situations was been found to contribute to QoL to persons with SCI (Hui, Elliott, Shewchuk & Rivera, 2007; van Leeuwen, Post, van Asbeck, van der Woude, de Groot & Lindeman, 2010).

Various studies have indicated that marriage is the major source of support and the relationship between the person with spinal cord injury and the spouse will determine the QoL to a great extent (Migliorini & Tonge, 2009). However SCI affects a big population of young people and children who are not married yet. Studies have shown that divorce is common among the spinal injured, leaving the person injured without the social support needed at this state and thus accounting for poorly perceived QoL (Post & van Leeuwen, 2010). If this is the case, individuals living in the already socioeconomically disadvantaged areas such as the rural area of Tanzania are likely to have a more disadvantaged life and poor QoL. Jelsma, Mkoka & Amosun (2008), found that availability of food and affordable services such as health care are hard to achieve in

the South African rural areas; this is possibly due to poor job opportunities and diversity of social services. The same social challenges would be expected in rural Tanzania, due to its poor socioeconomic and restrictive environment (Strydom, Fouche & Delport, 2002) and where persons with disability are considered marginalized and disadvantaged.

Among other socially valued constructs of QoL of persons with SCI is communication of necessary information on their condition and of issues happening in their community. In a qualitative study of 54 participants with SCI by Cox, Amsters & Pershouse (2001) it was found that 79% of all participants reported access to telephone and 43% were visited by a therapist as valued information sources. Use of cellular phones is a fast growing means of communication even in the rural areas of Tanzania and a study of its use in rehabilitation services is worth doing (Sife, Kiondo & Lyimo-Macha, 2010; Dorstyn, Mathias & Denson, 2011).

2.6.5 Physical environment and QoL

Inability to walk causes individuals with SCI to depend on alternative methods of mobility such as a wheelchair in order to be able to move within and away from their home environment. An efficient and barrier free environment is found to be a prerequisite for independence and social interactions which together play a role in achieving a desired QoL (Seekins et al., 2011; Richards et al., 1999). Ability to access environments in and away from home makes it possible to pursue employment and other income generating activities (Murphy, Middleton, Quirk, Wolf & Cameron, 2011) which in return leads to economic stability and satisfactory life style and these contribute to healthy QoL (Hammell 2004; Putzke, Richards, Hicken & DeVivo, 2002; Tasiemski, Nielsen & Wilski, 2010). It follows that accessible environment has an impact on the QoL of the persons with SCI by allowing the pursuit of activities that matter to the individual's life. On the contrary inaccessible environments act as a barrier to QoL as it causes inability to access places and activities desired by wheelchair users in order for them to lead a self-dependent productive life (Lysack, Komanecky, Kabel, Cross & Neufeld, 2007).

Even exercising has been found to facilitate QoL (Putzke, Richards, Hicken & DeVivo, 2002; Patricka, Kinnea, Engelberga & Pearlmanb, 2000; Cassini, 2009; Hampton, 2004; Rick Hansen Institute, 2011) a study which was conducted by William, Claire, Zemper, Eric & Denise, (2005) in America, found that more than half of the persons with SCI had difficulties adhering to exercises due to architectural barriers and other factors. One can argue that if environmental

barriers are still a concern in more developed countries like America, the situation might be worse or even worse in African rural settings. Together with harboring inactive and unproductive life, inaccessibility has other consequences such as social exclusion, which is also found to have adverse effects on the individual's QoL (Schopp et al., 2007; Diane, Penelope & April, 2009).

Considering this paramount effect of physical environment on the life of persons with mobility problems and the underdeveloped Tanzanian rural infrastructures, it is expected that rural inhabitants with spinal cord injury would have their lives intensely challenged (Cock, 2007; Seekins et al., 2011; HEM Trust Fund, Tanzania, 2011). However, there is a lack of studies in the Tanzania rural settings to determine the direct effect of environment on the QoL of persons with mobility related disabilities such as SCI.

Accessibility in the physical environment is a prerequisite for mobility for wheelchair users, as it enables a wheelchair user to have access to opportunities where economic activities and social interactions are possible. This will allow for participation in an occupation of choice and meet with other people for exchange of ideas as well as participation in various social events in the community which has been found to facilitate quality of life (Schopp et al., 2007; Diane, Penelope & April, 2009; Marcel et al., 1997). On the other hand where there has been inaccessible environment either at home or away from home, the individual's participation in various socioeconomic activities and events in the community is jeopardized leading to exclusion, dependency and generally poor quality of life (Murphy, Middleton, Quirk, Wolf & Cameron, 2011).

Tanzania rural areas have poor social services with additional poor infrastructure (The United Republic of Tanzania, 2010; The World Bank, 2007) which would create a very difficult life to persons with spinal cord injury whose mobility is limited. This makes it necessary for barriers and community based facilitators for persons with spinal cord injury in these areas to be identified and incorporated in a rehabilitation process for effective integration into the community.

When considering physical well-being, the definition of "health" is narrowed down to the state of anatomical and physiological well-being which deals with the clinical variables and these are found to be insufficient. In accounting for the individuals' perceived QoL there are more

intrinsic factors involved (Siassi, Weiss, Hohenberger, Lösel & Matzel, 2009). The problem of pain and other physiological changes brought about by SCI are also found to be a barrier to achieving the desired QoL which in this case is termed as health related QoL (Vissers et al, 2008; Kennedy, Lude & Taylor, 2006; Cox, Amsters & Pershouse, 2001; Chen, Li & Kochen, 2005).

2.7 Measuring quality of life

The extensive QoL phenomena, its complexity and variation in conceptualization by different disciplines has resulted in the development of as many measuring tools as there are definitions; each one having particular strengths and weaknesses. Most of the instruments are derived either from social or health domains while few tend to cover both aspects in full (Hallin, Sullivan & Kreuter, 2000; Prutkin & Feinstein, 2002). Health related quality of life (HRQoL) is the term which is commonly used when the subject(s) whose lives are being explored have been diagnosed with a particular health condition and several instruments have been used in this regard (Wade, 1995). Some of the instruments which have been used to measure health related QoL in the population of persons with spinal cord injury are such as the Behavioral Risk Factor Surveillance System (BRFSS), HRQoL modules and Reporting Technique, the Quality of Well-Being scale (QWB), the Medical Outcomes Study Short-Form 36 and Short-Form 12 (SF-36, SF-12), the Swedish SF-36 Health Survey, Satisfaction With Life Scale (SWLS) and instrumental activities of daily living (IADL) among many others (Andresen, Fouts, Romeis & Brownson, 1999; Dijkers, 2004; Wade, 1995).

These instruments measure level of function, participation or satisfaction in a certain area of the individual's life and one instrument can be specific to one area while others can cover more than one domain. The Satisfaction with Life Scale (SWLS) specifically measures life satisfaction which is one area in emotional well-being. Emotional wellbeing comprises of other constructs such as positive affective appraisal, mental health, self-esteem and negative affective appraisal which cannot be measured by SWLS (Corrigan, 2011; Renwick, Brown and Nagler, 1996). On the other hand, instruments such as Nottingham Health Profile (NHP) and the Medical Outcomes Study Short-Form 36 though not without shortcomings and limitations, measures general health related QoL and covers several domains (Noro & Aro, 1996; Wann-Hansson, Hallberg, Risberg & Klevsgård, 2004; Wade, 1995). Despite this variety of instruments, there has never been one which is found to fully cover all that should be assessed in subjective QoL. Dijkers (1997) took

22 studies which applied different instruments in searching QoL among persons with SCI with an average sample of 102 participants. Summary of findings showed that persons with SCI report lower subjective well-being compared to the general population and that functional ability had no significant correlation with the perceived QoL. This finding also shows that one should expect differences in perceived QoL as compared to the general population. Due to inconsistency of various instruments the best way to assess this phenomenon would be by doing a qualitative study.

2.8 Rehabilitation and quality of life

Rehabilitation of persons with spinal cord injury has been based on survival and to some extent recovering of physical function until the 1980's. This time witnessed a big movement towards improvement of QoL especially among groups of persons with permanent health conditions such as spinal cord injury (Chen, Li & Kochen, 2005; Renwick, Brown & Nagler, 1996; Kemp & Ettelson, 2001). As in other fields, the concept of QoL started in its narrowed view when it was first having its emphasis on the physical and socioeconomic factors such as functional ability, social integration and involvement in income generating activities, not considering how these factors affected the individuals subjectively (Campbel & Rodgers, 1972; Renwick, Brown & Nagler, 1996; Westgren & Levi, 1998).

In the rehabilitation field QoL has interchangeably and wrongly been exchanged with terms such as standards of living, satisfaction with life, functional status and state of well-being depending on the context in which it is used but these are now known to be components or factors contributing to QoL and they cannot stand individually to define this phenomena (Renwick, Brown & Nagler, 1996).

Following a number of studies and development of various models of QoL such as the WHO international classification of functioning, disability, and health (Rosenbaum & Stewart, 2004), it is now accepted that the main goal of rehabilitation is to improve the QoL to the highest level possible of the beneficiaries of the service. This incorporates both the measurable objective factors and the subjective ones which are best known by the individual client (Felce & Perry, 2011; Renwick, Brown & Nagler, 1996; Chappell & Wirz, 2003). There has been a difference in the perception of QoL between individuals who receive rehabilitation services and those who do not whereby the former reported more satisfaction with life (Chappell & Wirz, 2003).

Comprehensive rehabilitation contributes in reducing complications to physical health, facilitating reintegration in society and creating awareness from which individuals with disability such as SCI will be understood and accepted by their communities not only as persons with disabilities but also with abilities. It is in such reconstructed environments that Quality of life can be pursued (Scelza et al., 2007).

This is to say that positive outcome of rehabilitation programs in any case still depend on other factors such as the beneficiary's psychological wellbeing and the surrounding community's socioeconomic factors and attitudes towards the person with SCI and the service itself available.

This chapter reviewed various literatures on spinal cord injury and quality of life. Described earlier as a hopeless condition, SCI might be as old as man himself but documentations about the condition started in 1700 B.C. Due to its association with socioeconomic activities males are more affected than women. The leading cause of SCI in more developed world is MTA and falls are (though not exclusively) the potential cause in developing countries. It is a condition that affects all aspects of the individual namely physical, psychological and socioeconomic life with its consequences extending to affect families and community at large. On the other hand quality of life is a multidimensional phenomenon whose definition is complex and purely subjective. However QoL can be assessed in the four major domains of life which are physical, social, psychological and environmental status. Disability due to SCI has a massive effect of the QoL as things which were normal to able bodied person starts becoming barriers to a wheelchair bound individual. Various facilitators to reintegration have been highlighted. The most important are the social connections such as having a spouse and or family. Other facilitators are education, employment and accessible environment. Inclusive rehabilitation has been proved to facilitate the lives of persons with SCI while the level of injury does not influence the QoL of the individual.

CHAPTER 3

3. METHODOLOGY

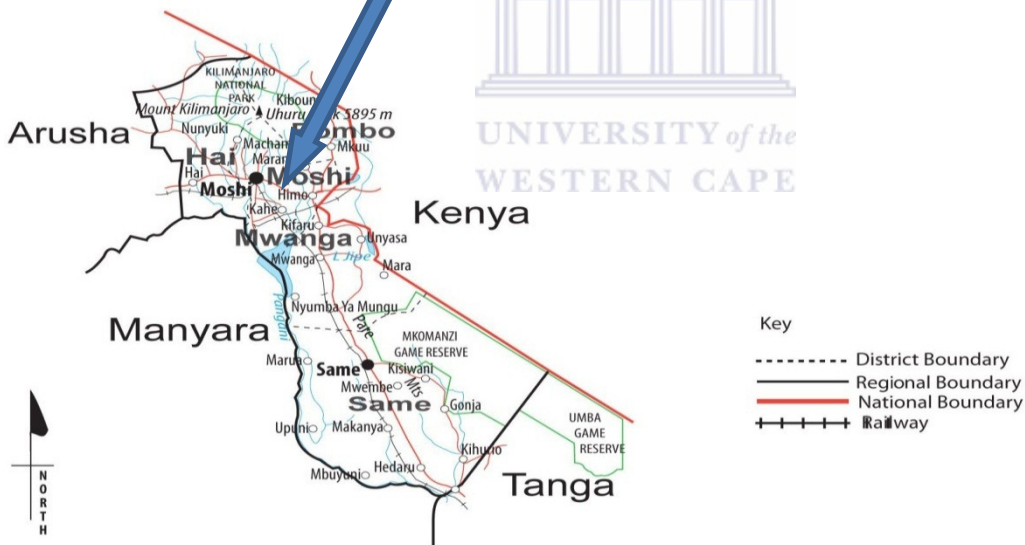
3.1 Introduction

This is a chapter on the methodology used in this study. The research setting is described, design justified by literature and explanation on the nature of the phenomena being studied given. In this chapter population and sampling is highlighted as well. Data collection and analysis procedures as well as strategies to ensure trustworthiness of the gathered data and ethical rules are included.

3.2 Research Setting

This study was conducted in three rural districts of the Kilimanjaro region, namely Rombo, Moshi rural and Hai (Map 3.1 page 26) in the northern Tanzania. These districts comprise of mountainous villages with poor infrastructure and scarce social services. Most of the inhabitants of this area have low social economic status, living on small scale farming and cattle grazing as the basic socioeconomic activities. In Tanzania, poverty levels are highest in rural areas, where 39.9 percent of households are below the basic needs poverty line, and they makes about 81 percent of the poor (Sarris & Karfakis, 2006). It is also documented that there are some more disadvantaged social groups within the rural population and that low access to assets increases their vulnerability. These include among others, persons with disabilities such as those with spinal cord injury. The study done at household level also found that persons in such vulnerable areas made use of assets (including human, social, political, natural, physical and financial assets) to cope with the hardship. There was found a very close relationship between poverty, risk environment, coping strategies and state of well-being. Thus poverty itself limits people's capacity to improve and safeguard their well-being consequently affecting their QoL (Sarris & Karfakis, 2010).

Few organisations including Friends of Para (FOP), Kilimanjaro CCBR and Kilimanjaro Association for Spinally Injured deals with provision of wheelchairs, accommodation and peer group trainings in this area. It is estimated that Kilimanjaro region has more than 100 persons with spinal cord injury at wheelchair dependence level (Nyamubi, 2010).



Map 3.1: Below is a map of Tanzania and Kilimanjaro region respectively showing the region and districts which were used for a setting of this study.

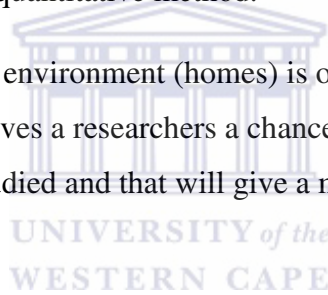
Source: <http://www.tpsftz.org/zoom.php?region=13&txt=Kilimanjaro> and

<http://geography.about.com/library/cia/blctanzania.ht>

3.3 Research design

Qualitative study was conducted utilizing observations and semi structured interviews (verbal interactions) as means of information gathering, focusing on the meaning, experiences and interpretations behind quality of life. In this study, a descriptive phenomenological approach is used as to disclose the QoL phenomena as perceived by the participants in their situation or context. This philosophy is rooted in the belief that truth and understanding of life can emerge from people's life experiences and is based on values of personal knowledge and subjectivity, and emphasizes the importance of personal perspective and interpretation (Byrne, 2001; Njoki, 2004). This approach is therefore powerful for understanding subjective experiences, gaining insights into people's motivations and actions, and discloses the importance of intrinsic issues which under normal circumstances are taken for granted. Furthermore this choice is advocated for by Kathryn, Mark and Judith (2005), who strongly suggest that life perceptions and living standards for persons with spinal cord injury could deeply and extensively be explored qualitatively as opposed to using a quantitative method.

Conducting the study in the natural environment (homes) is one of the core values of qualitative phenomenological studies as this gives a researchers a chance to observe the social environment in which the phenomena is been studied and that will give a more affluent results (Ingstad & Grut, 2011; Byrne, 2001).



3.4 Population and Sampling

According to the Kilimanjaro Association for spinally injured, 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 sample for this study was obtained from Kilimanjaro Friends of Para (FOP) database. Having highlighted the pre-determined geographic and demographic characteristics of the participants required for the current study, the founder of FOP provided a list, addresses and contact details of persons with SCI who would meet the criteria to the researcher. An extra list was also provided in case the first sample fails to reach data saturation.

In this study the researcher used purposive sampling, a method which depends on personal judgment used for prior determination of typical characteristics of the participants required to

fulfill particular study needs (Strydom, Fouche & Delpont, 2002; Bowling, 2002). Though data in qualitative study cannot be generalized to the population, the researcher purposefully chose from the persons with spinal cord injuries participants who vary in different ways so that the QoL phenomenon could be explored from the diversity of this population.

Primarily sampling was designed as shown below in figure 3.1 in order to obtain a sample which is as diverse as possible. From the fact that literature clearly indicates that male is more affected than female, adults than children and paraplegia more common than quadriplegia level of injury correlates with perceived quality of life (Stokes, 2004; Hicks et al., 2003; Warburton, Nicol & Bredin, 2006; Kannel & Sorlie, 1979), these demographic groups are given different ratios in the sampling procedure. However the researcher wouldn't restrict himself to the number or type of participants anticipated as they may not be available in the field and data collection would have to continue to the point of data saturation.



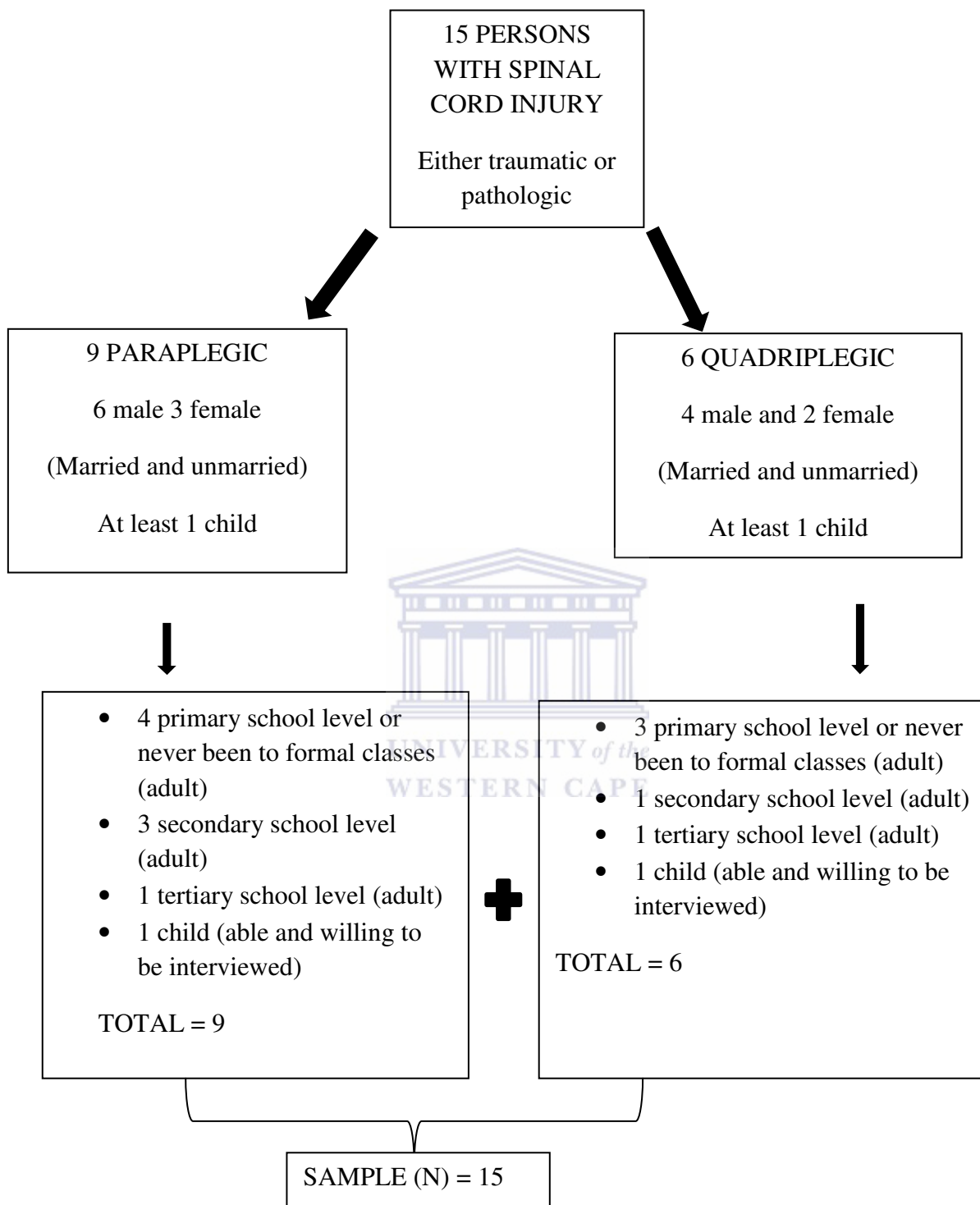


Figure 3.1: A systematic sketch of the purposeful sampling used to obtain participants for this study

Participants who were obtained from FOP database covered following characteristics; different levels of injury (3 quadriplegics and 12 paraplegics) different levels of formal education, gender representative (11 males and 4 females), marital status (6 married, 9 not married) and age difference (young and old, range between 10 and 66 years). There was at least one participant from each demographic group, giving a sample of fifteen participants. This study was planned on such a way that if data saturation wouldn't have been reached saturation using the purposely selected sample; further recruitment would have taken place. However the point of data saturation was reached at the 10th participant but due to the demographic and socioeconomic differences pre-expected among participants, data collection continued to the last participant. Three districts were covered, ensuring reasonable geographical distance between participants (map 3.1 pg. 27). This was done in order to for the study to benefit from the diversity of resources, cultural issues and socioeconomic within same community as experienced by different persons with SCI.

3.5 Procedure of information gathering

3.5.1 Groundwork

The first step was to obtain ethical clearance from The University of the Western Cape Research Grants and Study Leave Committee (Appendix K, page 143). Thereafter a permission to conduct the study was sought from the Tanzania National Health Research Ethics Committee (Appendix J, page 143) to perform the study in the specified area. This was granted after receiving and working on amendments as required by the Tanzania National Health Research Ethics Committee and re submission. One of the recommendations were to specify in the title districts within the Kilimanjaro region where this study was going to take place (this accounts for differences observed between the original topic and that indicated by the ethical clearance from NIMR i.e. appendix J, page 143 and translator's credential in Appendix M, page 145). While awaiting ethical clearance from the National institute for medical research (NIMR) Tanzania (Appendix J, page 143) 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 at the department of Kiswahili of the University of Dar es Salaam (Appendices B, C, D, E, F, G, H and I, pages 122-141). Few errors were identified and

communicated to the researcher who with the interpreters sat together to agree on the most reasonable translation.

The translated copy of the interview guide (Appendix C, pages 126-128) was subjected to a kind of piloting in which they were given to one person with spinal cord injury (not included in the study) to read and see if the questions were understandable. Few corrections were then made especially of the technical and more scientific words used. This was followed by recruiting the participants by using Kilimanjaro Friends of Para (FOP) which is one of the organisations which delivers rehabilitation services to persons with spinal cord injury in the rural areas of the Kilimanjaro region.

To ensure that all the issues under QoL in relation to spinal cord injury as found in the literature were covered, the researcher prepared and used an interview guide (Britten, 1995) which covered areas from which QoL is assessed which are “physical well-being, material well-being, social well-being, development & activity and emotional well-being” (WHO, 2004; Renwick, Brown & Nagler, 1996 p. 53). This interview guide composed of six major questions, each question covering a specific objective of this study in which the four domains of QoL were in cooperated.

Participants were visited in their homes for prior explanations about the study, familiarization with ethical rules that will be observed and requesting their free will participation. This visit was done together with the research assistant for her to be familiar with the environment and the study itself and as part of recruiting her for the task. 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 (either personal cell phone or use of a close friend or relative's 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 on the participants in their natural environment (homes). The last process of this study is compilation of all the data from all the participants

coding and building up common categories using statements that falls under each pre-determined theme ready for preparation of the results for submission.

3.5.2 Data collection

On the interview day, on the way to participants' homes important observations in the environment such as type of roads and pathways, distance from home to the main road and public transport, socioeconomic activities and home environment were observed and documented. This was to ensure that the participant is accurately and comprehensively described. The interview started by assessing the participants understanding of the phenomena in discussion (QoL) and the researcher commenced preliminary phenomenal disclosure (introduction to QoL) before continuing with the interview if it was found that participant had little understanding of what is being explored. This was to let the participant define the phenomena the way it means to them which would have some differences from one individual to another (Smith, Sinclair, Raine & Reeves, 2005; Renwick, Brown & Nagler, 1996). Data was collected in the natural setting of the participants (home) using semi structured interviews. Strydom, Fouche and Delport (2002, p 297) calls this method "general interview guide approach" and advocate for its use in eliciting information about certain topics, in this case the QoL. Participants were encouraged to let the normal family activities to run without major alteration and that minor interference such as toileting or attending a crying baby were allowed in between, during the interview. This aimed at letting daily activities in the setting observable and noted to be used as part of data.

Using the prepared interview guide the one on one talk was held aiming at exploring participants' perception of their impairments, physical limitation and participation in life. After each major question was answered it was followed by pre structured and or unstructured probes for clarification and to ensure coverage of the life area under exploration. The structured probes were brought up only if certain components of domain being explored were not covered when the participant was answering the main question. All questions were open ended starting from simple to the most complex and from broad to more specific. As demanded by the nature of the qualitative study, though these were formal interviews, they were carried out in more or less like ordinary conversation in a built up relationship between the interviewer and the interviewee (Holloway & Wheeler, 1995), giving room for some laughter and few jokes in between. Where the participant felt uncomfortable to disclose some information in the presence of research

assistant (possibly due to her relatively small age, culture and or sexual differences), she had to stay away from the interview area for a given period then join the session later. This was frequently noticed with the aged participants when it came to issues pertaining sexual relationship. During the interview all the discussions were tape recorded. This gave room to the researcher to become more interactive, observing and attentive to events and emotions at the scene during the interview as he did not have to write down everything that was said. The research assistant was noting and writing down observable events, emotional change and related activities which were taking place before, during and after the interview. In this study, tools for data collection were tape recorder and writing materials.

3.6 Data analysis

Data collection and content analysis was taking place simultaneously i.e. preliminary analysis after every interview by filling in the summary form of the findings (preliminary coding) of that particular day before interviewing next participant. Data analysis in this study is based on continuous noticing, collecting, and thinking about the evolving ideas and actions. This is built on the requirements of qualitative study which demands a continuous cycle of noticing/hearing, documenting and thinking about what is heard (making meaning out of the responses). In this way it was possible to note when saturation was reached as next participant would give constructs which were same as previous. This was noted on the tenth participant but the pre-determined sample was reached for inclusion of all the targeted demographics. Inductive reasoning is applied using the collected data to generate or complement ideas or themes for discussion (Strydom, Fouche & Delport, 2002; Bowling, 2002).

Coding:

After gathering, transcribing and translating information from all the participants, the data of the whole sample was coded, gathered into categories in order to gather the appropriate statements under their respective pre-determined themes from which sub-themes are construed (Bryne, 2001). Each theme was taken (one at a time), its statement re read through several times and meaning given to the statements. The translated sample was compiled (Cases 1 to case 15) in two phases and coded as follows:

Phase 1:

This phase involved assembling of the data in six groups, which are the major pre-determined themes and six colors were used to code the six themes using Microsoft Word program. All statements were cut depending on their colors and grouped in six groups, each statement indicating from which participant they were taken from. The following were the six major themes and the color (from Microsoft Word program) used in coding:

- Understanding of quality of life by participants (BROWN)
- Social constructs of quality of life (PINK)
- Physical, physiological, anatomical factors (YELLOW)
- Psychological components (RED)
- Economic factors (BLUE)
- Environmental factors (GREEN)

Phase 2:

The six groups (pre-determined themes) were then dealt with one at a time in separate files. The statements under each pre-determined theme were read several times and those that would form a common topic/idea were gathered (categorized) by cutting them and pasting the statements in a clustered manner using Microsoft Word computer program. Each one of these were then tested by coloring their frequency within that particular pre-determined theme and if it had sufficient support was taken as one of the sub themes. For a sub theme to qualify it had to be supported by more than a half of the sample or cut across all participants of certain demographical group e.g. all or most men, all or most married or all or most single participants. However, the less supported and negating statements are also taken in to account and appears in the results.

The themes are then presented in sections with the sub themes as sub sections to form the result part of this thesis. In addition, direct quotations from respondents, are used in results compilation to illustrate some features as: the strength of opinion or belief; similarities between respondents; differences between respondents and the breadth of ideas (Bowling, 2002). This is done also to

add to the reliability and validity of the data analysis. If an idea appears in the data frequently the frequency is measured the result of which appears in numerical and or tabulation form within the text (Bryne, 2001). The thesis supervisor (at the University of the Western Cape) continuously received reports on data collection as well as analysis process at every stage for reliability check.

All necessary information from the field was documented to provide social and geographical information to be in cooperated into the results and eventually in discussion.

3.7 Trustworthiness

In order to ensure credibility of this study the researcher purposefully recruited his participants from the demographic diversity of the population. Although by nature the qualitative study cannot be representative, this involvement of participants with different characteristics provides the study with richer, more multilayered and more credible data set than randomization or convenience sampling would have generated (Strydom, Fouche & Delport, 2002; Bowling, 2002). Regarding credibility, there was a form of member checking whereby the summary after every interview was read to the participant for approval and/or correction of the information. In line with this, the research assistant was involved in transcription and data analysis as they could work together in linking field observations with the conversations having been in the setting. Moreover the thesis supervisor received continuous feedback of data collection and analysis at least twice a week for approval of the procedures and advice accordingly. In this study, the researcher used more than one method of inquiry i.e. semi structured interview and observations of the physical environment, activities and emotions (Bowling, 2002; Porter, 2007). The use of tape recorder and having research assistant gave room to the researcher to become more interactive, observing and attentive to events and emotions at the scene, during the interview as he did not have to write down everything that was said. Enough time was arranged for with the participant for detailed interview and observation. Only one participant was interviewed per day and transcription started on the same day soon after interview. This was to ensure that the participant is accurately described, hence adding to the credibility of the study (Bowling, 2002; Golafshani, 2003).

To ensure transferability, the semi structured questionnaires are kept and will be made available on request from any other researcher who would like to work on this or related area of study. In

line with transferability, is thick description of the physical environment and the situations in the area of study, to make it clear to any other researcher who is interested in this particular setting. Though the issue of data saturation is still debated in qualitative research especially when purposeful sampling is applied, continuous data analysis of the results was used simultaneous with daily transcription as a strategy to provide an indication to the researcher as to whether the main question of the study was being answered and whether the collected information was enough to address the phenomena being studied. To address the issues of dependability and confirmability, the researcher worked with his research assistant at each level of data collection and analysis and all the results had to be agreed upon by both. For example the estimated distance from home to where one participant could get public transport is an average of the estimated distance by the researcher and that of his assistant. Furthermore the participant had a chance to affirm the information that was gathered after every interview.

Ensuring triangulation in data analysis:

For the sake of triangulation in data analysis the preliminary data transcription and analysis involved both the researcher and the research assistant who is a qualified physiotherapist. Furthermore each participant was given a post interview summary of findings for approval immediately after the interview. An independent observer (as enforced by NIMR Tanzania) reviewed data collection and preliminary analysis materials twice a week for approval of the process and provision of the necessary guidance. Transcription was done by the research assistant then proof read and translated by the researcher from Kiswahili (participants' language) to English before sending them for back-translation by two translators at the Kiswahili department of the Mwenge University of Education, Kilimanjaro (Appendix M, page 145). The whole process of generating pre-determined and sub themes were done by the researcher and his assistant in a manner that no topic or category was endorsed without agreement by both.

3.8 Ethical consideration

This study was conducted after obtaining ethical clearance from The University of the Western Cape Research Grants and Study Leave Committee (Appendix K, page 143) and permission from the Tanzania research Ethical Committee (Appendix J, page 143). The aim of the study was clearly explained to the participants (verbally and by information sheet) and informed consent was signed. Both information sheet and consent form were translated into participants'

appropriate language. The researcher assured the participants that the information obtained from them was going to be confidential. In line with this, the recorded tapes and the written materials are locked away from other people and will be destroyed after five years as required by the university regulations. The participants were informed of their right to either participate or not in this study as well as their right to withdraw at any time. In case of physical and/or psychological trauma (beyond researcher's ability to handle) in the process of this study was prepared to act by referring to the appropriate disciplines. However, there was none of such emergencies. After the study the results will be presented and/or submitted to the appropriate authorities.



CHAPTER 4

4. RESULTS

4.1 Introduction

This chapter contains results from the qualitative data gathered through semi structured interviews followed by content analysis from which major and sub themes are developed. The Participants' personal details and observed social and geographical features of their homes are presented in the first few pages. This is followed by results on preliminary understanding of the QoL concept by the participants. General constructs of QoL in the major domains of life namely social, physical, psychological, socioeconomic and physical environment are presented with the various sub themes.

Due to the presence of social constructs as a domain, for the sake of clarity, environmental constructs in this study refers entirely to the natural and man-made physical environment at home and away from homes of the participants. Economic factors are found to be very closely linked to social systems and for that reason are referred to as socioeconomic constructs.

Facilitators and barriers to QoL are presented within each theme and subsequent sub themes. Direct or verbatim translation from the way the participants express themselves is maintained in the included direct quotations and additional wording by the researcher indicated by [] with the added word inside the brackets. Where observations are included in the text they are held in brackets, (). In these results names of participants are changed to pseudonyms and those of other persons and places omitted and where omission is applied it is indicated by [] with mentioning of what has been omitted in the brackets.

4.2 Participant's demographic information

Introduction

Demographics of the participants were gathered from each participant prior as the starting point for the interview. Sex, age, classification of spinal cord injury, cause of injury, level of education as well as time since the individual was injured was gathered and are presented in table 4.1 below. Furthermore, table 4.2 shows the social and geographical information as inquired from the participants and as observed from the environment.

Table 4.1: Personal Details of the participants (N=15)

Pseudonym	Sex	Age (years)	Classification of SCI	Cause of Injury	Level of education	Time since Injury (years)
P1	Female	40	Paraplegia	Pathological	Primary 7	20
P2	Male	29	Tetraplegia	Fall from a tree	Primary 7	7
P3	Female	45	Paraplegia	Motor traffic Accident	Primary 7	21
P4	Male	37	Paraplegia	Fall from a tree	Primary 7	10
P5	Male	43	Paraplegia	Banana tree landed on him	Primary 7	7.5
P6	Male	40	Paraplegia	A tree landed on him	Primary 7	10
P7	Female	26	Paraplegia	Congenital (Spina bifida)	Primary 7	Since birth
P8	Female	60	Paraplegia	Fall from a tree	Primary 7	2

P9	Male	28	Paraplegia	Congenital (Spina bifida)	Never attended school	Since birth
P10	Male	66	Paraplegia	Fall from a tree	Primary 4	1.5
P11	Male	60	Tetraplegia	Motor traffic Accident	College/University	28
P12	Male	10	Paraplegia	Congenital (Spina bifida)	Attending Preschool classes	Since birth
P13	Female	38	Paraplegia	Motor traffic Accident	Primary 7	5
P14	Male	38	Tetraplegia	Fall from a tree	Primary 7	10
P15	Male	49	Paraplegia	Fall from a tree	Primary 7	4



Table 4.2: Social and geographical information (Observation)

PSEUDONYM	FAMILY STATUS	HOUSING	LOCATION & ACCESSIBILITY	MOBILITY AID & TYPE	ECONOMIC ACTIVITY
P1	never married & no children, living with her nieces	New furnished 3 room house built through FOP Neither running water nor electricity	About 3 kilometres away from the main road, with private car, the house is accessible all the way in dusty road between banana and coffee trees.	has a wheelchair (4Wheeler)	Runs a small shop in her house
P2	never married and no children, living with his parents	Brick, fairly furnished house Neither running water nor electricity	About 0.3kilometer away from the main road, about 3kilometres to the public transport	has a wheelchair (4Wheeler)	He keeps few local chickens
P3	never married and no children, her mother died, living with her father and two nieces	Poles and sticks (wooden) unfurnished house with concrete floor Neither running water nor electricity	About 0.1kilometer away from the main road, about 2kilometres to the public transport	has a wheelchair (4Wheeler)	She keeps few chickens and has two sheep
P4	never married and no children	Rented a room in small brick unfurnished house Neither running water nor	About 0.1kilometer away from the main road where one can get to the public transport.	He has a wheelchair (3Wheeler)	Begging

		electricity			
P5	married father of one child still living with his first wife	Muddy unfurnished house, lives in the same compound with his parents Neither running water nor electricity	About 0.8kilometer away from the main road across the river to the hillside, about 3kilometres to the public transport.	has a wheelchair (3Wheeler)	Shoes repairing
P6	Never married and no children, lives alone.	New furnished 3 room house built through FOP Neither running water nor electricity	House is by the main road and about 0.1kilometer away to the public transport.	He has a wheelchair (3Wheeler)	-Fixing bicycles, selling kerosene and keeping few local chickens
P7	single mother of 1child, living with her mother and her son	New furnished 3 room house built through FOP Neither running water nor electricity	House is at the main road and about 4kilometer away from the public transport.	has a wheelchair (4Wheeler)	-Sewing and weaving fabrics
P8	widowed mother of 4children, living with her sister	Old brick unfurnished 3 room house There is electricity and one water tap outside the house	House is at the main road and about 3kilometer away from the public transport.	She has a wheelchair (4Wheeler plastic seat type)	Not engaging in any economic activity
P9	never married and no	A hired room in a fairly furnished old house.	House is at the main road and about 0.2kilometer away from the public	He has a wheelchair	-Shoe repair and shining

	children	There is electricity and one water tap outside the house	transport (main bus stand).	(3Wheeler)	-Keeps few local chickens
P10	Married father of 4 children. Still lives with his wife and two children	Mud unfurnished 3 room house Neither running water nor electricity	About 0.5kilometers away from the main road, house is not accessible by car from the main road where one can get public transport.	He does not have a wheelchair or any other mobility aid	Not engaging in any economic activity
P11	Married father of 6 children, living with his wife and grandchildren	Brick nicely furnished big house with facilities There is electricity and running water in the house	About 0.4 kilometres from the main road, house is at private car accessible all the way in dusty road and about 1kilometre away from public transport	He has an old wheelchair (4Wheeler)	College/University
P12	He lives with his parents and with one sibling	Small muddy single room (shack) Neither running water nor electricity	House by the main road and about 0.4kilometer away from the public transport	has a new wheelchair (3Wheeler)	A child, just started preschool at 10years of age
P13	Married mother of five (she has a 1month old baby), living with her husband and	Muddy unfurnished two small roomed house Neither running water nor electricity	about 0.5kilometer away from the main road about 2kilometers away from the public transport, across the river	has a wheelchair (Old 4Wheeler)	-Keeping few local chickens -Selling cold drinks (occasionally)

	all children				
P14	divorced father of 2, living with his mother and his daughter	Muddy unfurnished two small roomed house Neither running water nor electricity	About 0.5kilometer away from the main road and about 1kilometer away from public transport	has a wheelchair (3Wheeler) with broken caster wheel	-Selling airtime (<i>voda rusha</i>) -Keeping few local chickens
P15	Married father of four, living with his wife and all children	Muddy unfurnished three room house Neither running water nor electricity	about 0.1kilometers away from the main road where one can get public transport	he has a wheelchair (3Wheeler)	Not engaging in any economic activity



4.3 Conceptualization of QoL by the participants

At the beginning of every interview, an open ended question was asked to inquire about the participant's understanding of what quality of life means to him. All of the participants responded to this question.

Most of them gave more than one definition, resulting into four sub themes which are: meeting necessary needs, having a satisfying occupation, good life free of any problem and achieving psychosocial stability. Among these sub themes seven participants regarded quality of life as meeting necessary needs and the least thought of is achieving psychosocial stability which is supported by three views only.

4.3.1 Meeting necessary needs

For most of the participants, one will be considered to have quality of life once his or her needs are met.

P11 mentions some of the needs which must be met for a quality life to be achieved. He says:

'...get food, be able to have a nice place to sleep, able to dressing well, you can provide for your child...able to get treatment...'

Adding to this, P6 insists that it should be more extensive. He says:

'Yea, quality life meaning that you have good life, clear life on such a way that you can meet your needs in every aspect, all needs!'

4.3.2 Having a satisfying occupation

To five participants, having occupation is one thing that would define someone's QoL. Being 28 years of age and never attended formal classes, P9 considers what is lacking in his life as an important prerequisite in his definition. He gives the following condition:

'First of all if you would help me with something like education, that is when you can expect me to have good life'

In more general terms, not specifying the type of occupation P4 says:

'...it is as to say if someone has a quality life it is either is satisfied with his works that gives him income...'

4.3.3 General good life free of any problem

Six participants in their attempt to define the phenomena of QoL referred to it as either general good life and or life that has no problems. For example P7 gives the following as her only definition:

'...getting no any problems of any kind'

And P5 seems to have almost the same view which he expresses by saying that it is:

'The way you live maybe...good life, clear life...'

4.3.4 Achieving psychosocial stability

To three of the participants QoL can be achieved if there is social support but also one must feel that one is happy with the life that he or she lives.

P10's one and only definition considers QoL as a product of relating in the best possible way with others. He says:

'It means living in a good way, in harmony, by loving each other and so on, by living with good relationship'

For P3 it is an intrinsic factor whereby one manages to move on against all odds. She puts it this way:

'By my own thinking, I can say that a person has managed to encourage self despite of whatever he is facing meaning that he has accepted whatever condition'

4.4 Social constructs of QoL

With an attempt to deduce the social constructs as a pre-determined theme, the question, “How does your relationship with the surrounding community affect your life?” was posed to each participant. The answers to this question are very diverse and extensive in comparison with other pre-determined themes of this study. Social factors of QoL that are found to affect the lives of persons with spinal cord injury either in a positive or negative way were then deduced.

Six sub themes emerged under social constructs, which are: positive impact of the family, negative impact of the family, Community’s attitude towards persons with spinal cord injury, Health and Rehabilitation social support, Leisure time, and Communication and information. Among these sub themes, relationship with the family, is found to be the most important area of concern.

4.4.1 Positive Impact of the Family

To most of the participants in this section, family is found to be the foundation of support, encouragement and socioeconomic solutions. To all married participants the spouse is identified as the closest supporter. For the case of children it is twofold whereby the grown up and reasonably established children would influence the lives of spinally injured parent positively but young school going children are reported to affect spinally injured parents more negatively even though their physical presence and support is appreciated.

In this study it is found that matured, educated children are regarded as a source of support to a parent with spinal cord injury. P8 is a mother of four and she says:

‘...then I went to Arusha to one of my children, he has not started working, he does temporary jobs. I was there for one year, continuing with exercises... if a child has worked a little bit and got something and send some money.

A well-educated man P11 calls the family basis for income as he says:

‘This is as I told you openly that the biggest capital is that family and that love from the family... you can see outside they are working, I do not have to shout at them, they know their responsibilities...’

For the married participants the following direct quotation indicates the paramount position of not only the family but more specifically that of the spouse. P15 reports:

'That means the closed person for my side I may say is my family and my wife. That is all! It is only my wife, maybe if she gets to go and get tablets for me or get a clinician from the dispe- who will come and examine me'

4.4.2 Negative Impact of the Family

Despite positivity and complements given to the family by most participants, this is not a general feeling. In fewer instances the family is dependent on the person with SCI or does not seem to be close and provide care as expected. This is perceived as a barrier towards psychosocial stability as P2 sorrowfully states:

'...the closest family members are not as close to me... they are here but not thinking about me... I must feel extremely bad!'

For the 38 years old mother of five the issue is more psychological as she is constantly concerned about the future of her young children and she says this adds to her worries:

'...I look at the house and the children are now growing up, in this small house, then I say if it was that time when I was walking... we would have added at least two more room for these children because they are grown up. But now we are failing to do that. When I look to this my head gets piled with thoughts even more... yes'

4.4.3 Attitude of the community towards persons with spinal cord injury.

In this sub theme, there are statements that give clues to the effect of how the community (other people away from individual's family) relates with and respects participants. Most of the participants report to either being accepted and or being involved in community or family matters but at a limited level. They also have friends, relatives and neighbors who provide support in one way or another. However there are some negative attitudes such as false beliefs, disregard and exclusion at some point which are said to be not in favor of the QoL and are a source of anger and perceived stigma. In the following sections such attitudes are presented as facilitators in the first two quotations, followed by two other quotations indicating the attitudinal barriers.

P11 who has been in a wheelchair for about 28 years is satisfied with the way the community regards him:

'... I can say they [community] really love me. May be it is my experience or whatever that I do not understand but being acceptable in the community has never being a problem to me. So I am hundred percent sure that I am very accepted!'

Children in particular are found to provide the much needed support more than any other group in the community as reported by P2, a single man 29 years of age and quadriplegic for about 7 years. He says that children do almost everything for him even though they are from the neighborhood:

'...there are neighboring children, they come here I ask them to help me with that, like giving them [chickens] water, food... In the evening before getting to bed, they [children] wash me, they dry me up what, then I request them to help me with the exercises and they do...'

However this support from friends and neighbors cannot be relied upon at all times as in the case of P6, who cannot always expect support when the need arises. He shares of his times of denied support:

'...when I was staying in that other house and you even call the neighbors but they won't show up. They say, "It is up to him" so you just struggle...'

Further P15 addresses the issue of unreliability as he reports of friends and relatives presence in the early days of injury but a complete disappearance with time. He tells of the trend of their disappearance:

'...After returning from the hospital they were all eager to know which condition I was in, they were coming...If someone tells you mister, I am leaving and I will come back again to see you, even that one who used to, even if is a relative, he does not come back'

4.4.4 Health and Rehabilitation social support

In this category, services that facilitate health and enhance functional ability of persons with spinal cord injury are presented. The availability or unavailability of such services made a big

difference psychologically, socially and economically. The Community Based Rehabilitation program (CBR), Kilimanjaro Association for spinally Injured (KASI), Kilimanjaro Christian Medical Centre (KCMC), Friends of Para (FOP) and churches are some of the organisations reported to provide free or cost subsidised Health and Rehabilitation services to persons with SCI injury in this region. However such services are generally reported as unsatisfactory.

To start with, P6 gives a general comment on the positive effect of being involved with rehabilitation programs:

'...the more the community and various organisations progressively continue to realize our needs, we get informed and trained so we become extensive in our thinking and acting...'

For P13, a paraplegic for about 6 years and mother of five who delivered a baby girl only a month before this interview, the support from such organisations was very crucial. She acknowledges:

'There is a support from [name of a place] Hospital... When they came one of them supported my son so that he can go to school. They also brought food to the house, it really helped me... the one [wheelchair] that I had before was broken so when this man [founder of FOP] came, he saw that and brought me another one...'

However where there is no or scarce social and medical support as in the case of P3, one has to consider the cost needed in treatment and where getting to the hospital is impossible one sends information to the doctor or pharmacist who will decide what medication to prescribe. P3 feels that it is not safe to have someone prescribing medication for her without investigation:

'...When I feel that am sick I can just write a piece of paper to be taken to the nearby health center so that in any way they can send some medications for me... but what is bad in this way is that you use medications without being assessed first...'

Where support from various organisations is missing or declines in service delivery, there is reported dissatisfaction and worries. P15, who says that he gets most of the support from such organisations, is worried because the services from such organisations are on the decline and the future of the rehabilitation service is blurred. He says:

'If it is true what they claim that there is no sponsorship anymore we can see that now our lives are near [we'll die soon] because if we were depending on the organisation in Moshi of KASI or that which was called CR- CBR- CCBR they have also rejected us . Now we have thoughts that, where we are now, we are just waiting to die because we won't have that ability to go to the hospital...'

4.4.5 Leisure time

In this sub theme there are recreational activities which are found to be part of lives of persons with spinal cord injury in these communities. Where there were no physical, social or psychological barriers, most of the participants informed that they had one type of recreational activity or another which they considered important such as evening social gatherings at or away from home and referring to a media such as radio or television.

P11, like most of the participants have a very personal kind of recreational life but also gets out of his house to elsewhere and coming back is a satisfying routine:

'...I am in radio, I listen to the radio, I watch TV a little bit I also have a sight problem. Or else I go outside, children pushing me around my environment to see the cows, all the way to the road then I come back. Sometimes I sit under the tree and start to study it because I used to teach, biology'

On the other some of the participants did not seem to be interacting with the community away from their homes even though they wanted to. This was due to either personal and or environmental barriers. P15 is one of them and he seems to have more psychosocial barriers. He tells of his leisure time:

'...Most of the time if I am out it is only outside the house...even issues of talks, by the way who will you talk to at that time?...I have never gone [to the road]! And I even do not want to because at the [main] road [people] are many, they are not coming to greet you, they are many who comes to find about you'

P5 like many others is limited by the environment which has restricted his recreational life at home:

'From this environment here? It is only a radio that I listen to...that [inaccessible environment] is the problem...'

4.4.6 Community's false beliefs, unawareness and perceived stigma

Among things which are found to affect lives of the participants in this study is culture, beliefs within their community, ignorance about spinal cord injury leading to perceived stigma.

False beliefs identified are those associated with witchcraft, curse and punishment from supernatural powers being the cause of spinal cord injury.

P3, who had her spinal cord injured in a motor traffic accident, tells of what she hears from her community:

'They tell you openly that a human being must have done this to you [associated with witch craft] and that there are traditional healers in some places who can help you out'

In some cases it is clear that the community does not have enough awareness of spinal cord injury and this has adverse effects such as generation of statements or actions that are potential for stigma, exclusion and isolation. For example P9 hears from his girlfriend what other people say about their belief of his physical function ability among other things. He says:

'...then she told me, I see you as if, maybe I am afraid to ask you to be my fiancé without making sure that you can function sexually because I am told that persons with disability like you do not function sexually...'

Isolation and stigma is perceived by five participants. This is demonstrated by words and or actions by the community. P14 reports of his perceived isolation:

'...because you know the community knows that when someone has become a disabled, that is it! Even to stay away from you, they even stay also, many!'

4.4.7 Communication and information

Most of the information on issues in the community is found to be communicated through close friends or family member who happens to have heard the news. National and international news

through the media, especially radio (13 participants were found listening to the radio on their days of interview). The church or mosque is mentioned as institutions in the community that are close to persons with SCI not only in spiritual services but also in communicating community issues to the individuals in these areas. Although only few participants reported cellular phones as one of the means of communication within the community, most of them used this media to communicate with friends elsewhere particularly on financial needs and they were all contacted by the researcher using their cellular phones before the interview.

P14 tells of his two sources of information one of which being his business which draws people to him every day and who in return keeps him abreast with whatever is happening. He says:

'Information?, honestly sometimes is the radio and because the radio is here many hours, I am very fond of listening to the radio, and other means are the people, maybe this selling airtime keeps me very close with people to get information, you see? So information, I just get!'

Two of the participants rely on close family members and friends for information from the community. One of them P10, says:

'...She [the wife] goes to jumuiya [house to house prayers], the leaders of the jumuiya would have gone wherever people meet to, to, where, where they get informed. Sometimes they announce in the church... Someone to give me such information it is difficult. Maybe mama is there so if they blow a horn mama will go there...' P10

There are few issues reported as a barrier to successful dissemination of information to and by persons with SCI such as inability to join communal events and social gatherings mostly due to restrictive physical environment. P15 feels that inability to meet other people is the reason for not to get informed directly as he shares:

'...Maybe if in the church is it that a neighbor went to the church or a child that is when I get such information... But I cannot get that information completely because I am not a person who gets to the cabinet of people...'

4.5 Physical constructs OF QoL

The researcher asked each participant of the things within ones body that were most important or of concern for life. In response to this question participants' views over their physical bodies were identified which include perceived functional ability, mobility, perceived fatigue and involvement in activities of daily living. Four sub themes are constructed which are: mobility and functional ability, health and complications, activities of daily living and subjective physical feeling. Among these, the most frequently mentioned one is mobility and functional ability while physical impairments received the least concern.

4.5.1 Mobility and functional ability

All participants spoke of mobility as one area that matters. On the one hand there are those who are enjoying their freedom of mobility and function while on the other hand there are those whose mobility and or functional ability are restricted and to a greater extent affect their lives negatively. For all the participants the wheelchair is identified as the most important device and a prerequisite to mobility.

The section below first presents the functional ability as a facilitator to QoL and the advantages of having a wheelchair and then a quote (among many) given where it was stated that if a wheelchair was available they would be more mobile.

P6 is a fit fully functional 40 years old paraplegic who uses his ability to move with his wheelchair from the village to town where he can engage in other income generating activities. He says:

'Ah, my ability is big! I have ability of getting from home to town' [about 10 kilometers away]

Although others did not talk of their abilities to propel far distances, just being able to propel within the home environment is crucial for independence, self-care and running daily chores of the family. This is evident in the statement of P13 who is a housewife with 5 children as she shares:

'...Sometimes perhaps I am cooking while washing clothes, or cooking while cleaning outside, I am used to this life but if I do not have this wheelchair, then I will find life difficult...if I feel that I want to go and wash now, I just go' P7

Where mobility has been either impossible or impaired, it has been found that participants are affected in various ways and this is a barrier to quality of life. P2 says what happens to him:

'...I cannot even lift my legs, you cannot even raise yourself up to your wheelchair like am sitting now...this wheelchair sometimes I cannot push it around. So I cannot even move away from the sun...I have to request a young boy to assist because personally I can't [propel the wheelchair], yes. I have to ask a friend what, to take me, yes'

4.5.2 Health and complications

Among major concerns which were found in this study are those which are related to physical health and complications following spinal cord injury. While to some, health conditions and complications interfered with their physical exercising progress, to others it had a negative psychological impact as they have to live with worries that they may get complications such as pressure sores. Spasms were found to hinder activities in one participant. Four participants are concerned about pressure sores.

There are some complications such as those related to urinal and bladder organs as pointed out by five participants. P10 is one of them and he says:

'...Stool, stool just comes suddenly but I feel when it is coming, but I can't feel...urine I used not to feel it as well. I used to pass in a tube [intermittent catheter] but now luckily I stop' P10.

Other conditions which may not be related to spinal cord injury are as well found to affect lives of some participants. P11, 60 years quadriplegic, says he likes keeping active but this is hindered when he gets sick. He puts it this way:

'...the first thing at six in the morning I do exercises every God-given day except such days when I maybe having severe fevers like in malaria or pneumonia. I stop'

And for P10, despite being paraplegic and immobile for not having a wheelchair for two years, his current main complaint is not the disability due to spinal cord injury itself but another condition as he says:

'...what worries me is, the insidious pain that I get, it is I don't know with the lungs or what, and the way this part of chest pains me connecting with the spirit [heart] continues to the kidneys...it will just finish me!'

4.5.3 Activities of daily living, self-care and exercising

In this sub theme the participants talked of their physical ability to conduct some of the activities of daily living. Most of the participants reported that they are able to carry on activities of daily life which are within their physical abilities. However some participants had to depend on able bodied people for some of the activities of daily living due to either physical inability (quadriplegic) complications such as spasms or other health conditions.

Even though he has lost the ability to grasp, P2 still manages to do some things for himself within his limitations. He says:

'Nowadays I can feed myself, I can brush my teeth, and I can wipe myself, oiling my skin, to, like putting on a shirt'

P4, who lives alone in a small rented room in a poorly furnished house, says he does most of the things for himself and feels good about it:

'I can cook, I can wash clothes, wash myself...and if you get some water you can just wipe somehow, put on clean clothes you know you are better, you smear yourself a bit of oil [lotion]'

On the other hand there were restrictions to performance of such activities of daily living to a few participants due to not having a wheelchair or their physical dysfunctions. P15 is paraplegic

and has full power in his upper extremities but due to pain and back stiffness he depends on his wife for some basic activities of daily living despite of having a wheelchair as he discloses:

'This area (he touches the waist) is very painful and the legs are burning from the toes to the buttocks...so she has to wash it, she has to cook, boil hot water lukewarm water she has to wash you and apply oil [lotion] on you'

4.5.4 Subjective perception of fatigue and physical inability

This sub theme is twofold as it contains the findings of the more subjective physical feelings which sound almost psychological but also it has dimensions of physiological dysfunction. Five participants reported a feeling that is referred to as heaviness and or state of tiredness and fatigue which negatively affects their functional ability.

P1 says this is her main physical problem and she feels like almost falling from the wheelchair. She says:

'I won't talk of anything more than this heaviness feeling...to the extent of feeling that the wheelchair is falling!'

In the area of functional abilities, except for ten year old P12 who was not asked about sex, physical ability to conduct sex was a major area of concern among men in this study. Three men acknowledged that they are able to engage in physical sex with some shortcomings.

P9 puts together some difficulties that he faces, even though he physically manages:

'...It cannot be like yours! It is small...when the two parts comes into contact because of that temperature inside you pees first...the biggest problem is that we take very short time to ejaculate, they come out just like that...'

The remaining eleven male participants reported physical inability to perform sex specifically due to inability to erect despite several trials. Here are two of the quotes which address this problem:

'Sexual intercourse? No! The guy [penis] is powerless. I have tried [sexual intercourse], yes, there are times it goes like shocked only, it stands [erects] for a second' P5.

4.6 Psychological constructs of QoL

The major question, “Please tell me how do you feel about and react to things happening in your life nowadays as compared to that before the injury” was posed, followed by few probes in explaining this pre-determined major theme. Most of the findings uncovered in this theme were barriers to QoL such as anger, worries and feeling bad about self. Most of these psychological disturbances are a response to what is perceived by participants as maltreatment by the community.

However the strongest psychological component in these findings which cuts across the whole sample is faith in God and staying positive which almost overshadows the negative components. Five sub themes are generated which are: Faith in God and staying positive, increased anger, anxiety, insecurity and depressive mood, self-esteem and body image and Feeling bad about self and of failure to achieve goals.

Faith in God and staying positive and increased anger are equally strong sub themes while feeling bad about self and of failure to achieve goals constituted the least attribute to psychological constructs in this study.

4.6.1 Faith in God and staying positive

Except for the child 10 years old, who only got his first wheelchair when starting to attend madrassa a year ago, the rest of the participants addressed faith in God as a strong component of their lives in a manner that they know the God that they associate themselves with. Every participant had almost a different view on what God meant and they address him as supreme, the one behind their conditions and who will determine their destiny and basis for security.

To most, believing in God creates a hope that he will do something for their lives as stated by the following three participants:

P6 was found in church on the day of interview which is possibly an indication of his active persuasion of faith to God. He strongly believes that God will help him at some point but he also knows that God has a plan for his life as he adds:

‘Still I have hope that I will see God’s miracle one day...God decided let me put you in this situation and see that I get my person because we are the children of God, God want

to get us also and he knows if I put this person in this condition even though he will lament, I know that I want him, I do not want his works'

Few participants shared their experiences showing that they once related with witchcraft for healing and now they have come to believe in God. Having tried other means, P13 settles down with Faith in God believing that he will enable her:

'...in the past I used to move from place to place but now I have given my life to Jesus and I told God that he is the one who knows all this because it is his will. And I know that there is nothing impossible to God. I was thinking maybe someone had done witchcrafts on me or someone is behind this but now I have accepted...'

The following participant's quotes represent others who indicated that they were positive not only by faith in God but also to life itself:

'And I the future I know God will continue blessing me especially when I have started keeping that goat that I told you about, I know God will help also from there...' P3

4.6.2 Increased anger

All participants who had traumatic spinal cord injury reported that they had increased anger as compared to before the injury. This anger is described as what words cannot describe and which has a potential to put peace and a healthy mind in jeopardy and creates grudge. Inability to walk away or reacting physically against the offender is blamed for this increase in anger.

Except for P15, the rest of the participants reported of increased anger. For example P2 describes his anger as a feeling that is overwhelming:

'... I feel very bad inside if someone annoys me! Yes! I mean I become like, I get a certain kind of anger that I cannot describe... You get that strange anger and feel very bad about it...'

There is a desire to revenge if someone is the reason for the anger and a feeling that offenders do so to persons with disability because of the victim's inability to counter attack physically, as pointed out in the following statement by P4:

'...I cannot run and catch him. So I will have to tell him "I will catch you one day" I must keep memory in my head that I must catch him, beat him...'

For P14 what causes this anger may not be that noteworthy and that not being able to walk away from the incidence adds to the inner pain:

'...like now just a small thing makes you very angry...but in the past maybe you were walking what you see that someone has annoyed you, then you just say "leave him, by the way what does it matter?" But now for example even that deciding let me walk away, how will you move now?'

Even though persons who were born with Spina Bifida could not compare life between before and after the injury two out of three spoke of their anger as being high compared to their non-disabled friends. A 28 year old person with Spina Bifida, P9 speaks not only about himself but of other people that he knows of as he shares of their anger:

'...at KCMC we are four of us with Spinal Bifida who are old enough and know each other very well. If you see how we get angry, it is not like a normal human being! We get very angry, very easily!'

4.6.3 Anxiety, insecurity and depressive mood

Among many other psychological components which were found to affect the life of a person with spinal cord injury were anxiety and uncertainty. Getting into relationships and involvement in sex comes as one of the areas where most female participants are scared to venture and or worried about especially of contracting a disease from sexual relationship, sinning against God and failing to satisfy the partner.

Even though very few participants sounded worried about dysfunction, possible complications and inability to get health services, almost all adult participants reported that they are worried that their properties might be stolen and this puts them in a state of insecurity. Two participants gave statements that indicated possible depression.

Fear of contracting diseases is addressed by three participants; P1, P3, and P8. Being a widow for about eight years P8 wouldn't even associate with men. She discloses her worries:

'No! For what will I need an affair? (They laugh together). Why should I bring diseases to myself? For what? I even don't want people. For money for what I do not want'

Another one of the reasons for fear and worry is that related to properties being stolen (insecurity) which made others quit running small income generating activities such as keeping chickens and running a small shop as could be heard from the following statement from P4 who says:

'...Truly my friends I do not like very much to have friends here because most of them here are street boys and if I give them access they will endanger my life because here I stay alone...'

Two participants sounded depressed due to various factors. One of them is P15 who says:

'Now you will find that the child is kicked out of school and is there. The mother is crying and the child is crying. What will I do? That is when you see completely that rather than living this kind of life it is better to die'

4.6.4 Circumstantial Self-esteem and body image

Under this sub theme there are findings on how participants perceive themselves in different circumstances. Most of the participants expressed their perception of self as worthless if some able bodied individual did something annoying to them. However when it came to body image, most of the participants indicated that they valued and loved their bodies although few still did not seem to appreciate their bodies. The following quote represent others which indicated the perceived worthlessness:

'May be I am seen as someone worth nothing that is why this is done to me... you see yourself maybe if I was walking that person wouldn't have done this to me...' P3

However concerning body image most participants saw their bodies as worth of being cared for. P9 suggests that even photographs can show the difference between him in the past and in current life as he recalls:

'... even looking at my body, I am fresh, no problem. I get such a good picture because that time when I used to-[crawl]... Looking at my current photos, I can tell you I like my body... They past pictures show things, bad destructions!'

On the contrary when it came to P10's perception of himself, it became a different story altogether. He sees himself like none existing as he said it:

'...If I have to tell someone, it is like now I am dead! If I am dead, I cannot help anything, nothing...becomes pressure [depression] that now I am inside the grave. Thoughts become that I am not human being'

4.6.5 Feeling bad about self and of failure to achieve goals

This sub theme emerged as the smallest as compared to the rest under psychological domain. Under this sub theme, some participants indicated their state of feeling bad either about their physical conditions and or failing to achieve certain goals in life. Anticipated goals are such as mobility, exercising, engaging in income generating activities and catering for the family. As a 29 year old young man and quadriplegic, P2 feels bad about his physicality and much reduced functional abilities and he says:

'I feel very bad to tell you, meditating about myself...sometimes I see myself, I mean I feel very bad to tell you, So I cannot even move away from the sun?... I still feel so bad inside my spirit...'

A mother of five P13 is unhappy for the fact that she could not accomplish the plans that she had for her family. She says:

'...You may stay the whole day without eating, thinking of life!...the family is there but they cause me pain because if what, the things that I thought I would be able to give my child I have failed to deliver...'

P15 sounds depressed because of unmet family needs:

'Now you will find that the child is kicked out of school and is there. The mother is crying and the child is crying. They are all crying to me! What will I do? That is when you see

completely that rather than living this kind of life it is better to die'

4.7 Socioeconomic constructs of QoL

Under this theme are the findings on the explored participants' attempts to achieve economic stability. Except for a child P12 who shows a total dependence on his parents, the rest of the participants reported engagement into economic activity either directly or indirectly. While some of the participants participated physically in the economic activities within their homes, others played a more administrative and advisory role in such activities or projects. Economic activities identified are small scale business, livestock keeping, handworks and agriculture. Furthermore there is identified other means of getting money such as support from friends in which cellular phones are used as a way of money transfer. Theft, lack of empowerment and environment are found to hinder economic activities among participants. Five sub themes are developed under economic constructs which are; socioeconomic connections, farm produce and livestock keeping, creativity and self-initiative into self-employment, budgeting and saving for future and dissatisfaction and major economic barriers.

4.7.1 Socioeconomic connections

In this sub theme, participants use the available social resources and connections in attempts to stabilize their economy. Family, friends and available social services are used to facilitate achievement of economic needs of either the participant personally or those of his/her family.

Nine participants of this study mentioned of their dependence on a couple, children or close relatives to meet their financial needs. P11 says the family as whole is the foundation for economic stability. Here is what he says:

'As I told you that the biggest capital is the family...you will find it is like here, you can see outside they are working, I do not have to shout at them, they know their responsibilities...'

From six participants, distant friends are reported to provide economic support by either physical visits to the beneficiaries or most of the times by means of cellular phones money transfer services. P13 speaks of various people who support him economically as he shares:

'I get helped by people. I mean like the way you came. Sometimes as I sit here with my phone it just happen that someone tells you that "I have transferred a little amount of money". I get the credits and sell them, and then the money helps me out'

Few participants reported being empowered economically by being given a working premise, capital or advice from none governmental organisations for persons with disabilities. P1 says she was economically unstable in her small business until when one organisation started supporting her, as she discloses:

'I used to sell very few things, when [name of FOP founder] came, I started going to school and they were teaching us how to run life'

4.7.2 Farm produce and livestock keeping

Farmlands are found surrounding houses of most of the participants with chickens freely feeding all around and animals like cows, sheep and goats as heard during the interviews. Banana and coffee are among the crops seen in these small individuals' farms here known as *vihamba* [which means inherited piece of land]. Twelve participants acknowledged that these farmlands are part of their economic asset by either the crops obtained or livestock accommodated therein especially freely feeding local chickens which are found in almost every visited home.

P10 says it is like a tradition to have livestock and he mentions other economic related activities as he says:

'...as you know in our areas there should be someone keeps his goat one and goats, and a cow there...you must look for what- somebody's cow that you feed so that you get manure yes. For banana, I agree that I get one for sell...So even if we have some beans I sell part of it...'

Despite the death of her mother a year ago upon whom she depended, P3 still manages her economic needs and she discloses one of the secrets of her achievements. She says:

'Because we have a farm we depend on banana harvest and sometimes maize as well, sometimes I sell a chicken and get some money to buy medicine... Now when I get this goat that I am constructing house for, I know it will be of more help'

And P6 says

'I have another means now in which I keep local chickens from which I get eggs and chicks so I get some "change" [small amount of money]...'

4.7.3 Creativity and initiatives into self-employment

Eight participants of this study were running small income generating activities mostly within their home environments which include business and hand work. All of them were self-initiated and managed by self and few obtained advice from nongovernmental organisations for persons with disabilities. Some of the activities which participants reported to be engaged in are small scale business, repairing broken items, sewing and weaving. P1 is one of them and she runs a small shop in her house. She says:

'This business gives me what I need to eat...I started my small business progressively, beans, kerosene, I continued like that...'

And P7 would get money from attending events and plan how to multiply it:

'...when I hear, say I have come to a place; may be CBR...then I go there and I may get "a bit of money" ...when I have got this may be let me buy maize say one bag. If I sell the maize I know even if I get my five shillings, that is it!'

The nature of the handwork done by P9 has forced him to be getting from home every morning to the main bus stand near his home. He was found at his working place on the day of interview and he sounds satisfied by his job as he says:

'What is giving me what I can say a better life is shoe repair and shinning'

4.7.4 Budgeting and saving for future

In this sub theme there were found statements from six participants, which demonstrated a sense of budgeting and saving for the future at some point in life. This saving is being intended for doing some developmental activities or solve future emergencies. P1 kept some of her earnings to renovate her house. She says:

'Whatever profit I get here I do not eat it all, I keep some. Few days ago I bought, what, these paints for the house!'

P4 and P5 keep some of the money that they get to be used in the future emergencies. Here is what they say:

'Because I do not eat all the profit that I used to get there I do keep some balance at least to see if anything happens...' P4.

'And if I get that money I keep it, if in case I will have a problem...' P5.

P9 seems to have gathered from other sources, kept the money and later expanded into business as he says:

'I had kept some money for myself and started a small shop at home; I had a reasonable capital for such'

4.7.5 Dissatisfaction and barriers to economic activities

Most of the participants clearly indicated that at some point there was either dissatisfaction and or failure of the designed economic activity for various reasons. Unreliable sources, theft, lack of empowerment and environmental restrictions are found to hinder economic activities among most of the participants.

P3 talks of indistinct and unreliability of the friends who she depends upon for financial support. She says:

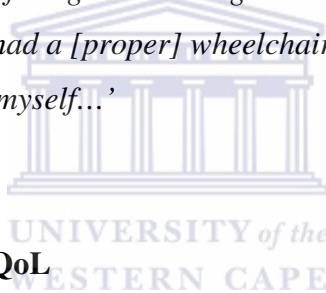
'There are those who come from town and they come over to visit me. He can bring sugar for you or sometimes they even buy clothes and give to me. But they are only few of them, not many people would do that. I gave up because thieves were stealing them...'

Theft is reported to affect self-initiated income generating efforts hence impeding the pace of the participants towards economic stability. Seven participants reported to have been affected by theft particularly of their chickens which they were keeping as a small income generating activity and shop items. Theft is not addressed in livestock only but also in business and particularly small shops initiated by some of the participants. P9 is one of the unfortunate victims of shop robbery as he shares of these horrendous incidences:

'...the first time I was on my way to CCBRT...I met people near that place and they held a knife against my throat! The second time it was here at [name of a place]. They took all my money and left me without my wheelchair...The third time they almost...I started a small shop at home... two men came as customers...after sometime two more came and they became six. One took me inside and ordered me to stay silent while the remaining five were busy taking all my properties on their bicycles and so they cleared all that I had'

The empowerment needed by persons with spinal cord injury in this setting is equipment, particularly mobility aids and capital to start or sustain income generating activities. Most of the participants indicated clearly that they would like to lead an independent life except for lack of availability of necessary social support. P14 says lack of proper mobility aid and capital to start a project are the major hindrance for him to lead an economically less dependent life:

'Example of empowerment, if we get something like working equipment for example my issue is the wheelchair, if I had a [proper] wheelchair and get something like a project of something, I could work by myself...'



4.8 Environmental constructs of QoL

Participants were asked what they would say about inside and outside of their houses as well as the environment where they had been or would like to go? This question aimed at inquiring the effect of both the natural and man-made physical environment at home and away from home to the life of the person with SCI.

Under this theme, major environmental factors that affect the life of the individual with spinal cord injury in this setting are gathered. Four sub themes emerged which are accessibility of home environment (inside and around the house), experienced condition of environment away from home, effect of weather on accessibility and effects of environment on the socioeconomic activities. The results also include whether these environmental conditions were reported as barriers or facilitators of QoL.

4.8.1 Accessibility of home environment (inside and around the house)

Under this sub theme are the participants' views about their home environments. Ten participants reported to have no difficulties moving with their wheelchairs within and around their houses. Out of these, three participants had newly constructed houses by Friends of Para (FOP). P1 is one of the beneficiaries and says, the new more accessible houses have made their lives better, as they say:

'After the construction of this new house they also modified that side (she points at behind the house where the toilet is) and now I can move that side freely and get to the toilet. But before this I really suffered!'

There was however a number of participants who had accessibility difficulties within their home environment and these are reported to negatively affect the individuals' lives. Major barriers reported are related to spacing, surfaces and toilets. On the day of interview P12 was found inside the house while his wheelchair was outside and when he was asked what he thinks about the space of the shack in which he and his family live he says:

'...I wouldn't say that the space inside the house is enough to move with the wheelchair, I wouldn't say that...'

Most of the participants had concerns about the issue of toilet whereby some did not have toilets and others had toilets which were only accessible by non-wheelchair users.

P9 has to use same toilet with the general population and here is what he has to encounter:

'You find the floor is soil/sand and someone else has just been there leaving it dirty' Now when you get to that toilet with this wheelchair you have to get off and get in by crawling, in all that process you find that you are wet already [wet and dirty]'

4.8.2 Experienced condition of environment away from home

Under this sub theme participants' experiences to the environment away from their homes were explored. Inaccessibility is reported from the village paths that connect one home to another the main roads, public buildings such as shops and distance between home and social services which in return negatively affects socioeconomic lives of the participants.

Most of the statements from participants who had wheelchairs indicated that there were difficulties in accessibility of the environment away from home. One of the hardships was reported to be the bad condition of the roads at all times. Talking of environment away from home P7 says:

'If it [the environment] was good it would have been better because even now you wouldn't have found me here. I would have gone completely independently, and downhill, you know coming to our yard there is such a hill'

Few commented that there is a concern about accessibility of public service buildings such as shops and banks as addressed by two participants. One of them is P9 who says:

'...others as you can see, have stairs and you cannot get in... our bank is that side. If you get there you cannot get to your account, and that bank is on top of a hill, that is why I have to sit outside and wait for help'

Distance between home and where one can get certain social service such as public transportation and health services is addressed as a barrier. Geographically one notes the average distance from home to where one can get public transport is about 1.5 kilometers.

P3 who is constructing a new den for goat keeping project has faced this difficult and it has a financial implication:

'Carrying one bag of cement from that place to here is one thousand and that makes a total of six thousand for six bags, carrying one iron sheet is one thousand, you see what it will come to carrying nine iron sheets? So I used a lot of money just to get those things from the bus station to this place'

4.8.3 Effect of weather on accessibility

Most of the participants reported that despite bad roads, they still manage to get out of their homes for socioeconomic reasons mostly with assistance from someone else. Except for P10 who has never had a wheelchair, P5 whose house is on top of a hill and P8 who had a wheelchair but never been out of her home, the rest of the participants informed that mobility away from their houses is possible in dry season at least with assistance but completely impossible during rainy season.

P6 is a very active man who has gone all the way to participating in a marathon. Despite his fitness and experience he says:

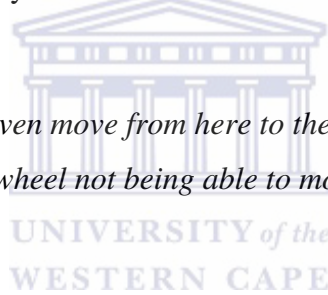
'...and you just came at a nice season where there is some sun! There is a season of mud! Truly it becomes that the environment is so tough...Sometimes you have to ride on these two wheels [wheelie] for, it is a bit difficult'

P9 has been on his wheelchair for eight years and able to face various hardships of bad roads in his area. As a shoe shiner he depends on being on busy places to get customers and rain would stop him:

'...Rainy season is terrible! I cannot get out of the house during such season. Yesterday it rained and I had to stay in the house until the roads were dry again because of mud'

P4 is a fully active paraplegic whose house is only about a hundred meters away from the tarmac road that leads to town but he equally finds it difficult to cover this short distance during rainy season. He says:

'...if it rains here I cannot even move from here to the main road! It is mud! Heavy mud! It sticks to the extent of the wheel not being able to move you get so dirty...'



CHAPTER 5

5. DISCUSSION

5.1 Introduction

This chapter contains discussion on the results obtained from the study on the most valued constructs of Quality of life (QoL) to persons with spinal cord injury in three districts (Hai, Moshi rural and Rombo) of Kilimanjaro region, northern Tanzania. These findings are discussed based on the results from the semi structured interviews conducted in the homes of the participants with some of the observed features incorporated in relation to the available literature. Major topics of discussion are demographic information of the participants, conceptualization of quality of life by participants, social, physical, psychological, socioeconomic and physical environmental constructs of QoL.

5.2 Demographic information of the participants

In this discussion, demographic information of the participants includes personal information and the observed social and geographical information.

5.2.1 Personal Details

The majority of traumatic spinal cord injuries in this study resulted from farm yard accidents particularly falling from trees. Of the eleven participants with traumatic SCI, eight were from farm yard accidents and only three from motor traffic accidents. Bearing in mind that cause of injury was not one of the sampling criteria, the causes may be described by the fact that major socioeconomic activities in Kilimanjaro rural are basically small scale agricultural activities and livestock keeping which necessitates frequent climbing up to the trees for leaves for animal feed, fruits and firewood for domestic use (The United Republic of Tanzania, 1998). Falling from heights has been found to be the leading cause in few other studies conducted in less developed settings such as by (Gupta, Solomon & Raja, 2008; Singh, Sharma, Mittal & Sharma, 2003) both in India. In one of the recent studies in India it is found that 54% of the causes to spinal cord injury are due to fall from height (Singh, Shrivastva & Dulani, 2011). This may be the pattern of etiology in the rural, poverty stricken and less developed areas and differs from findings from other studies conducted in more developed regions and townships where most of the injuries are due to MTA (Lali & Michael, 2001; The National Spinal cord injury Database, 2010). These

results are evident of the fact that etiology of traumatic spinal cord injury depends on 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. It also reflect the findings that 95% of disability in the sub-Saharan countries is poverty related (Vanneste, 2001) whereby poverty could be liable for the risky economic activities from which such injuries are resulting.

The average age at the time of injury for traumatic cases is found to be about 35 years which is in agreement with many other studies which reports average age to be 40-50 (Gupta, Solomon & Raja, 2008; New & Sundararajan, 2008). This is a very active and productive age group and age of responsibility as far as parenting is concerned which means failure to lead productive life at this age would have extensive socioeconomic consequences. This may account for dissatisfaction reported by all parents who had young and school going children at the time of their injuries.

Male are more affected than female which is possibly due to the socioeconomic activities they are involved in such as climbing up to the trees. This is as found in other studies such as male to female ration of 4:1(Lan, Lai, Chang, Jean & Lien, 1993; Dawodu, 2011; The National Spinal cord injury Database, 2010) in Taiwan and America respectively and 5: 1 estimated worldwide (Stokes, 2007).

The average age since the time of the injury for this study is approximately 13 years and the oldest injury is 28 years (N=2) and newest was 18 months.

Most of the adult participants in this study did not have formal employment instead they had to design income generating activities preferably those which can be done at home. This may be due to their level of education as most of them had not attended class levels that would guarantee formal employment. Another reason may be because of the inaccessible environment which would cause getting to the work place and or accessing facilities at the work place difficult. The unemployment findings in this study would be expected bearing in mind that even in the most developed countries with efficient infrastructure and necessary socioeconomic support still have low rates of employment to persons with spinal cord injury (Frieden & Winnegar, 2011) and yet having an occupation is one of very important prerequisite to desired quality of life (Kathryn,

Mark & Judith, 2003). So the finding of unemployment would concurrently yield low perceived quality of life.

5.2.2 Social and geographical information

Although most of the homes were accessible by private car on dry season, the average distance from the homes to where one can get public transport is averaged to 1.5 kilometers, across bad roads which are inaccessible during rainy seasons. This would be expected to hinder several socioeconomic activities such as their small scale business as most of the commodities are obtained from town and involvement in social gatherings such as church service which is valued by majority of the participants which has an effect on the QoL (Newman, 2010; Levins, Redenbach & Dyck, 2004). Rainy season has been reported to completely prevent participants from visiting even the nearest neighbors. Transportation is very important for socioeconomic activities. The following diagram adopted (Maunder, Venter, Rickert & Sentinella, 2011) shows vicious cycle of the interaction between disability, transportation and socioeconomic life.

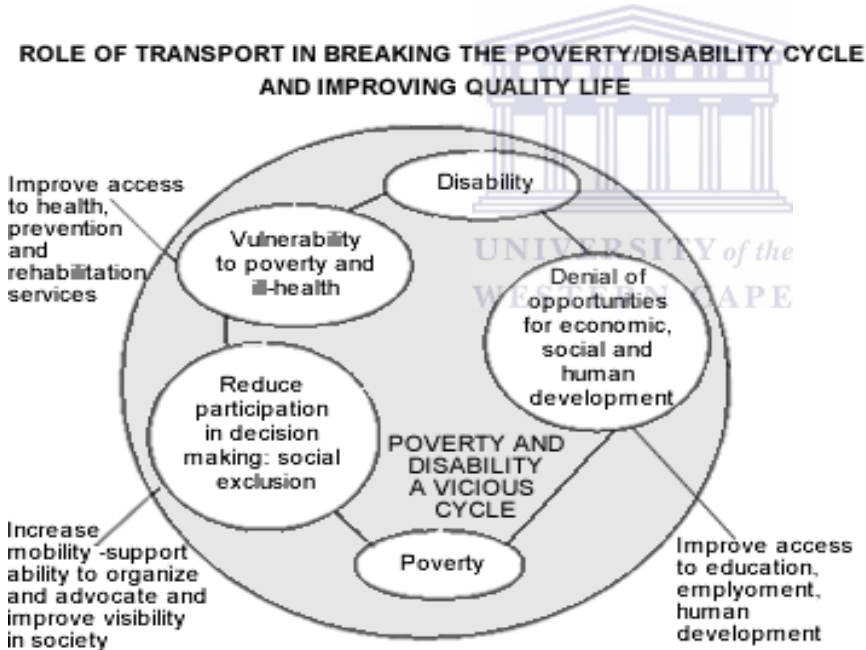


Figure 5:1: The disability-poverty cycle and the role of transport (adapted from DFID 2000)

In the above cycle, disability (participation restriction) denies individual chances to interact in various important areas of life leading to poverty and poor quality of life but with education one is enabled to access most of these. When transportation is improved and made accessible to person with disability it gives opportunity to access basic socioeconomic places and services

leading to enhancement of participation, inclusion, poverty reduction and better quality of life. Lack of accessible roads as found in this study may be associated with poverty seen in most of the families visited and economic dissatisfaction addressed by majority of participants as it is one of the major barriers to participation in the community.

5.3 Conceptualization of quality of life by the participants

Majority of the participants in this study defined QoL in more than one dimension and two accounting for the subjectivity as well as objectivity of this phenomenon. Two participants declared it a difficult question. This difficult though only by two participants in this study, may be universal as other literatures (Felce, Perry, 1999; Peruzzi, 2011) acknowledges the debates, misconceptions and difficulties in defining QoL due to its extensiveness and differences in which different people value certain components of their lives (Pukeliene & Starkauskiene, 2011).

5.3.1 Meeting necessary needs

Even though there was diversity in defining QoL majority of the participants in this study had their definitions based on whether one has his needs being met or not. This may be due to the fact that generally Tanzania rural areas are socioeconomically underserved (The World Bank, 2007; Wangwe & Lwakatare, 2004) and this would have even a greater impact on the population of persons with disability in this setting. There is a global scarcity of studies done in the rural areas on this subject but definitions of QoL based on whether one's needs are being met or not were previously found in other studies (Hammell, 2004; Dijkers, 2005). This implies that meeting socioeconomic needs may be universal criteria in defining QoL among persons with disabilities and spinal cord injury in particular not mattering whether one lives in the rural or urban area.

5.3.2 Having a satisfying occupation

Another criterion that was used in defining QoL is having a satisfying occupation. This is a very strong criterion as every adult participant indicated that they would like to have an income generating activity that they would be able to run within their limitations. These were not mere statements as most of them had small self-initiated income generating activities running within their homes. This definition supports study findings which indicate that occupation correlates

with QoL (Hammell 2004; Tasiemski, Nielsen & Wilski, 2010; Putzke, Richards, Hicken & DeVivo, 2002) in a manner that persons with jobs would experience better life. In one of the grounded theory studies it was found that if persons with spinal cord injury get to stage of acceptance, they became creative in finding ways to sustain their lives and that is what is seen in the results of this study.

5.3.3 General good life, free of any problem

Six participants in their attempt to define the phenomena of QoL referred to it as either general good life and or life that have no any problems. Although this term is short and too general, it was found in common use (Duggan & Dijkers, 2001) and in other studies such as Dijkers (2005) who presents sixteen phrases used to define QoL, three of them containing the word “good”. One can argue that being less educated would make people shorten the way of describing complex and multidimensional phenomena such as QoL and that they would prefer putting it in the shortest most general form. As this phrase may not serve a purpose when attempting to identify level of satisfaction and rehabilitation needs, so one would need to ask the participants to clarify more in simple terms that break down the word “good” to its components such as economic stability, subjective feeling of satisfaction, social stability and psychological stability (Scollon & King, 2004).).

5.3.4 Achieving psychosocial stability

From the fact that most of the communal living in Africa which is rooted in religious principles (Collette, 2011) and philosophies of great African leaders such as the late Mwalimu Nyerere (Smith, 2011), in the rural areas to a big extent individuals depends on each other for solution of socioeconomic issues encountered (Soro, 2007), how one relates with family, friends and community at large is of great importance. To fewer participants in this study QoL is defined as having social support but also one must feel satisfied with relationship with the rest of community members. This definition address the need of having people around such as family and friends and living with them in harmony which throughout this study was found to be key facilitator of QoL to this population. This takes us back to the legendary Nigerian writer Chinua Achebe (2005) who believes that having people is better than material possessions in his book “No longer at ease”. Dijkers (2005) also found in his study that QoL was defined as harmonious living.

5.4 Social constructs of QoL

According to International Classification for functioning, disability and health (ICF) of the World Health Organisation, factors discussed under this theme relates to social environment (Rosenbaum & Stewart, 2004) and for the sake of clarity of this study, social and physical environment are treated as different themes. Five sub themes which emerged under social constructs are Effect the family, Attitude of the community towards persons with spinal cord injury, Health and Rehabilitation support, Leisure time, and Communication and information. Among these, relationship with the family is found to be the most important area of social support but all sub themes were important and are discussed in other dynamics more than just a support. Facilitators and barriers can also be seen throughout the discussion.

5.4.1 Effect of the Family

Family in this context refers to father mother and their children unlike definitions in other African contexts where other biologically connected members (extended family) are referred as one unit. To most participants in this study, family is found to be the foundation of support, encouragement and socioeconomic solutions. All married participants reported the spouse as the closest supporter. For the case of children it is twofold experience whereby the grown up and well established children are found to facilitate lives of spinally injured parent but young school going children are reported to affect their parents more negatively even though their physical presence and support was appreciated. In other previous studies having and relating well with a spouse has been identified as a facilitators of QoL, mobility and economic independence (Sherman, DeVinney & Sperling, 2004; Rahman, Forchheimer & Tate, 2004; Migliorini & Tonge, 2009; Isaksson, Skär & Lexell, 2005; Manns & Chad, 2001; Tasiemski, Nielsen & Wilski, 2010). Spouse or family members are the most involved in caretaking from early on (Martin, Cherian, John, Tharion & Bhattacharjee, 2010). However, caregiving has been reported to negatively impact the care providers especially spouses such as being source of depression and lost jobs (Dreer, Elliott, Shewchuk, Berry & Rivera, 2007; Weitzenkamp, Gerhart, Charlifue, Whiteneck & Savic, 1997; Timothy, Richard, Scott, 2001).

Although in their study, Alexander, Hwang & Sipski (2002) did not find difference between parenting with spinal cord injury and that in normal state it is different from the findings in this study in which parenting especially to small children (Trieschmann, 1988) is addressed as cause

of worry, feeling of failure to deliver and dissatisfaction. This may be explained by the possibility that such studies were carried in a more resourceful setting where children did not have to depend on the injured parent for education and other social service in comparison to this setting. Further studies need to be done to compare perceptions of parents with spinal cord injury with the general population in the same setting.

5.4.2 Attitude of the community towards persons with spinal cord injury

Among community actions which were found to have negative effect on the lives of persons with spinal cord injury are false beliefs about the cause of the condition and of the participants' abilities which is possibly due to community's lack of understanding about spinal cord injury. Reported beliefs are such as associating the condition with witchcraft and punishment from super natural powers, resulting into participants' feeling of rejection, isolation and feeling stigmatized. These beliefs seems specific to African and more of rural communities issue as there is no much written on it from more developed and civilized world. A study which was done in Kenya the neighboring country to Tanzania and very near to this setting addressed the same issues of culture, false beliefs and other negative attitudes as barriers to perceived better life (Monk & Wee, 2008). These results supports other previous findings which suggests that being accepted and or involved in community or family is important facilitator to QoL (Noreau, Fougeyrollas & Kathryn, 2004; Tasiemski, Nielsen & Wilski, 2010; Murphy, Middleton, Quirk, Wolf & Cameron, 2011) . Feeling that one is needed and inclusion into the dynamics of the community is one of the key components of definition of quality of life (Renwick, Brown & Nagler, 1996). Rejection, isolation, stigma and exclusion has associated with negative affect (Kortte, Gilbert, Gorman & Wegener, 2010) which has reported as a barriers to quality life (Manns & Chad, 2001). Results of perceived stigma and being under punishment in this study are found to be purely circumstantial as they were experienced only under certain situations caused by the community and were not necessarily persistent which is different from the findings by Marini & Glover-Graf (2011) whereby participants perceived themselves as being under punishment regardless of the community views. Associating spinal cord injury with witch craft has resulted into witch doctors consultation for possible solutions and that by itself is costing for a family which is already struggling to cater for basic needs. The fact that all participants who tried this "way of healing" stopped and turned their faith to God, it is obvious that it did not work for them. When Spinal cord injury is linked to curse or punishment from super natural power the

victim is viewed as an object of wrath and cursed and these would have massive psychological consequences as far as self-esteem is concerned and eventually affect the quality of their lives negatively (Trieschmann, 1988).

Despite these reported few cases of negative attitudes which are not in favor of QoL to persons with spinal cord injury, friends, relatives and neighbors are to a greater extent reported to provide support in one way or another which compliments findings elsewhere in West Africa (Santos-Zingale & McColl, 2006) and in Kenya (Monk & Wee, 2008) where these groups are identified as of supreme support. Support provided is such as financial as well as physical assistance where necessary (Babamohamadi, Negarandeh & Nayeri, 2011) which is so much needed by persons with spinal cord injury. Even the income generating activities initiated by persons with spinal cord injury in this study would depend on service or product consumers response to what is been rendered for provider to excel economically.

5.4.3 Health and Rehabilitation social support

Rehabilitation of persons with ailments such as spinal cord injury is very costing (Price, Makintubee, Hemdon & Istre, 1994) especially due to their physical limitations that may necessitate need for both human and equipment support. In rural areas like this setting communal living which was nourished by “*ujamaa*” philosophy by late Mwalimu Nyerere who is the father of the nation of Tanzania (Smith, 2011) solves the issue of human support to a big extent, leaving the financial and medical needs pending. This is the point where other various health and rehabilitation supporting organisations gets involved. For many years it has been found that social support is very important for the life of a person with spinal cord injury (Kathryn, Mark & Judith, 2003; Richard & Susan, 1985; Krause, DeVivo & Jackson, 2004). In this study, most of the highly needed self-care training, housing, mobility aids and information about spinal cord injury itself is conveyed to the participants by local none governmental organisations. Such services are reported to make a big difference psychologically, socially and economically. However there are shortcomings with this mode of service provision by dependence on non-governmental and charity organisations as most of them are on contract and suffer from recurrent financial instability (Duhu, 2008). Another problem with this system is that it may not allow for clear view of the state of persons with disabilities under full responsibility of their government

and so the achievement claimed in rehabilitation may be coming from unreliable and unsustainable sources.

5.4.4 Leisure time

Leisure time in this context is that which is used for social and refreshing purpose out of work and routine responsibilities. Where there were no physical or social environmental barriers, majority of the participants informed that they had one or another type of recreational activity which they considered important such as evening social gatherings at or away from home and attaching to a media such as radio or television. Leisure time was found to correlate with QoL in a study by Rahman, Forchheimer & Tate (2004) who studied participants from three ethnic groups and that persons with spinal cord injury uses more time in leisure activities than the able bodied individuals (Pentland, Harvey, Smith & Walker, 1999). The importance of leisure time is also addressed in terms of enhancing social connections, mental and physical health (Kathryn, Mark & Judith, 2003; Askins, 1994). Major hindrance of recreational activities in the current study is inaccessible environment which involves roads and recreational places. These barriers are addressed elsewhere in less developed settings such as one rural area in Taiwan (Jang, Wang & Wang, 2005), India (Sekaran et al., 2010) and Kenya (Newman, 2010) which suggests that poverty and environmental barriers may be associated.

5.4.5 Communication and information

Communication is a key prerequisite for development in any population (Diouf, 2011) and information by rural inhabitants is commonly by one person talking to another. The setting of this study is mountainous region encompassing difficult terrain, compounded with poor levels of transport infrastructure (Wangwe & Lwakatare, 2004; The United Republic of Tanzania, 2005) in which communication by physical visits is difficult and almost completely impossible by wheelchair users. In their assessment to Uganda suggests that communication is very important for rural development (Scott et al., 2010). In this study most of the information on the issues within the community is found to be communicated through close friend or family member who happens to have heard the news which is one of the attributes of communal living communal (Smith, 2011; Collette, 2011). National and international news through the media, especially radio (13 participants were found listening to the radio on the days of interview). The church or mosque is mentioned as institutions in the community that are close to persons with SCI not only

in spiritual services but also in communicating community issues to the individuals in these areas. Although only few participants reported cellular phones as one of the means of communication within the community, most of them used this media to communicate with friends elsewhere particularly on financial needs and they were all contacted by the researcher using their cellular phones before the interview day. This fast growing means of communication in rural Tanzania (Sife, Kiondo & Lyimo-Macha, 2010) can be used by rehabilitation service providers in rendering services such as counseling and advice on issues which do not require physical meetings as has been used in other studies elsewhere (Dorstyn, Mathias & Denson, 2011; Cox, Amsters & Pershouse, 2001). However, use of phones should not be a substitute to social meetings which are of so much value to persons with disabilities. Major national issues on disability will efficiently be communicated through radio which has been afforded by majority of the participants in this study.

5.5 Physical constructs of QoL

Under this theme participants' views over their physical bodies were identified which includes perceived functional ability, mobility, perceived fatigue and involvement in activities of daily living. Four sub themes are constructed which are; mobility and functional ability, health and complications, activities of daily living and subjective physical feeling. Among these, the most frequently mentioned of is mobility and functional ability while physical impairments received the least concern.

5.5.1 Mobility and functional ability

All participants in this study spoke of mobility as one area of functional ability that matters very much to their lives. Mobility and functional ability has been reported as of paramount to QoL in other studies (Putzke, Richards, Hicken & DeVivo, 2002; Patrickka, Kinnea, Engelberga & Pearlmanb, 2000; Cassini, 2009; Hampton, 2004; Rick Hansen Institute, 2011) and that it contributes to both physical (Hicks et al., 2003; Warburton, Nicol & Bredin, 2006; Kannel & Sorlie, 1979) and mental (Richardson et al., 2005; Hicks et al., 2003) health. There are findings that show that mobility and or functional ability correlate positively with QoL and self-esteem (Stevens, Caputo, Fuller & Morgan, 2008), independence (Manns & Chad, 1999). Where mobility has been either impossible or impaired, it has been found that persons with spinal cord

injury are negatively affected in various ways; physically, psychologically, socially and economically (Hampton, 2004; Dallmeijer, 2004).

Majority of the participants reported to be needing assistance with their mobility at some point especially when going away from home regardless of their level of lesion which concurs with findings from Osterthun, Post and van Asbeck (2009) who could not find correlation between level of lesion and perceived QoL even though their study was not done in rural area. This may be due to both social and physical environmental barriers encountered in the rural setting which would hinder even a full powered paraplegic from getting into the community.

Even under accessible environment mobility declines following discharge into the community (Amatachaya, Wannapakhe, Arrayawichanon, Siritarathiwat & Wattanapun, 2011) due to lost motivation to exercising. This general decline may be even more severe when one is discharged to restrictive environments like those in the rural areas where environment is additional barriers on the lost motivation (Haglund, 2000).

Wheelchair is the only means of mobility by persons with complete spinal cord injury in less developed regions (Ndegwa, 2011; Disabled World, 2011) being needed in various areas of life such as activities of daily living, socioeconomic activities, exercising and sports (Disabled World, 2011). In this study, wheelchair is clearly identified as the most important device and a prerequisite for mobility and independence. However majority of the participants had either inappropriate wheelchair based on definition by WHO (World Health Organisation, 2008), old or broken and one participant did not have a wheelchair, a possible additional explanation behind unemployment and dissatisfaction with the self-initiated income generating activities. However, not having a wheelchair seems to be a problem of the less developed world as there were no studies addressing this as a problem from developed countries.

5.5.2 Health and complications

Among major concerns to persons with physical disabilities like spinal cord injury is general health and associated complications. Perceived health has been found to relate with QoL in various studies involving persons with spinal cord injury (Putzke, Richards, Hicken & DeVivo, 2002; Hampton, 2004). Possible complications following spinal cord injury which have been found to affect QoL are such as pressure sores and urinary tract infections (Langemo, 2005;

Gorecki, 2009; Spilsbury, Nelson & Cullum, 2007). It is found in the current study that related health conditions and complications to persons with SCI interfered with their exercising progress, functional abilities and had negative psychological impact as participants had to live with fear that they may get complications such as pressure sores and urinary tract infections. Spasms as a common sign of upper motor neuron lesion were found to hinder activities in one participant and position on a wheelchair to another.

5.5.3 Activities of daily living and self-care

In this sub theme the participants talked of their physical ability to conduct some of the activities of daily living. Majority of the participants reported that they are able to carry on activities of daily life which are within their physical abilities. However some participants had to depend on able bodied people for some of the activities of daily living and exercising due to either physical inability (especially quadriplegic participants) or complications such as spasms and associated health conditions which supports studies where correlation between level of lesion and level of functional activities was found (McKinley, 2011; Hicks et al., 2003; Warburton, Nicol & Bredin, 2006; Kannel & Sorlie, 1979). However home environment barriers such as not having a toilet or having inaccessible one was found to hinder persons of all levels of injury from proper self-care of the bowel and bladder suggesting that independence is determined not only by the functional ability but also the surrounding environment (Rosenbaum & Stewart, 2004; Lysack, Komanecky, Kabel, Cross & Neufeld, 2007).

5.5.4 Subjective perception of fatigue and physical inability

This is a sub theme is twofold as it contains the findings of the more subjective physical feelings which sounds almost psychological but also it has dimensions of physiological dysfunction. Five participants reported a feeling that is referred to as heaviness and or state of tiredness and fatigue which negatively affects their functional ability.

Physical inability to conduct sex was a major area of concern among participants in this study. Eight male participants reported physical inability to perform sex specifically due to inability to erect despite several trials. Due to masculinity traits attached to male victims inability to perform sexual intercourse has been found to have psychosocial consequences which in return affect QoL negatively (Levi, Hultling, Nash & Seiger, 1995). Such consequences are such as low self-esteem, poor body image and perceived stigma and disrespect (Wassersug, 2009; Stokes, 2007;

Burr, 2011; Sheldon, Renwick & Yoshida, 2011; International Labor Organisation, 2009) which will subsequently have negative effect on the perceived QoL (Potgieter & Gadija Khan, 2005; Renwick & Yoshida, 2011).

5.6 Psychological constructs of QoL

Under psychological constructs as a major theme most components were barriers to QoL such as anger, worries and feeling bad about self but the strongest psychological component in these findings which cuts across the whole sample is faith in God and staying positive which almost overshadow the negative components. Five sub themes are generated which are; faith in God and staying positive, Increased anger,, Anxiety insecurity and depression, Self-esteem and body image and Feeling bad about self and of failure to achieve goals.

5.6.1 Faith in God and staying positive

Religion and faith in God among other things have been found to boost QoL in various studies (Babamohamadi, Negarandeh & Nayeri, 2011; Johnstone & Yoon, 2009; Matheis, Tulskey, & Matheis, 2006; Songhua et al., 2009; Marcel et al., 1997; Krause, 1992; Kennedy & Rogers, 2000; Matheis, Tulskey & Matheis, 1998; Putzke, 2000) which are supported by the findings from this study in which except for a child 10 years old, the rest of the participants reported faith in God as a strong component of their lives. God is associated with provisions, security, life sustenance, meaningful life and hope. Previous studies among persons with spinal cord injury have found spirituality and particularly faith in God as important coping strategy (Chlan, Zebracki & Vogel, 2011; White, Driver & Warren, 2010; Marini & Glover-Graf, 2011; Anderson, Vogel, Chlan & Betz, 2008) and yet a neglected area in rehabilitation. (Jenkins & Amakwaa, 2011). It is suggested that when individuals are troubled and or have a condition that is beyond their handling, they are likely to seek help from super natural powers (Babamohamadi, Negarandeh & Nayeri, 2011; Duggan, 2000) and this may be the main reason why most persons with ailments like spinal cord injury as found in this study tends to have more attachment to God. Even though the participants in Marini & Glover-Graf (2011) showed fulfillment in believing in God, it is also reported that there was a pattern in which the state of faith to God increases seeking for healing in the beginning and diminishing with time a pattern that was not found in the results of this study.

5.6.2 Increased anger

Spinal cord injury has been reported as one of the conditions which have several negative psychological consequences one of which being anger (Craig, Tran, Lovas & Middleton, 2008). All participants who had traumatic spinal cord injury in this study reported that they had increased anger after as compared to before the injury. An increase in anger has been found in other studies (Sanchez, Perez & Vila, 2004) among subjects with spinal cord injury where states of anger before and after injury was compared and that this anger has a negative impact on QoL (Wollaars, Post, van Asbeck & Brand, 2007). Anger is reported to increase perception of symptoms such as pain (Conant, 1998; Summersa, Rapoff, Vargheseb, Porterc & Palmera, 1991) and pain in return has been reported to have adverse effect on QoL (Que, Siddall & Cousins, 2007; Vall, Costa, Santos & Costa, 2011).

This anger is worth of attention as is described as having potential to put peace and health mind in jeopardy and creates grudge. Johnstone & Yoon (2009) found that forgiveness is important for health mind and likely to enhance QoL. This would most likely reduce chances for one to get angry hence promoting healthy mind so anger management (Mehta et al., 2011) should be included in rehabilitation of persons with spinal cord injury. However it seems that some old studies reports no difference on the states of anger between spinally injured subjects and normal population (Bermond, Schuerman, Nieuwenhuijse, Fasotti & Elshout, 1987) and even older findings by Hohmann (1966) reported a decrease in anger following spinal cord injury. One may argue that there is a possibility that the current community actions are harsher to persons with spinal cord injury leading to more anger or this discrepancy may be due to the type of the assessment tools used by then as compared to current ones.

5.6.3 Anxiety, insecurity and depressive mood

Among many other psychological components which were found to affect the life of a person with spinal cord injury in this study are Anxiety and uncertainty. Getting into relationships and involvement in sex is found as one of the areas where most female participants are scared to venture and or worried about especially due to the risk of contracting a disease from sexual relationship while few men were scared that they might be sinning against God or fail to satisfy their partners. Anxiety and discomfort has been found to affect involvement in sex and marriage especially to women with spinal cord injury (Bradford & Meston, 2006; Chau et al., 2008;

Brown & Giesy, 1986), findings which are to a large extent supported by the results from this study.

Few participants sounded worried about dysfunction, possible complications and inability to get health services. Almost all adult participants reported that they are worried that their properties might be stolen and this puts them in a state of feeling unsecured. Fear and worries are found to affect persons with spinal cord injury elsewhere (Hancock, Craig, Dickson, Chang & Martin, 1993) and are known to be a component of unhealthy mind which consequently affects QoL (Craig, Tran, Lovas & Middleton, 2008). Two participants gave statements that indicated possible depressive mood associated with suicide. The fact that it was only two participants out of fifteen, these results are supported by Craig, Hancock & Dickson (1994) who found that only 30% had anxiety severe enough to lead into depression.

5.6.4 Circumstantial Self-esteem and body image

Self-esteem is a term that describes individual's self-worth and perceived position in the community in which he lives and is subject to change depending on both intrinsic and extrinsic factors and is found to correlate positively with QoL (Bailey, 2003; Loanna & George, 2002; Trieschmann, 1988). Majority of the participants in this study expressed their perception of self as worthless if able bodied individual did something annoying to them and that this feeling was only when something unpleasant is done to them. This supports other findings (Piazza, Holcombe, Foote, Paul, Love & Daffin, 1991; Sheldon, Renwick & Yoshida, 2011) negative community actions are the major reason behind devaluing of self. Another study done in South Africa (Potgieter & Gadija Khan, 2005) found that intrinsic factors were not as strong in judging how one perceives self as it was for extrinsic ones. These results indicate that solution to problems pertaining self-esteem should involve not only the subject but also the surrounding community.

Concerning body image majority of the participants indicated that they loved their bodies and saw them as worth of being cared for. This is a strong facilitator of QoL as it has been found that positive body image have positive effect on the QoL (Bassett, Ginis & The SHAPE-SCI Research Group, 2009; Sheldon, Renwick & Yoshida, 2011).

5.6.5 Feeling bad about self and of failure to achieve goals

This sub theme emerged as the smallest when compared to the rest under psychological domain. Under this sub theme, some participants indicated their states of feeling bad either about their physical conditions and or failing to achieve certain goals in life. Such anticipated goals are such as mobility, exercising, engaging in self-initiated income generating activities and catering for the family needs. The feeling by itself could mean a desire to excel in life and can be used as inner motive towards achievement of various goals in life unlike the situation where one accepts even the poorest performance of abilities.

5.7 Socioeconomic constructs of QoL

Under this theme are the findings on the explored participants' attempts to achieve economic stability. Except for a child P12 who showed a total dependence on his parents, the rest of the participants were found to engage in economic activity either actively or administratively at family level. Economic activities identified are small scale business, livestock keeping, handworks and agriculture. Furthermore there is identified other means of getting money such as support from friends in which cellular phones are used as a mode of money transfer. Theft, lack of empowerment and inaccessible environment are found to hinder economic activities among participants. Five sub themes are developed under economic constructs which are; socioeconomic connections, Farm produce and livestock keeping, Creativity and self-initiatives into self-employment and budgeting and saving for future and dissatisfaction and major economic barriers.

5.7.1 Socioeconomic connections

In this sub theme, participants use connections with people in attempts to achieve economic stability. Family, friends and available social services are used to facilitate for attainment of economic needs of either the participant personally or those of the family.

Nine participants of this study mentioned of their dependence on couple, children or close relatives to meet their financial needs. Family is found to be the most reliable foundation for economic solutions to unemployed persons with SCI in other studies (Sherman, DeVinney & Sperling, 2004) and a spouse is the cornerstone in this regard (Weitzenkamp, Gerhart, Charlifue, Whiteneck & Savic, 1997; Kathryn, Mark & Judith, 2005)

For six participants, distant friends are reported to provide economic support by either physical visit to the beneficiaries or most of the times by means of cellular phones money transfer services. It is clear in this study as was found by Botticello, Chen, Cao, Tulsy (2011) that socioeconomic solutions to persons with spinal cord injury depends to a high extent on involvement of the people surrounding them starting with the family but the manner in which friends are involved around the individual's economic needs in this study is unique in which they offer cash one on one or transfer through cellular phone. This flags the critical area of needs to person with spinal cord injury in disadvantaged rural areas which is finance but also reflects the increased use of cellular phones even in underdeveloped regions of Africa and Tanzania (Sife, Kiondo & Lyimo-Macha, 2010; Diouf, 2011).

Fewer participants reported being empowered economically by none governmental organisations for persons with disabilities which in this area are mostly run by persons with disability who in part provide mentorship and sharing experiences with the individuals. Involvement of fellow persons with spinal cord injury are found to be efficient for socioeconomic breakthrough in other studies (Sherman, DeVinney & Sperling, 2004) from the fact that individuals with same type of disability have a lot in common and can speak "the same language". It is also encouraging to see someone who has same dysfunctions leading a successful life.

5.7.2 Farm produce and livestock keeping

Farmlands are found surrounding houses of majority of the participants with chickens freely feeding all around and sounds of animals like cows, sheep and goats heard during the interviews. Banana and coffee are among the crops seen in these small individuals' farms (The United Republic of Tanzania, 1998) here known as *vihamba* (which means inherited piece of land). Twelve participants acknowledged that these farmlands are part of their economic assets by either the crops obtained or livestock accommodated therein especially freely feeding local chickens which are found in almost every visited home. In most of Tanzania rural areas, land is inherited from generation to generation (Berkes, 2008; Meyer, 2009) which implies that even persons who are not able to afford land could inherit one. This seems to be the only guaranteed asset to the participants in this study. However this asset may not be owned by women traditionally (Agrawala et al., 2003) and number of children and genealogy would determine the

size of plot obtained by the son from the father, making it indefensible source of income over time.

5.7.3 Creativity and self-initiatives into self-employment

Majority of the participants in this study were already engaging in self-invented small scale business, handworks or livestock keeping, and none had formal employment. Previous studies have also indicated occupation as one of the valued constructs to the lives of persons with spinal cord injury (Hammell 2004; Tasiemski, Nielsen & Wilski, 2010; Putzke, Richards, Hicken & DeVivo, 2002; Webb, Wrigley, Yoels & Fine, 1994; Manns & Chad, 1999) and that to a big extent formal employment depended on infrastructure especially transportation (Franceschini, Clemente, Rampello, Nora & Spizzichino, 2003; Schopp, Clark, Gray & Boninger, 2007; Murphy, Middleton, Quirk, Wolf & Cameron, 2011) and education (Krause, Terza, Saunders & Dismuke, 2010; James, Krause & Reed, 2009; Jang, Wang & Wang, 2005; Frieden & Winnegar, 2011; Krause, Sternberg, Maides & Lottes, 1998) but majority of the participants of this study are located in the poverty stricken regions of Tanzania rural where infrastructure is very poor (The United Republic of Tanzania, 2005; The World Bank, 2007) and so the findings that there was none with formal employment would reflect socioeconomic states of such regions.

Unemployment is likely to have a big effect on QoL the reason why all adult participants in this study were involved in self-invented projects in order to survive. Lack of education may be another major underlying obstacle to gaining formal employment to participants in this study as majority were having very low level of education which wouldn't guarantee a formal employment in the current Tanzania education scheme. Even though various studies found factors like level of lesion (Martin, Cherian, John, Tharion & Bhattacharjee, 2010), age at the time of injury and marital status correlating with employment (Jang, Wang & Wang, 2005), all participants did not have formal employment regardless of their ages and marital status which suggests that such factors wouldn't make a difference in this setting. In cooperation empowerment programs to enable persons with spinal cord injury in establishing self-income generating activities within their communities and enhancement of the related education would benefit them in these areas by giving them ability to self-employ and lead more productive lives which will eventually better the quality of their lives.

5.7.4 Budgeting and saving for future

In this sub theme there was found statements from six participants, which demonstrated a sense of budgeting and saving for the future at some point in life. The saving being intended for doing some developmental activities or solve future emergencies. There was not found in the literature studies supporting this pattern of life among population of persons with spinal cord injury. Due to the fact that all participants did not have employment and guaranteed payment, it is likely that naturally one will have to keep the extras of today for tomorrow. This could as well be due to anticipated complications and or associated health conditions as most of them informed that they are saving in case of anything. This behavior should be encouraged in the rehabilitation programs as it prepares one for future emergencies and it is a key to success in business and economic sustainability (Roux, 2009).

5.7.5 Dissatisfaction and barriers to economic activities

Majority of the participants clearly indicated that at some point there was either dissatisfaction and or failure of the designed economic activity for various reasons. This dissatisfaction in the literature could be associated with financial instability as the prime intention of the aforementioned activities aimed at solving financial needs (Babamohamadi, Negarandeh & Nayeri, 2011). Unreliable resources, theft, lack of empowerment and environmental restrictions are found to hinder economic activities among majority of the participants. These economic hindrances are found in other previous studies (Babamohamadi, Negarandeh & Nayeri, 2011)

Theft is reported to affect self-initiated income generating hence impeding the pace of the participants towards economic stability. Seven participants reported to have been affected by theft particularly of their chickens which they were keeping as a small income generating activity and shop items and some of them had to quit for this reason. These are some of the community behaviors which are barriers to economy and subsequently to quality of life.

The empowerment needed by persons with spinal cord injury in this setting is working equipment particularly mobility aid and capital to start or sustain income generating activities.

5.8 Environmental constructs of QoL

Rural areas of Africa and in this case Kilimanjaro are characterized by various environmental barriers to socioeconomic to general population and to a greater extent to persons with

disabilities (Cock, 2007; Seekins et al., 2011). Major environmental issues raised in this study are accessibility of home environment (inside and around the house), experienced condition of environment away from home and effect of weather on accessibility. The results also includes whether these environmental conditions were reported as barriers or facilitators of QoL.

5.8.1 Accessibility of home environment (inside and around the house)

Environment surrounding individual with spinal cord injury has been found to have a great impact on the life lived by the subject and affect the way one perceives QoL (Seekins et al., 2011; Richards et al., 1999). Home is a place where persons with mobility difficulties especially in the rural areas are likely to spend most of their time and exercise their abilities due to barriers in the physical environment surrounding them. Unlike results from previous studies (Lysack, Komanecky, Kabel, Cross & Neufeld, 2007) in this study ten participants reported no difficulties moving with their wheelchairs within and around their houses. Out of these, three participants had newly constructed houses by Friends of Para (FOP). In this case home environment was more of a facilitator to activities of daily living in this study.

There was however five participants who had accessibility difficulties within their home environment and these are reported to negatively affect the individuals' lives. Major barriers reported are related to spacing, surfaces and toilets affecting hygiene and socioeconomic activities such as self-initiated small business within homes as was found elsewhere in the studies (Lysack, Komanecky, Kabel, Cross & Neufeld, 2007; Cock, 2007; Seekins et al., 2011). Except for few who were lucky enough to have new houses constructed for them by a non-governmental organisation, the issues of home modification is completely individual's and his or her family which in poverty stricken areas like rural Tanzania it is almost impossible (The United Republic of Tanzania, 2010).

5.8.2 Experienced condition of environment away from home

Under this sub theme participants' experiences to the environment away from their homes were explored. Inaccessibility is reported from the village paths that connect one home to another, the main roads, public buildings such as shops and distance between home and social services which in return negatively affects socioeconomic lives of the participants. Most of the statements from participants who had wheelchairs indicated that there were difficulties in accessibility of the environment away from home as has been found in previous studies (Newman, 2010; Levins,

Redenbach & Dyck, 2004). These barriers may count for inability to access formal employment as was found in other studies (Murphy, Middleton, Quirk, Wolf & Cameron, 2011).

5.8.3 Effect of weather on accessibility

Majority of the participants reported that despite bad roads, they still manage to get out of their homes for socioeconomic reasons mostly with assistance from someone else but no mobility out of their houses that would be possible if it rains. Geographically Kilimanjaro region is mountainous with few main tarmac roads and a number of dusty roads which would be muddy and very slippery during rainy season (The United Republic of Tanzania, 1998; HEM Trust Fund, Tanzania, 2011). Tanzania have two rainy seasons with the heaviest rains been continuous from March to May and lighter ones (United States Agency for International Development, 2011) which implies that out of the 12 months of the year, there are about four to five months whereby even a fully functional paraplegic cannot get out of his house and this will inevitably have great psychological, social and economic impact to the individual.



CHAPTER 6

6. SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

This chapter contains summary of what is within this thesis from the point where the topic was conceived to the major findings, conclusion drawn and recommendations from the researcher point of view based on these findings.

6.2 Summary

The researcher questioned himself as to what would be the major issues of concern to the lives of persons with spinal cord injury in the rural area where he comes from. This question triggered him to conduct a qualitative study on the topic “exploration of the most valued constructs of QoL among persons living with spinal cord injury in three rural districts (Hai, Moshi rural and Rombo) of Kilimanjaro region, northern Tanzania”. This study was conducted with aim of generating a package of intrinsic needs from persons with spinal cord injury at this area which if addressed would enhance their QoL.

Appropriate ethical clearance procedures and virtues were adhered to both at the University of the Western Cape, Tanzania National Health Research Ethics Committee and in the field throughout. The sample was purposefully diversified in cooperating 10 male, five female, age range 10-66 years, 4 pathological causes and 11 traumatic cause of the injury. Data was collected from the homes of the participants using semi structured interviews and observation of the setting scenario. Transcription and verbatim translation were done before content analysis from which major themes and sub themes were developed for the results while preserving the original statements from the participants as much as possible.

The results of this study shows that major cause of spinal cord injury is fall from heights particularly trees and that men are more affected than women. The average age at injury time for traumatic cases was about 34 years and none of the participants had formal employment but instead all adult participants had self-initiated income generating activities within their homes.

The participants defined QoL in more than one way, conceptualizing it in terms of meeting necessary needs, having a satisfying occupation, good life free of any problem and achieving

psychosocial stability. However majority considered having the necessary needs met as the most important criteria in defining ones QoL.

Mobility and functional ability is found to be the most valued physical construct and support from the family and friends as the most valued social facilitator to QoL. Psychologically majority of the participants informed that faith in God is what gives them inner strength to move on with life. Economic solutions are achieved in very unique ways for example mobilizing family resources such as farming and livestock keeping together with small scale family business but also connecting with friends who sometimes transfer money to participants through their cellular phones.

Various barriers to QoL were identified in all domains of life the major ones being presence of associated health conditions and complications which adds to the complexity of their already compromised physical condition compounded by inaccessible health services. Negative community attitudes are found to cause anger and poor self-esteem to majority of the participants. Lack of empowerment and theft especially of the livestock and shop items from the participants' self-initiated projects are reported as one of major economic barriers. Inaccessible physical environment especially away from home is another barrier whose consequences are even more extensive as it negatively affects social and economic life and one may not exclude its psychological impact. During rainy season these environments are declared completely inaccessible even with support from someone else.

6.3 Conclusion

QoL is as extensive as it is complex phenomena to deal with at any given time and setting. Although one may not answer all questions related to this phenomenon, this study to its level has come up with the following conclusions on the valued constructs of QoL by persons with spinal cord injury particularly the rural inhabitants of Tanzania: The majority of the participants depend on close family and friends for survival with no reliable social support from elsewhere. Positive attitudes towards life are a result of strong faith to God. Most of the barriers to QoL are extrinsic (social and physical environment) and that there is willingness and continuous strive to make life possible by majority of the participants. However due to such barriers most of the participants indicated dissatisfaction in various areas of their lives. Dissatisfaction is associated with the absent or partially provided social support, unavailability and or affordability of health services,

unavailability of mobility aids and their accessories, insecurity particularly of properties, inaccessible environment and poor infrastructure. One can conclude that persons with SCI in rural Tanzania are not satisfied with their current life which is one of the major indicators of poor QoL. This is even truer based on the responses given when participants were responding to the question on their QoL as most did not indicate having a desired quality life.

6.4 Recommendations

- The major causes of traumatic spinal cord injury in this study are found to be falling from heights particularly trees which shows a link between socioeconomic activities and the cause. Preventive measures should prioritize on this prominent cause which means one should target safety as far as being on heights is concerned including avoiding climbing on trees as much as possible. Alternative means for provision of animal feed and fuel (firewood) which is currently obtained by climbing up the trees and cutting branches should be thought of.
- Family is found to be the basic foundation of psychological stability and socioeconomic solutions to person with spinal cord injury. With this in mind, it is necessary that the relationship between the spinally injured person, family and friends is maintained from very early days of injury and sustained thereafter. 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 family as a whole.
- In African context and particularly Tanzania rural where “*undugu*” culture (brotherhood) is very strong as seen in festivities and interments all biologically connected and other community members (extended family) are referred to as one unit and so the re integration program can involve as many members as possible. Rehabilitation personnel may have to sit with the client to find out the best ways of connecting the relatives around persons with spinal cord injury and create a sustainable family based rehabilitation.
- All parents who had young children in this study 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 spinal cord injury in catering for

their young children for QoL to be achieved. The Ministry of Social Welfare has to have a plan to the disadvantaged children and such plan should be made known to the beneficiaries.

- Inaccessible roads proved to be major barriers to many socioeconomic activities to all participants. This needs a politically sound leadership; it is the responsibility of the local, main government and legislative bodies to see to it that roads are constructed and public buildings accessible. For example in the past there was communal works in rural communities known as “*kazi za utawala*” in which the community members would work on the infrastructures like roads and water sources once a week but this does no longer exist, as reported by 60 years old well educated participant. However, rehabilitation service providers are to facilitate the current leisure activities in which persons with spinal cord injury gets visited by friends in their homes.
- All participants were communicated to by using cellular phones mostly personal and few owned by a relative or friend. They also reported that their friends in town occasionally transfers money to them using cellular phones. This fast growing means of communication in rural Tanzania (Sife, Kiondo & Lyimo-Macha, 2010) can be used by rehabilitation service providers in rendering services such as counseling and advice on issues which do not require physical meetings (Dorstyn, Mathias & Denson, 2011). However, use of phones should not be a substitute to social meetings which are of so much value to persons with disabilities in these areas. Major national issues on disability will efficiently be communicated through radio which has been afforded by majority of the participants in this study and so rehabilitation information at national level would more effectively communicated through this media.
- Wheelchair is clearly identified as the foremost important necessity by all participants. However majority of participants had broken or inappropriate wheelchairs to WHO standards (definition of appropriate wheelchair) and one did not have one. These findings calls for effort to make sure that all persons with spinal cord injury are enabled to obtain an appropriate wheelchair as one of the basic necessities that none can do without for enhancement of QoL.
- It is clear in the literature and in the findings from this study that spirituality is one part of life which is valued by persons with spinal cord injury in this setting reported as psychological facilitator. It is important that rehabilitation helps persons with spinal cord injury to pursue their faith and spiritual practices. However a basic knowledge on spirituality by rehabilitation

personnel should be encouraged during the training for a mutual understanding between the service provider and the client.

- The anger reported by most participants is worth of attention as is described as having potential to put peace and health mind in jeopardy and creates grudge. Johnstone & Yoon (2009) found that forgiveness is important for health mind and likely to enhance QoL. This would most likely reduce chances for one to get angry hence promoting healthy mind so anger management (Mehta et al., 2011) should be included in rehabilitation of persons with spinal cord injury.
- Bearing in mind that this study is qualitative with a sample of fifteen participants only and from the fact that the participants were purposefully selected, these results may or may not represent the condition of lives of most persons with spinal cord injury in this setting and this call for a study with larger sample. Eleven participants had concerns on the issue of toilet as most had toilets which were only accessible by non-wheelchair users.
- Most barriers to QoL in this study are environment related (social and physical environment). A comprehensive rehabilitation should identify and address these environmental barrier best methods being educating the community about disabilities and spinal cord in particular. It would be more fruitful to include issues pertaining disability in the primary and tertiary school syllabuses as children are more receptive and responsive. Children either own or from the neighborhoods were found to be the closest support provider to majority of participants in this study.

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APPENDICES

Appendix A: Image of vertebral column indicating levels of injury

Complete injury at this level

C1 to C8 leads to

Tetraplegia

Complete injury at this level

T1 to S5 leads to

Paraplegia

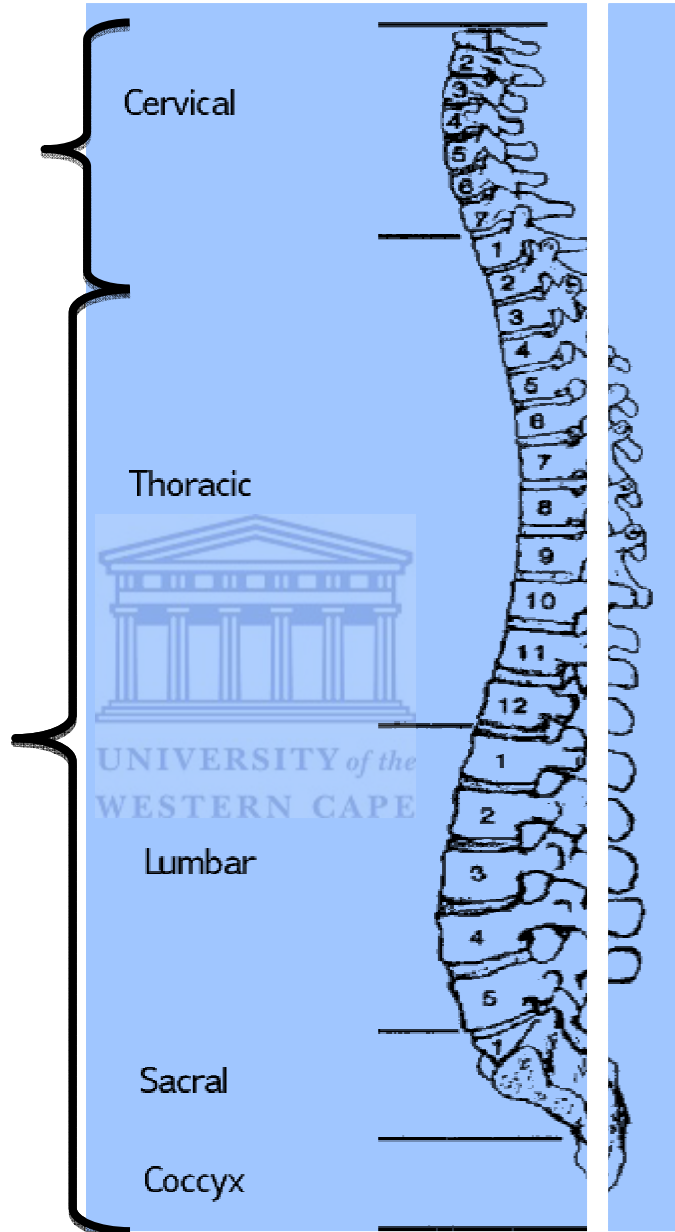


Image indicating vertebral column and two different levels of functional disability that may result following injury. **Source:** Quadriplegic, Paraplegic & Caregiver Resources (2009). Spinal Cord & Column Information. Retrieved 9th October 2011 from <http://www.sci-info-pages.com/general.html>

Appendix B

AN INTERVIEW GUIDE FOR THE STUDY

Research Title: *Exploration of the most valued constructs of Quality of life among persons living with spinal cord injury in Tanzania rural area*

Demographic information:

Name:..... **Age**
(years).....**Sex**.....

Residential Address**Family**.....**Time**
since injury.....

Cause of the injury (disability).....



Question 1: Please tell me of your understanding of quality of life.

Probes:

What would you say about your own quality of life?

How does your current life compare with that of before the injury?

Question 2: what are the things within your body that are most important for your current life?

Probes:

How do you current describe your physical being?

How do you perceive your body?

How would you describe your level of being active, involvement in exercises and activities of daily living?

Question 3: How does your relationship with the surrounding community affect your life?

Probes:

After the injury how would you describe the relationship between you and your family?

Please tell me about your friends

Explain to me of the way you manage life financially

How is your recreational life?

Please give me an overview of your sexual life

How is your ability to provide for yourself and others

Tell me of the community's reaction and beliefs about your condition and how does that affect your life?

Question 4: Tell me how do you feel about and react to things happening in your life nowadays as compared to that before the injury.

Probes:

How would you describe your state of happiness in the past, recent and today?

Tell me of your spiritual life and how has that affected you

How secure do you feel?

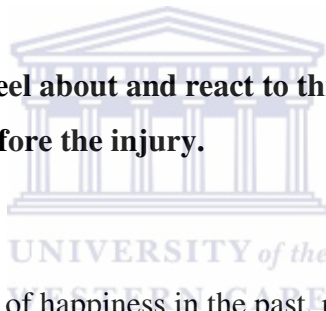
Question 5: What would you say about the inside and outside of your house as well as the state of the environment where you have been or you would like to go?

Probes:

What can you say about the environment you live in?

Tell me about the roads and pathways

How can you explain the possibilities to move within your environment and away from home?



Question 6: What would you say are the things that enable you to successfully engage in full life?

Probes:

What about availability of assistive devices?

Where would you say you get most of the important support that you need?


How do you describe availability and accessibility of health services?

Talking of getting necessary information; how is it with you?

Question 7: Please tell me of other things which matters to your life which were not included in our discussion.

NECESSARY INFORMATION ABOUT THE ENVIRONMENT:

.....
.....
.....



The logo of the University of the Western Cape, featuring a classical building with columns and a pediment, with the text "UNIVERSITY of the WESTERN CAPE" below it.

BEHAVIOURS AND NECESSARY EVENTS WHICH TAKING PLACE DURING THE INTERVIEW:

.....
.....
.....

Appendix C.

MWONGOZO WA MAHOJIANO KATIKA UTAFITI HUU.

Mada ya Utafiti:

Uchunguzi juu ya mambo yanayopewa kipaumbele katika kuboresha maisha ya watu walioumia uti wa mgomgo waishio katia eneo la vijijini - Tanzania

WASIFU WA MSHIRIKI:

Jina:..... Umri

(miaka).....Jinsia.....

Anwani ya makazi.....Familia.....Muda tangu kuumia.....

Kilichosababisha kuumia (ulemavu).....



MWONGOZO WA MAHOJIANO KATIKA UTAFITI HUU.

Swali la 1: Tafadhali nieleze unachofahamu kuhusu ubora wa maisha.

Maswali ya udodosaji:

Unaweza kueleza nini kuhusu ubora wa maisha yako?

Una mtazamo gani kuhusu maisha yako ya sasa ukiyalinganisha na yale kabla hujaumia?

Swali la 2: Ni vitu gani mwilini mwako ambavyo unavichukulia kuwa muhimu zaidi kwa maisha yako ya sasa?

Maswali ya udodosaji:

Unazungumziaje hali yako ya sasa ya mwili wako?

Una mtazamo gani juu ya mwili wako?

Unazungumziaje kiwango chako cha ushiriki katika mazoezi ya mwili na shughuli za kila siku?

Swali la 3: Je, uhusiano wako na jamii inayokuzunguka una athari gani katika maisha yako?

Maswali ya udodosaji:

Uhusiano wako na familia yako ukoje baada ya kuumia?

Niambie pia kuhusu rafiki zako

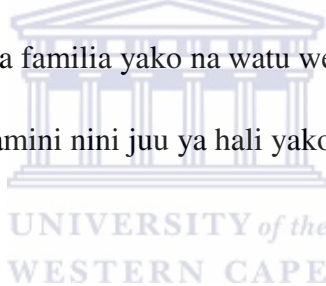
Nieleze unawezaje kuyamudu maisha kifedha

Vipi muda wako wa kujiburudisha?

Ninaomba unieleze kwa ufupi kuhusu maisha yako ya kujamiiana

Uwezo wako wa kukidhi mahitaji ya familia yako na watu wengine ukoje?

Nieleze jamii imechukuliaje na inaamini nini juu ya hali yako, na hali hii inakuathirije wewe



Swali la 4: Nieleze unavyojisikia na unavyochukulia mambo yanayotokea katika maisha yako ya sasa ukilinganisha na yale ya kabla ya kuumia.

Maswali ya udodosaji:

Unaelezeaje hali yako ya kufurahi hapo zamani, siku za hivi karibuni na sasa?

Nieleze juu ya maisha yako ya imani na jinsi yalivyoathiriwa

Unajiskiaje kiusalama?

Swali la 5: Unazungumziaje hali ya ndani ya nyumba, mazingira yanayokuzunguka, na sehemu ambazo umewahi kwenda au ungependa kwenda?

Maswali ya udodosaji:

Unayazungumziaje mazingira unayoishi?

Unazungumziaje barabara na njia?

Unaelezeaje uwezo wako kutoka sehemu moja hadi nyingine nyumbani kwako na unapokuwa mbali na nyumbani?

Swali la 6: Ni vitu gani ambavyo unaweza kusema vinakuwezesha kushiriki katika maisha kikamilifu?

Maswali ya udodosaji:

Vipi kuhusu upatikanaji wa vifaa vya kukusaidia?

Unaweza kusema ni wapi unapopata msaada muhimu unaohitaji?

Unazungumziaje uwepo na upatikanaji wa huduma za afya?

Tukizungumzia upatikanaji wa taarifa muhimu; Hii inakuwaje kwa upande wako?

Swali la 7: Tafadhali nieleze kuhusu mambo ambayo ni muhimu katika maisha yako, ambayo hatukuyataja katika mazungumzo haya.

TAARIFA MUHIMU KUHUSIANA NA MAZINGIRA:

.....

TABIA NA MAMBO MUHIMU YALIYOONEKANA KATIKA MAZINGIRA WAKATI WA UCHUNGUZI:

.....

Appendix D

INFORMATION SHEET

Project Title: EXPLORATION OF THE MOST VALUED CONSTRUCTS OF QUALITY OF LIFE AMONG PERSONS LIVING WITH SPINAL CORD INJURY IN TANZANIA.

What is current study about?

This is a research project being conducted by Haleluya I. Moshi, a student at the University of the Western Cape. We are inviting you to participate in this research project because you have sustained a spinal cord injury and living in the rural area. The purpose of this research project is to find out what are the most important things in the life of a person with spinal cord injury which can be used in planning for a better rehabilitation.

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

You will be asked to show that you agree to participate by signing the form that I will give you. Then you will give me a day that suits you so that I can come to spend a day at your home and ask you questions about your life. In case I find out that there is some information that I still want to know I will request you to give me another appointment to come back again, this time for a shorter period. Basically I will ask you about the most important things which you consider most important for your body, your state of feeling good about yourself, your association with people around you and things that hinder or supports what you want to achieve in life.

Would my participation in the current study be kept confidential?

We will do our best to keep your personal information confidential. To help protect your confidentiality, we will not mention your name to anyone. The recorded tapes will be kept out of the reach of other people and eventually destroyed at the end of the study. The computer that will be used to write the information that you give us will have a secret code so that only the researcher will be able to access your information. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

What are the risks of this research?

There may be some risks from participating in this research study. When you tell of your life something may hurt you by giving you a bad memory of the past. Other questions may be too personal and you may feel uncomfortable answering them. This may as well hurt you. During the process things like catheters or bowel movement may happen and interrupt the proceedings. If any of this happens we will have to find out how to handle the situation to the best of our ability

What are the benefits of this research?

This research is not designed to help you personally, but the results will help the investigator learn more about the most important things for the life of persons with spinal cord injury in the rural area. These could be incorporated in the rehabilitation program whenever possible. We hope that, in the future, other people might benefit from the current study through improved understanding of necessary components of quality of life. This will provide better rehabilitation services to persons with spinal cord injury in rural areas. We also expect that the society will come to the realization of the things which matters most to persons with spinal cord injury. Thus know better way of living with such persons in a way that enables them to be respected and involved so that they can be as productive as possible.

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 the current study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

Is any assistance available if I am negatively affected by participating in the current study?

In case you are negatively affected in the process to an extent that we think you need help such as counselling. We will arrange for a counselling session with the counsellor that you know or find one for you.

Audio taping/Digital Recordings

This research project involves making audiotapes of our discussions. This is necessary so that after the interview with you, we can write all that you told us and rearrange the ideas. It will be translated into English so that it can be understood clearly by readers who do not understand Kiswahili. This written information will be submitted to the University of the Western Cape and people who want to read about this study will have access to it only after it has been proved to be of maximum confidentiality. As for the tapes, these will be destroyed soon after notes were recorded on paper.

What if I have questions?

This research is being conducted by Haleluya I. Moshi at the University of the Western Cape. If you have any questions about the research study itself, please contact

Haleluya I. Moshi at Kilimanjaro Christian Medical Centre, P.O.Box 3010 Moshi, Tanzania.
Telephone number: +255 755 029640. E-mail: luluwayesu@gmail.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:

Head of Department: Professor J. Phillips

Dean of the Faculty of Community and Health Sciences: Professor R. Mpofu

University of the Western Cape

Private Bag X17

Bellville 7535

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

Appendix E

FOMU YA MAELEZO

Mada ya utafiti: UCHUNGUZI JUU YA MAMBO YANAYOPEWA KIPAUMBELE KATIKA KUBORESHA MAISHA YA WATU WALIOUMIA UTI WA MGOMGO WAISHIO KATIKA ENEO LA VIJINI (WILAYA ZA MOSHI VIJINI, ROMBO NA HAI) MKOANI KILIMAJARO – TANZANIA

Je utafiti huu unahusu nini?

Huu ni utafiti unaofanywa na Haleluya I. Moshi, mwanafunzi wa uzamili katika chuo kikuu cha Western Cape. Tunakuomba ushiriki katika uchunguzi huu sababu wewe ni mmoja kati ya watu walioumia uti wa mgongo na wanaoishi vijini. Lengo la utafiti huu ni kuchunguza ni nini haswa kinapaswa kupewa kipaumbele kuhakikisha huduma kwa watu walioumia uti wa mgongo zinaboreshwa na kukidhi mahitaji yao kwa kiwango cha kuridhisha.

Nitaulizwa maswali gani endapo nitakubali kushiriki?

Kwanza utaombwa kusaini fomu za kuthibitisha ukubali wako katika kushiriki kasha tutakuomba utupe miadi ya siku ambayo utakuwa na muda wa siku nzima ambayo mtafiti atakuwa na wewe akiuliza maswali juu ya maisha yako katika hali ya ulemavu na kuangalia baadhi ya mambo yanayojitokeza katika maisha yako ya siku nzima. Ikiwa mtafiti atahitaji baadhi ya taarifa baada ya kuondoka utaombwa kupanga tarehe nyingine ambayo atafika kukuuliza japo kwa muda mfupi. Kimsingi maswali yote yatalenga katika kutambua ni mambo gani ambayo unaona ni muhimu sana ili maisha yako yawe bora.

Je, ushiriki wangu katika utafiti huu utatunzwa kwa siri?

Tutafanya kila liwezekanalo kutunza taarifa zako kwa siri. Ili kusaidia kutunza usiri wa taarifa zako mikanda ya sauti na picha zote zilizopigwa wakati wa uchunguzi huu vitafichwa mahali ambapo mtu mwingine hawezi kuviona. Pia baada ya kutumia mikanda na picha hizi zitaharibiwa na hatutataja jina au majina ya mshiriki yeyote katika kuandika, kurepoti au kuandika makala yoyote kutokana na matokeo ya utafiti huu.

Kulingana na makala ya kisheria na/ au viwango vya weledi, tutatoa taarifa kwa watu husika na/ au mamlaka kuhusu taarifa zozote zitakazotufikia kutokana na utafiti huu.

Madhara ya kutokana na kushiriki katika utafiti huu ni nini?

Hakuna madhara yanayoweza kutokea kutokana na kushiriki katika utafiti huu. Hata hivyo katika mahojiano ya jinsi hii, unaweza ukakumbuka mambo ambayo yatakuletea majonzi au hali ya huzuni na ifikiapo hali kama hiyo kwa pamoja tutatafuta njia mbadala au muafaka ili kuendelea na utafiti.

Je, nini faida za utafiti huu?

Utafiti huu uko kwa namna ambayo matokeo yake ni kusaidika kwa jamii ya watu walioumia uti wa mgongo kwa njia ya kuwaelimisha zaidi wale wanaowahudumia juu ya mambo muhimu ya kuzingatia wakati wa kutoa huduma hii ili kuboresha maisha ya walengwa. Tunategemea pia matokeo ya uchunguzi huu, jamii itatambua na kuyazingatia mahitaji muhimu ya watu walioumia uti wa mgongo. Pia matokeo ya utafiti huu yatamwezesha mtafiti kujifunza zaidi jinsi ya kuhudumia watu walioumia uti wa mgongo.

Je, ninaweza kushiriki katika utafiti huu na nikaamua kuacha muda wowote?

Ushiriki wako katika utafiti huu ni wa hiari kwa asilimia zote. Unaweza kuamua kutoshiriki kabisa. Kama utaamua kushiriki katika utafiti huu, unaweza pia kuamua kuacha wakati wowote. Kama utaamua kutoshiriki katika utafiti huu au kama utaacha kuendelea kushiriki kwenye utafiti hautapata adhabu yoyote au kupoteza maslahi yako yoyote yanayokuhusu.

Matumizi ya vinaso sauti na picha :

Utafiti huu unahusisha matumizi ya vinaso sauti (kurekodi mazungumzo). Hii ni muhimu ili baada ya kuzungumza na wewe tuweze kusikiliza na kuandika yale ambayo tumezungumza kwa lengo la kuyapa tafsiri kwa lugha ya kingereza ili taarifa ya uchunguzi huu iweze kueleweka kwa wakufunzi na watu wengine ambao si wazungumzaji wa lugha ya Kiswahili. Taarifa ya uchunguzi huu itakabidhiwa kwenye chuo cha Western Cape na kila atakayetaka kusoisoma ataruhusiwa baada ya kuhakikishwa na chuo kwamba siri zote za washiriki zimefichika kwa

kiwango cha juu kabisa. Mikanda ya vinasau itaharibiwa mara baada ta uchunguzi kumalizika.

Inakuwaje kama nina maswali?

Utafiti huu unafanywa na **Haleluya I. Moshi** mwanafunzi wa uzamili wa mahiri wa Mazoezi katika Chuo Kikuu cha Western Cape. Kama una swali lolote kuhusu utafiti wenyewe, tafadhali wasiliana na:-

Bw. Haleluya I. Moshi.

Kilimanjaro Christian Medical Centre (KCMC)

S. L. P. 3010,

Moshi - Kilimanjaro-Tanzania.

Simu ya mkononi +255755029640

B-pepe luluwayesu@gmail.com

Ikiwa una maswali yoyote kuhusiana na utafiti huu na haki zako kwenye ushiriki katika utafiti huu au kama unataka kuripoti tatizo lolote ulilokumbana nalo kkuhusiana na utafiti, tafadhali wasiliana na:



Mkuu wa Idara: Prof. J Phillips, Barua pepe : jphillips@uwc.ac.za.

Namba ya simu: 021 9592542

Mkuu wa Kitivo cha Sayansi za Afya na Jamii: Prof. R. Mpofu, Barua pepe : rmpofu@uwc.ac.za. Namba ya simu: 021 9592631

Chuo Kikuu cha Western Cape

Private Bag X17

Bellville 7535.

Utafiti huu umeidhinishwa na Kamati za Seneti, Kamati ya Utafiti na Kamati ya Maadili, za Chuo Kikuu cha Western Cape.



Appendix F

CONSENT FORM (ADULT)

Title of Research Project: Exploration of the most valued constructs of quality of life among persons living with spinal cord injury in Tazania rural area.

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant’s name..... Witness name.....

Participant’s signature..... Witness’s signature.....

Date.....



Should you have any questions regarding current study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator’s Name: Prof. Anthea Rhoda

Student’s name: Haleluya I. Moshi

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: (021)959-

Appendix G

FOMU YA UKUBALI (MTU MZIMA)

Mada ya Utafiti:

Uchunguzi juu ya mambo yanayopewa kipaumbele katika kuboresha maisha ya watu walioumia uti wa mgomgo waishio katia eneo la vijijini - Tanzania

Nimeelezwa juu ya utafiti huu kwa lugha ninayoielewa na kwa hiari yangu mwenyewe ninakubali kushiriki. Maswali yangu kuhusu utafiti huu yamejibiwa. Ninatambua kwamba taarifa zozote zinazonihusu mimi zitatumizwa kwa siri na kwamba ninaweza kuacha kuendelea kushiriki bila kulazimika kutoa sababu yoyote na haitanithiri mimi kwa namna yoyote.

Tafadhali andika “Ndiyo” katika sentensi ya kwanza (kuikubali) au “Hapana” katika sentensi ya pili (kukataa) matumizi ya vifaa vilivyotajwa katika utafiti huu.

.....Nakubali kupigwa picha na kunaswa sauti wakati wakati wa utafiti huu

.....Sikubali kupigwa picha na kunaswa sauti wakati wakati wa utafiti huu

Jina la Mshiriki:.....

Sahihi ya mshiriki:.....

Jina la shahidi.....Sahihi ya shahidi.....

Tarehe.....

Ikiwa una maswali yoyote juu ya utafiti huu au haki yako ya ushiriki katika utafiti huu, au kama unataka kuripoti tatizo lolote ulilokumbana nalo kuhusiana na utafiti huu, tafadhali wasiliana na mratibu utafiti.

Jina la mratibu wa utafiti: Prof. Anthea Rhoda, Barua pepe: Anthrhoda@uwc.ac.za, Namba ya simu: 021 7757748

Jina la mwanafunzi mtamtafiti: Haleluya I. Moshi, Barua pepe: 3074028@uwc.ac.za, Namba ya simu +255755029640

Chuo kikuu cha Western Cape

Private Bag X17

Bellville 7535

Simu ya mezani: (021) 059-2542



Appendix H

CONSENT FORM (PARENT OR GUARDIAN OF THE CHILD)

Title of Research Project: Exploration of the most valued constructs of quality of life among persons living with spinal cord injury in Tazania rural area.

The study has been described to me in language that I understand and I freely and voluntarily allow my child to participate. My questions about the study have been answered. I understand that my child’s identity will not be disclosed and that my child may withdraw from the study without giving a reason at any time and this will not negatively affect me or my child in any way.

Please write “yes” before the first sentence to accept use of cameras and voice recorder or “No” at the beginning of the second sentence to refuse use of such tools in this interview.

.....I agree to be photographed and voice-recorded

.....I disagree to be photographed and voice-recorded.

Parent’s name..... Child’s name.....

Parent’s signature.....

Witness’s Name..... Witness signature.....

Date.....

Should you have any questions regarding current study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator’s Name: Prof. Anthea Rhoda

Student’s name: Haleluya I. Moshi

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: (021)959-

Appendix I

FOMU YA UKUBALI (MZAZI AU MLEZI WA MTOTO)

Mada ya Utafiti:

Uchunguzi juu ya mambo yanayopewa kipaumbele katika kuboresha maisha ya watu walioumia uti wa mgomgo waishio katia eneo la vijijini - Tanzania

Nimeelezwa juu ya utafiti huu kwa lugha ninayoielewa na kwa hiari yangu mwenyewe ninamruhusu mtoto wangu kushiriki. Maswali yangu kuhusu utafiti huu yamejibiwa. Ninatambua kwamba taarifa zozote zinazomhusu mtoto wangu zitatumizwa kwa siri na kwamba mtoto wangu anaweza kuacha kuendelea kushiriki bila kulazimika kutoa sababu yoyote na haitanithiri mtoto wangu kwa namna yoyote.

Tafadhali andika “Ndiyo” katika sentensi ya kwanza (kuikubali) au “Hapana” katika sentensi ya pili (kukataa) matumizi ya vifaa vilivyotajwa katika utafiti huu.

.....Nakubali mtoto wangu kupigwa picha na kunaswa sauti wakati wakati wa utafiti huu

.....Sikubali mtoto wangu kupigwa picha na kunaswa sauti wakati wakati wa utafiti huu

Jina la Mzazi/mlezi:.....Jina la mtoto.....

Sahihi ya Mzazi/mlezi:.....

Jina la shahidi.....Sahihi ya shahidi.....

Tarehe.....

Ikiwa una maswali yoyote juu ya utafiti huu au haki yako ya ushiriki katika utafiti huu, au kama unataka kuripoti tatizo lolote ulilokumbana nalo kuhusiana na utafiti huu, tafadhali wasiliana na mratibu utafiti.

Jina la mratibu wa utafiti: Prof. Anthea Rhoda, Barua pepe: Anthrhoda@uwc.ac.za, Namba ya simu: 021 7757748

Jina la mwanafunzi mtamtafiti: Halleluya I. Moshi, Barua pepe: 3074028@uwc.ac.za, Namba ya simu +255755029640

Chuo kikuu cha Western Cape

Private Bag X17

Bellville 7535

Simu ya mezani: (021) 059-2542



APPENDIX J:

Ethical clearance letter from National Institute for Medical Research Tanzania



THE UNITED REPUBLIC OF
TANZANIA



National Institute for Medical Research
P.O. Box 9653
Dar es Salaam
Tel: 255 22 2121400/390
Fax: 255 22 2121380/2121360
E-mail: headquarters@nimr.or.tz
NIMR/HQ/R.8a/Vol. IX/1076

Ministry of Health and Social Welfare
P.O. Box 9083
Dar es Salaam
Tel: 255 22 2120262-7
Fax: 255 22 2110986

24th January 2011

Mr Haleluya I Moshi
KCMC Physiotherapy Department
P O Box 3010, MOSHI
KILIMANJARO

CLEARANCE CERTIFICATE FOR CONDUCTING MEDICAL RESEARCH IN TANZANIA

This is to certify that the research entitled: Exploration of the most valued constructs of quality of life, among persons with spinal cord injury in one of the rural areas of Tanzania, (Moshi I H *et al*), has been granted ethics clearance to be conducted in Tanzania.

The Principal Investigator of the study must ensure that the following conditions are fulfilled:

1. Progress report is submitted to the Ministry of Health and the National Institute for Medical Research, Regional and District Medical Officers after every six months.
2. Permission to publish the results is obtained from National Institute for Medical Research.
3. Copies of final publications are made available to the Ministry of Health & Social Welfare and the National Institute for Medical Research.
4. 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. NIMR Act No. 23 of 1979, PART III Section 10(2).
5. Approval is for one year: 24th January 2011 to 23rd January 2012.

Name: Dr Mwelecele N Malecela

Signature

CHAIRPERSON
MEDICAL RESEARCH
COORDINATING COMMITTEE

Name: Dr Deo M Mtasiwa

Signature

CHIEF MEDICAL OFFICER
MINISTRY OF HEALTH, SOCIAL
WELFARE

CC: RMO
DMO

APPENDIX K:

Ethical clearance letter from the University of the Western Cape



UNIVERSITY of the
WESTERN CAPE

**OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT**

21 October 2011

To Whom It May Concern

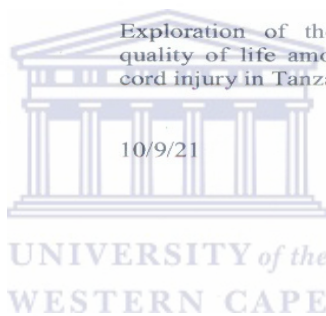
I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and ethics of the following research project by:
Mr H Moshi (Physiotherapy)

Research Project:

Exploration of the most valued constructs of quality of life among persons living with spinal cord injury in Tanzania rural area.

Registration no:

10/9/21



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

Private Bag X17, Bellville 7535, South Africa
T: +27 21 959 2948/2949, F: +27 21 959 3170
E: pjosias@uwc.ac.za
www.uwc.ac.za

A place of quality,
a place to grow, from hope
to action through knowledge

Appendix L:

Editor's credentials

This is to certify that I undertook and completed the language editing of the research project titled:

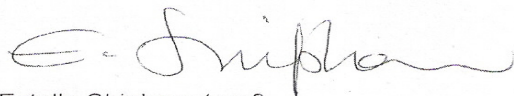
EXPLORATION OF THE MOST VALUED CONSTRUCTS OF QUALITY OF LIFE
AMONG PERSONS LIVING WITH SPINAL CORD INJURY IN A TANZANIA
RURAL AREA.

BY

HALELUYA IMANUELI MOSHI

A full thesis submitted to the Department of Physiotherapy, Faculty of Community and Health Sciences, University of the Western Cape in fulfillment of the requirement for the degree of Master of Science in Physiotherapy

UNIVERSITY *of the*
WESTERN CAPE



Estelle Shipham (prof)
10 May 2012

Tel: 012-346-3296

Fax: 086-662-5114. Cell: 083-342-5911. e-mail: estellesh@webmail.co.za

APPENDIX M: Translator's credentials



MWENGE UNIVERSITY COLLEGE OF EDUCATION
(A Constituent College of St. Augustine University of Tanzania)
DEPARTMENT OF KISWAHILI
P.O. BOX 1226, Moshi, Tanzania. E-mail: mwengeuniversity@gmail.com
Phone: +255 27 2754156 Fax: +255 27 2751317
Website: www.mwuce.org



To the respective authorities:

RE: TRANSLATION OF INTERVIEWS ON EXPLORATION OF CONSTRUCTS OF QUALITY OF LIFE AMONG PERSONS WITH SPINAL CORD INJURY AMONG PERSONS WITH SPINAL CORD INJURY IN THREE RURAL DISTRICTS (HAI, MOSHI RURAL AND ROMBO) OF KILIMANJARO REGION, NORTHERN TANZANIA.

Would you please refer to the heading above.

This is to notify you that the sample of the study mentioned above (00 interviews) has been translated from Kiswahili to English at the Kiswahili department of our university from the transcribed copies of interviews as submitted to us by Mr. Haleluya Moshi who has been authorized to carry out the above mentioned study.

For ethical and or academic purposes please consider the English copy of this interview as a true translation from the original Kiswahili which was submitted to us.

Kulwa A. Kindija
For Head of Department of Kiswahili

.....

Date: 07th February 2011

APPENDIX N:

LETTER TO THE EXAMINER(S)

To the examiner(s),

Thank you very much for examining my thesis. I have addressed the recommended comments as below:

- The whole thesis has been re-edited by a professional editor (see her credentials on page 144) as required
- Numbering in every chapter is changed to the required format and sequence
- Every pre-determined theme is introduced with the research question which was asked particularly for that theme.
- Direct quotations are reduced in every sub theme to at least three
- The first eight parts of the thesis are re arranged in the required order

TITLE PAGE: Topic is rephrased back to the original one with the deleting of the specified rural districts. The word “partial” is deleted in the last sentence as this is a full thesis

PAGE ii: Aim and objectives are added to the Abstract

PAGE 5: The situation in Tanzania as far as quality of life to persons with spinal cord injury in rural Tanzania is added.

PAGE 6: The objectives are rephrased the objectives as recommended by the examiner

PAGE 7: Definition of "spinal cord injury" and "quality of life" are added in the definition of terms

PAGE 27: Further description as to where the sample was taken from: Further explanations and references are given as to how the number 15 was decided upon as well as the characteristics of the participants. Added diagram to demonstrate the sampling procedure

PAGE 32-33: Further description for triangulation is given

PAGE 33: Data analysis is described further.

PAGE 36: Added to "Ethical consideration" that the collected data will be destroyed after 5 years.

PAGE 39-44: Results tables changed from portrait to landscape as advised

PAGE 93: Added in conclusion what is found to be the QoL to persons with SCI in this setting.

Regards,

Haleluya

