

**COMMUNITY EXPERIENCES OF PERSONS WITH LOWER
EXTREMITY AMPUTATION IN MALAWI.**

By

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Masters of Science in Physiotherapy in the department of
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Keywords

Lower limb Amputation, Experiences, Psychological, Social effect, Functional status, Prosthesis, Community integration, Rehabilitation, Quality of Life, cultural stigmatization



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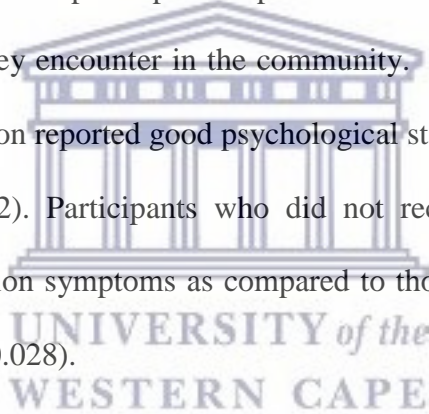
ABSTRACT

Persons with lower limb amputations (LLA) experience different challenges in the community. These challenges include the physical, psychological and social function of an individual. Little is known in Malawi on what persons with lower limb amputations go through in the communities where they live. Therefore, the study aimed at exploring and determining community experiences of persons with LLA in Malawi. The study sought to address the following objectives: 1) To determine the functional and psychological status of persons with LLA in the community; 2) To explore and describe experiences on social participation of persons with LLA in the community; 3). To explore experiences on community re-integration following LLA.

A mixed method approach was applied where quantitative and qualitative data were collected simultaneously to provide a more holistic overview of the experiences of persons with LLA at one point in time. The study setting was Queen Elizabeth Central Hospital (QECH) and Kamuzu Central Hospitals (KCH) (500 miles), located in Malawi. A sample of 180 participants was recruited to participate in the study. Three self-administered questionnaires (socio-demographic questionnaire, OPUS module of lower extremity functional status, and a Beck's depression inventory scale) and a semi-structured interview guide were used for data collection. Thematic data analysis was used to analyze qualitative data, while quantitative data was analyzed using descriptive and inferential statistics. Ethical clearance was obtained from the University of the Western Cape Biomedical Research Ethics Committee (BMREC) and College of Medicine Research Ethics Committee (COMREC). Permission to conduct the study was obtained from KCH (500 miles) and QECH. Privacy and

confidentiality was strictly observed such that data obtained was anonymous. It was kept in a secure place, and electronic data was secured using a password.

The results of the study showed that of the 180 participants, 45% (n = 81) had difficulties in executing functional activities. This was substantiated by the qualitative results which showed that many participants reported challenges in executing functional activities. Non prosthetic users presented with worse functional status compared with prosthetic users ($p = <0.001$). The results of the study showed that depression is present among 48% (n= 87) of people with lower limb amputations. These results are also supported with the qualitative findings of this study where some participants reported emotional problems as one of the experiences that they encounter in the community. Participants who received in-patient rehabilitation reported good psychological status compared to those who did not ($p = 0.002$). Participants who did not receive out-patient rehabilitation showed depression symptoms as compared to those who received out-patient rehabilitation ($p = 0.028$).



The qualitative results of the study indicated that there are barriers and facilitators to social participation and community integration. The barriers identified in this study include problems with body image, social stigma, physical and environmental challenges and the emotional challenges. The facilitators include community and family support and access to prosthetic use.

The study concludes that people with lower limb amputations experience functional and psychological challenges in the community. These challenges and other experiences like problems with body image, social stigmatization, physical and environmental challenges affect social participation and integration in the

community. Management of people with LLA requires a multidisciplinary approach, where by the phsyiotherapists, doctors, occupational therapist, psychologist/ cancellors, prostheticians and nurses should work hand in hand to improve management of people with LLA. Rehabilitation should emphasize on mobility training, and facilitation of ADLS. The government stake holders have a role in facilitating adequate fabrication of the prosthesis and decentralization of rehabilitation services. The community and family members should assist people with LLA to adjust and cope with their condition and people with LLA should also learn to adjust and adapt to their new identity. This may enhance good functional status, psychological stutus and minimize the barriers to social participation and community integration.



Declarations

I hereby declare that “Community experiences of persons with lower limb amputations in Malawi” is my own work, and that it has never been submitted or any part of it for a degree program at any univeristy. All the sources that have been used or quoted have been indicated by means of complete references.

Signature.....

Date.....

Stella Mpezeni.

Witness

Dr. Liezel Ennion.



Dedications

I dedicate this work to my family for everything that they have done to me throughout my study period. To my husband Victor, thank you so much for your endless love, financial support, encouragement and motivation throughout my study period. You have inspired me to reach greater heights. To my children, thank you for your understanding, support and encouragement. You have always been there for me. To my father and sisters, thank you for your encouragement and prayers. Lastly, I thank the almighty God for making it possible. Without his blessings I wouldn't have done it.



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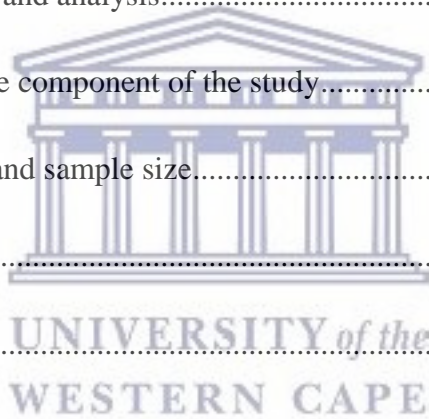
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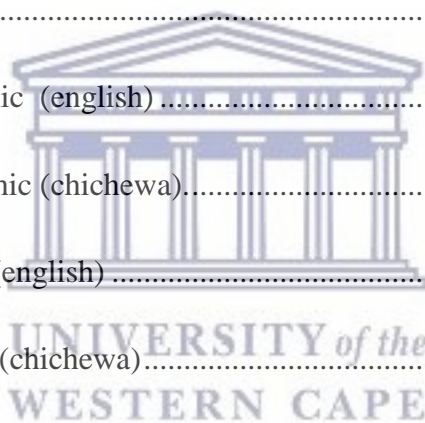
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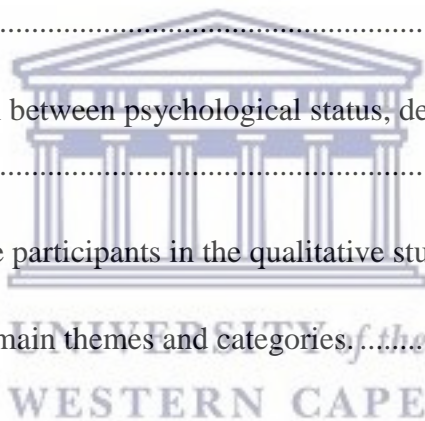
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List of Abbreviations and definitions.

LLA.....Lower limb amputation

DM..... Diabetes Mellitus

ADLS..... Activities of daily living

QOL.....Quality of life

WHO..... World health organization

QECH..... Queen Elizabeth Central hospital

KCH.....Kamuzu central hospital

UWC.....University of the Western Cape

OPUS..... Orthotics and prosthetics users' survey

LLFM.....Lower limb functional measure

ICF.....International classifications of function disability and health

COMREC.....College of medicine research ethics committee.

SPSS.....Social package for the social sciences.

BMREC..... Biomedical research ethics committee.

PVD..... Peripheral vascular diseases

N.S. O..... National statistics office



ICIDH.....international classifications of impairment, disability and handicap.

DFU..... Diabetic foot ulcer.

IQR.....Interquartile range

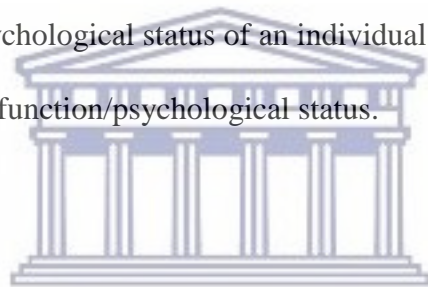
RR..... Risk ratio

COM..... College of medicine

UNCRPD.....United Nations Convention of Rights of people with Disabilities.

HRQOL.....health related quality of life.

Suboptimal function/psychological status..... Is a state characterized by disturbances in functional /psychological status of an individual. Or refers to being below standard level of function/psychological status.



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CHAPTER ONE

INTRODUCTION

1.1 Introduction and background

Amputation is considered a life changing experience and a lifesaving event that has a significant impact on an individual's everyday life (Desmond, Coffey, Ghallagher, MacLauchlan, Wegener & Keefee, 2007). Regardless of the cause, lower limb amputations (LLA) affect the physical, psychological and social function of an individual (Sjodahl, Gard & Jarnlo, 2004; De Godoy, Braile, Buzatto, Longo & Fontes, 2002). Amputation is a removal of part or the whole extremity either through surgery or trauma. When amputation is done surgically, its main aim is to save life, control pain and the disease process (Wald & Alvaro, 2004). Lower limb Amputations (LLA) are classified as major or minor. A major amputation refers to any amputation performed through or proximal to the tarso-mertatarsal joint while a minor amputation is performed distal to the tarso-mertatarsal (Unwin, 2000).

Etiological factors associated with amputation are vascular diseases, diabetes mellitus (DM), trauma, tumors, infections or congenital deformities where the limb has lost its function (Frederiks & Visagie, 2013; Wong, 2005). Motala and Ramaiya (2010) reported that 90% of amputations done worldwide are associated with DM and 70% of these are LLA. In developed countries, vascular diseases are the leading cause of amputations while in developing countries trauma is the major cause (Esquenaz, 2004). Trauma might be the

leading cause in developing countries due to the increase of cases of road traffic accidents, violence such as war which plays a great role in etiology of amputations.

Psychological and cultural stigmatizations are some of the greatest challenges associated with persons with amputations in the community. This is because people who have lost a limb are often viewed as incomplete (Ertl & Calhoun, 2012). Desmond et al. (2007) reported that there is a great variation on experiences among individuals with amputation and the experiences are influenced by a number of factors such as personal, clinical, social, physical and environmental. Gallagher and MacLachlan (2001) reported social discomfort among persons with LLA due to change of body image. Similarly, Godlwana, Nadasan and Puckree, (2008) also reported that amputation is accompanied by sense of loss and psychological stress since the body image and mobility is affected. A reduction in self-esteem, social isolation, perception of being vulnerable, problems of body image and the sense of stigmatization are some of the problems that are associated with amputation of the limb (Williams et al., 2004). In addition, amputations can also result into restrictions on leisure, employment as well as unforeseen expenses (Godlwana et al., 2008; Whyte & Carroll, 2002). This may in turn affect interpersonal relationships and sexuality (Geertzen, Vanes & Dijkstra, 2009).

On International Classifications of Function, Disability and Health (ICF) perspective, amputation of a limb changes the body structure and body function. Therefore, people with lower limb amputation have impairments of body structure as well as body function (Van Velzen, Van Bennekom, Polomski,

Sloutman, Van der Woude, & Houdijk, 2006; Pezzin, Dillighan, & Mackenzie, 2000; Burger & Marincek, 1996). Apart from the functional loss of the limb, a person with limb amputation also suffers from the consequences of the underlying cause of amputation and comorbidities or associated injuries (Jensen, Chodroff, & Dworkin, 2007). To bring back a positive impact on the body function, management of the underlying cause is very important. Provision of a prosthesis will compensate for the limb loss and function of the amputated limb. According to Jensen et al. (2007), experiences of phantom pain and phantom sensation may also bring an impact on function of people with lower limb amputation. In addition, psychological, social and sexual issues may as well affect function of an individual though in management of limb amputations, they receive less attention as compared to physical or functional issues (Desmond & MacLachlan, 2002).

People with LLA also experience problems in social participation and re-intergration into the community post discharge. Social participation refers to an extent to which an individual participate in social activities within the community (Williams et al., 2004). According to international classifications of functions disability and health (ICF), some of the social activities include participation in community gatherings, church, festivals, sports and recreation activities (WHO 2001). On the other hand, community re-intergration involves, independent living, employment, engagement in productive activities and participation in social activities (Sander, Clark & Pappudus, 2010). After amputation, one experiences change in their lifestyle, source of living is affected and the perception of how people see them in the community also changes (Burger & Marincek, 2007). Persons with amputations also experience a wide

range of activity limitations and participation restrictions. The most common activity limitations are related to self-care and mobility for lower limb amputations, and this may affect return and maintain work (Burger & Marincek, 2007; Whyte & Carroll, 2002; Schoppen et al., 2001). In addition, persons with limb amputation also meet limitations in maintaining social relationships, participating in leisure activities and be an active member of the society (Wetterhahn, Hanson & Levy, 2002).

Several factors influence participation restrictions in people with limb amputations and these include age of an individual, level of education, ability to adjust (Ephraim, Mackenzie, Wegener, Dillingham, Penzin, 2006; Whiteneck et al., 2004). According to Ephraim et al. (2006), persons with lower limb amputations also encounter community barriers to participation such as physical or structural environment.

Many studies have explored the psychological effects of limb loss, and coping and adjustment following amputations has also been well studied. However, little is known on how persons with LLA in Malawi experience (in terms of physical, psychological, and social) life after amputation back in the community.

1.2 Problem statement

Persons with LLA face many challenges in the community. These challenges include psychological such as depression and anxiety (Phelps, Williams, Raichle, Turner & Ehde, 2008), physical such as poor balance and mobility which leads to difficulties in walking long distances and standing for a long time (Frederick & Visagie, 2013), social such as poor participation in social activities (Ghallager, O'Donovan, Doyle & Desmond, 2011) and cultural stigmatization (Sjodahl et al., 2004). The challenges affect re- integration into the community after LLA, and this may in turn affect an individual's independence (Ertl & Calhoun, 2012). There is no documented prevalence and incidence of amputations in Malawi. However, a study conducted in Rwanda at Butare-teaching University, indicated a prevalence of 3.08% among people who underwent surgery (Murwanashyaka, Ssebuufu & Kyamanywa, 2013). Based on the statistics from Rwanda, a country which shares similar social economic status with Malawi, one may conclude that amputations are on increase in Malawi as well. Therefore, little is known about experiences of people with lower limb amputation in Malawian communities. Considering the importance of early rehabilitation for improved functional outcome in LLA, experiences and challenges of LLA in the community can provide valuable insight in designing and improving rehabilitation services. Hence the need for this study to explore and determine post – amputation experiences of community- dwelling persons with LLA in Malawi.

1.3 Research Question

What are the experiences of persons with lower limb amputation in the community?

1.4 Aim of the study

To explore and determine experiences of persons with lower limb amputation in the community.

1.5 Specific Objectives

1.5.1 To determine the functional status of persons with LLA in the community.

1.5.2 To determine the psychological status of persons with LLA in the community

1.5.3 To explore experiences on social participation of persons with LLA in the community.

1.5.4 To explore experiences on community re-integration following LLA



1.6 Rationale /significance of the study

Exploring patients' experiences will assist the rehabilitation personnel to understand the challenges that persons with LLA are going through in the community. This will help to improve on the delivery of services and quality of care. The results of this study might highlight some gaps in the rehabilitation process of persons with LLA. This may in turn establish the need of care continuum from hospital based to the community after discharge. The results

may also serve as a basis to inform the policy makers on the need to allocate sufficient funds for rehabilitation services in order to improve quality of life and achieve effective re-integration of persons with LLA in the community.

1.7 Outline of the thesis

This thesis has six chapters. Chapter one has given an overview to the impact of lower limb amputation to an individual and an explanation of the definition of limb amputations. The chapter has also provided a brief history of incidences and etiologies of limb amputations. It has also outlined the significance and importance of undertaking the study including the aims and objectives which have been achieved.

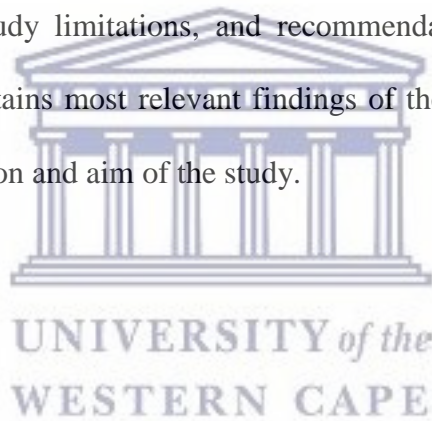
Chapter two reviews literature that is available nationally and internationally regarding lower limb amputations. This includes prevalences / incidences, the causes of lower limb amputation, and rehabilitation following lower limb amputations. The chapter also provides information on functional and psychological challenges that people with lower limb amputations encounter in the community. Experiences on community participation and integration are also reviewed.

Chapter three provides the outline of the methodologies used to execute this study. The chapter describes study setting, research approach and designs and the study population. The chapter also describes the sampling technique used and the sample size of the study. It also explains the data collection procedure and instruments of data collection used and how the data was analyzed. Trustworthiness of the data is also explained. The chapter also describes the ethical considerations adopted in the study.

Chapter four presents both quantitative and qualitative results. The quantitative results comprise of the findings on functional and psychological status following lower limb amputations. The qualitative results show the experiences on community participation and intergration following lower limb amputations.

Chapter five discusses both qualitative and quantitative findings of the study. The quantitative and qualitative findings are related and compared. The results of the study are also related to the available literature and the clinical implications they pose.

Chapter six concludes the study by providing an over view of the study, a summary of findings, the study limitations, and recommendations for future research. The conclusion contains most relevant findings of the study and how they fulfill the research question and aim of the study.



CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter will focus on experiences of people with lower limb amputations in the communities where they live. Prior to the experiences, an overview of amputations will be outlined to provide the understanding of amputations in terms of the incidences and prevalences of lower limb amputations, and etiology of limb amputations. Later on, rehabilitation of people with lower limb amputations and experiences in terms of functional / physical, psychological, social and community integration and the cultural stigmatization will be reviewed in detail.

2.2 Incidence and prevalence of lower limb amputations

Internationally, the incidence and prevalence of amputation is difficult to determine due to several reasons; i) Multiple pathological etiologies associated with amputations, ii) Various definitions of clinically significant amputations, iii) Multiple amputations performed on the same individual and on the same limb and iv) Difficulties and incompleteness of data collection in most of the studies (Ephraim, Dillingham, Sector, Pezzin & Mackenzie., 2003; Spichler et al., 2001; Unwin & the global lower limb amputation study, 1995). However, Moxey et al. (2011) reported that the Global incidence of LLA ranges from 5.6 to 31 per 100 000 people in the total population and the incidence increases in areas where there is high incidence of diabetes mellitus (DM) and it ranges from 46.1 to 9600 per 100 000 people. Furthermore, the global incidence of major LLA ranges from 3.6 – 68.4 per 100 000 people in the total population, and 5.6 -

600 per 100 000 people in areas where there is high incidence of DM (Moxey et al., 2011). Similarly, Kasiya et al. (2018) reported that the rate of amputation due to DM is 15 times higher than non DM with an approximation of 50-70% of amputations due to diabetic foot ulcer (DFU). The researchers further reported that in every 30 seconds one leg is amputated due to DFU worldwide.

In sub-Saharan Africa, there is no clear incidence of amputations. Motala and Ramaiya (2010) reported an estimate of 12.1 million people having Diabetes. Fifteen percent of these have already been diagnosed and out of those diagnosed 169, 400 had amputations due to DM complications. However, the number seem to be increasing according to a report from the international diabetes federation (2017) which indicated that there are more than 16 million people with DM in Africa and the figures are expected to rise to 41 million people by the year 2045 (Carracher, Marathe & Close, 2018). The prevalence of DM in Malawi has been estimated to be 5.6% among adults aged between 25-64 years (Msyamboza et al., 2011). There is no documented data on incidences of amputation in Malawi. However, based on statistics of prevalences of DM in sub-Saharan Africa and Malawi, one would conclude that the incidence of amputations would be on the increase due to the fact that DM is currently one of the major health problems.

The incidence of LLA can be predicted by gender, age, education level, social economic status and the presence of DM (Goldwana et al., 2008). The incidence increases with age, most persons with amputations are above 55 years of age and the average age being 51-69 years (Coletta, 2000). Apart from age, the researchers further reported that the presence of peripheral vascular diseases

(PVD) and DM also increase the risk of amputations. Men are more likely than women to undergo amputations surgery as approximately 75 % of all reported amputations are performed on men (Rotter, Sanhueza, Robles & Godoy, 2006; Colleta, 2000). This could be because more men go to work and travel everyday while women stay at home. This makes men vulnerable to traumatic amputations (work related as well as road traffic accidents). Trans-tibial amputations are the most common amputations among major LLA (Rotter et al., 2006).

2.3 Etiology

The etiology of amputations emanates from a wide range of factors. The factors generally are categorized as traumatic or non- traumatic (Wong, 2005). The traumatic factors include industrial accidents, motor traffic accidents and assaults, while non-traumatic factors are mainly due to conditions like DM, burns, PVD, infections, malignant tumors and congenital malformations (Wong, 2005). Etiological factors differ depending on the geographical areas. Thus, non traumatic causes like peripheral vascular diseases secondary to DM is the leading cause of amputation in developed countries while trauma is the most common cause of amputation in developing countries (Ephraim et al., 2003). The increase of incidences of amputations in developing countries is as a result of increased motor traffic accidents, war, violence and work related accidents like land mines. According to Walsh and Walsh (2003), the predicted increase in conflict worldwide will in turn result into increased prevalence of amputations.

In comparison, non-traumatic amputations are more common (60.2%) than traumatic, and the main cause is attributed to excessive smoking, PVD and DM (Dunbar, Hellenberg & Levvit, 2011; Tudhope, 2011). Similarly, a review study

which was conducted in South Africa by Godlwana et al. (2008) reported DM being the leading cause of LLA. In addition, other risk factors like coronary artery disease, hypertension, and complicated renal disease are also considered the main contributors for development of vascular complications, leading to amputations (Abou- Zamzam, Teruya, Killen & Ballard, 2003). Poverty has also been earmarked as the main contributing factor for development of diabetic ulcers particularly in low income countries, as it makes the hygienic measures extremely difficult to be adhered to (Boulton, Vileikyte, Ragnarson, Tennvall & Apelgrist, 2005).

2.4 Importance of early Rehabilitation

Lower limb amputation causes significant impairments in body function which result in activity limitation and participation restriction for an individual. The most commonly described impairments of body function include 1). Reduction in muscle strength and range of motion (Van velzen et al., 2006; Burger & Marincek 1996), 2) balance problems (Van velzen et al., 2006; Matjacic & Burger, 2003; Burger & Marincek, 1996, 3) change of gait pattern (Sansan, Neumann, O'Connor & Bhakta., 2009), 4) pain (Pezzin et al., 2000) and 5) skin problems (Meulenbelt, Dijkstra, Joinkmah & Geertzen., 2006). Mobility has been reported as the most common activity limitation which people with lower limb amputation encounter (Burger, Kuzelicki, Marincek., 2005; Geertzen, Bosmans, Vander Schans & Dijkstra., 2005). In addition, activities of daily living (ADLS) are also reported as a challenge after limb amputation (Kohler et al., 2009). According to De Godoy et al. (2002), areas which are reported to be mostly affected after limb amputation include physical capabilities, general state of health, social, emotional aspect and pain. Therefore, a comprehensive and

holistic rehabilitation of people with limb amputation is very important because they experience various physical and psychological problems (Wald & Alvaro., 2004). The main goals of rehabilitation management in persons with LLAs are: 1) to improve mobility and functional status (Htwe et al., 2015), and 2) to achieve optimal community re- integration (Miller, Speechley & Deathe, 2002). Similarly, recovery and rehabilitation after limb amputation involves re-integration into the family, community and work place for some people. Therefore, an individual is expected to take part in different roles, relationships and identity (Gallagher et al., 2011; Sjodahl et al., 2004).

To ensure a successful outcome, an experienced multidisciplinary rehabilitation team is very important in management of people with limb amputation (Davidson, 2002). Similarly, Siedel, Launge, Wetz and Levvit (2006) recommended an interdisciplinary management of persons with lower limb amputations to assist in prevention of the psychological disorders. However, Burger (2012) reported that although an individual with limb amputation might have completed a comprehensive rehabilitation management, will still have several impairments which will result into activity limitations and participation restrictions.

According to Zidarov, Swane and Gagnon (2009), important outcome measures in rehabilitation of people with lower limb amputations include mobility, functional ability and prosthesis. As reported by Saradjian, Thompson & Datta, (2008) a prosthesis is used to restore the body image and improve physical function as well as for cosmetic purposes. Several factors have been reported to contribute to the outcomes of prosthetic rehabilitation and these include

psychological and cognitive, medical co morbidities, the level of function before the amputation and compliance (Rommers, Vos, Groothof & Eisma, 2001; Condie, Scott & Treweek, 2006; Deathe, et al., 2009). Similarly, Htwe et al. (2015) and Wong (2005) reported a number of factors which influence the outcomes of rehabilitation. Firstly, the age of the person should be considered. Elderly persons with LLA experience lower functional levels and more restriction in activities of daily living (ADLS) when compared to younger persons. The level of amputation should also be taken into account as it also predicts successful rehabilitation. The higher the level of amputation the less functional the person will be because more energy is required for mobility (Horgan & MacLachlan, 2004). Saradjian et al. (2008) reported that men with lower limb amputation are more concerned with regaining function while women are concerned with regaining a feminine body image.

2.5 Experiences following Lower limb Amputations

Persons with amputations have different community experiences depending on their context and support structures.

2.5.1 Functional challenges

Amputation has a great impact on the functional level and quality of life (QOL) of an individual, because the standard of living and the sources of income of a person may be partially or greatly affected (Burger & Marincek, 2007). In addition, amputation greatly affects people's lives and they end up losing many physical functions (Saradjian et al., 2008). Impairment in physical function, use of the prosthesis and pain may limit activity performance and impair occupation status of a person following LLA (DudkiZelwiz, Gabrielov Zelig & Helm, 2004;

Whyte & caroll, 2002). Therefore, prosthetic mobility improves the quality of life of an individual with lower limb amputations (Pell, Donnan, Fowkes & Ruckley, 1993). This is because there is an increase in social involvement and activities of daily living (Collins, Wade, & Cochrane, 1992). Furthermore, prosthetic mobility is also essential in participation on employment as well as recreation roles (Brown, Yamanda, Smith, Zick, Kowaleski-Jone & Fan, 2009). The status of unaffected limb plays a vital role in the function of prosthetic and non- prosthetic users. Generally, the functional prognosis of people with lower limb amputation is poor if a person is unable to stand on the unaffected limb without support (Frederiks & Visagie, 2013; Zidarov et al.,2009). Therefore, lack of confidence and poor balance may predict whether a person will be independent in mobility as well as in ADLS performance (Miller et al., 2002). The main functional challenges of persons with LLA with regard to mobility are lifting objects from the floor and carrying them (Miller et al., 2002), walking outside in bad weather like rain and heavy wind, doing shopping and accessing public services (Frederiks & Visagie, 2013). Furthermore, persons with LLA experience difficulties in walking distances like one kilometer or more (87.7%), and standing for 30 minutes (81.5%) (Frederiks & Visagie, 2013). Co-morbidities such as DM, vascular diseases, and cognitive impairment may reduce functional independence of a person with LLA (Zidarov et al., 2009; Schoppen et al., 2003; Miller et al., 2002). In addition, factors like level of amputation, cognition, age, the level of function before the amputation, personal coping styles, level of social support, environmental factors and availability of

financial resources significantly contribute to the functional outcome of an individual following limb amputation (Asano, Rushton, Miller & Deathe, 2008). The functional status of people with higher level amputation and the elderly is worse than the functional level of people with lower level amputation and the young (Geertzen, Martina, & Rietman, 2001). Similarly, Schoppen et al. (2003) reported that elderly people with lower limb amputations present with low levels of function a year after the amputation.

2.5.2 Psychological challenges

Psychological challenges such as depression and anxiety are the most common challenges persons with LLA face after surgery (Phelps et al., 2008). High incidences of psychiatric symptoms and depression are also reported in persons with lower limb amputations (Hawamdeh, Othman & Ibrahim, 2008). Therefore, early identification and management of psychological problems assist to prevent long term disabilities in people with limb amputations (Horgan & MacLachlan, 2004). Psychological problems may arise due to alterations of body image and poor acceptance of the amputation (Desmond & MacLachlan, 2006). In addition, pain and poor acceptance of the prosthesis have also been reported as the precipitating factors to development of psychological problems (Siedel et al., 2006). As reported by Cansever, Uzun, Yildiz, Ates and Atesalp (2003), psychological function varies according to an individual, i.e. many people function well while some experience significant problems. The psychological reactions are manifested at different stages post- amputations: at an early stage, one may present with anger, fear, disbelief, rage, grief and despair and at a later stage may present with depression and anxiety (Srivastava, Saldanha, Chaudhury, Ryali & Basannar, 2010).

The psychological factors in lower limb amputations depend on several factors such as age, gender, type of amputation, level of amputation, mechanism of coping with stress, the value that one places on the amputated limb and expectations from rehabilitation (Canserver et al., 2003). Increased social isolation and perceived social support are also factors which increase depression rate among persons with lower limb amputations (Rybarcyck, Nyenhuis, Nicholas, Cash & Kaiser, 1995). According to Horgan and MacLachlan (2004), factors which are associated with positive adjustment to lower limb amputations include increased social support, greater satisfaction with the prosthesis, increased period of time when the amputation was done, active coping attempts, optimistic personality and low level of phantom pain and stump pain. Similarly, Hawamdeh et al. (2008) indicated that the social demographic factors are very essential in psychological adjustment to limb loss. Furthermore, the researchers reported that with time, a person with an amputation discovers how best he/ she can adjust and cope with the amputation (Horgan & MacLachlan, 2004).

2.5.3 Depression

Depression is a late manifestation of psychological problems in people with limb amputation (Strivastas et al., 2010). High levels of depression are experienced within one to two years' post-surgery; afterwards the rates decline (Horgan & MacLachlan, 2004). According to Singh et al. (2009), depression symptoms resolve during in-patient rehabilitation period and rise again after discharge. Depression symptoms are present among 60-69% of people with LLA at 18 months' post surgery (Gallagher et al., 2011; Ide, 2010). However, some studies indicated a prevalence of depression within the range of 21%-35% of people

with limb amputations (Williams et al., 2004; Darnall et al., 2005; Siedel et al., 2006). Furthermore, other studies reported lower prevalences of depression symptoms which is found among 17.6% - 20% of people with limb amputations (Singh et al., 2009; Hawamdeh et al., 2008). The differences in the estimates of prevalence's may arise due to different methodologies, sample sizes and assessment tools that were used by the researchers.

The risk factors to development of depression among 18-54 age groups are identified as being divorced/ separation, living near poverty line, comorbid condition, back pain, phantom pain and residual limb pain (Darnall et al., 2005). Furthermore, Seidel et al. (2006) indicated that pain and poor acceptance of the prosthesis predict development of depression symptoms. The presence of depression is associated with increased pain intensity, activity restriction, anxiety, body image anxiety, public self-consciousness, vulnerability and reduction in the quality of life (Asano et al., 2008; Jensen et al., 2007; Atherton & Robertson, 2006; Ephraim et al., 2005; Rybarczyk et al., 1995). Therefore, proper management of pain and medical comorbidities may result into reduction of depression symptoms.

The factors associated with high prevalence of depression among people with lower limb amputations include the following: female gender, lack of social support, unemployment, traumatic amputations, below knee amputation and shorter time since amputation (Hawamdeh et al., 2004). In terms of relationship between time since amputation and the prevalence of depression, Hawamdeh et al. (2004) reported that the time since amputation was done and the depression symptoms are related in a way that the longer the time since amputation was

done the lesser the prevalence of depression. The researchers further reported that the symptoms of depression resolve in a second month (54.3 days) after a period of in-patient rehabilitation. However, Horgan and MacLachlan (2004) reported that there is no relationship between time since amputation and the depressive or psychiatric symptoms.

People with traumatic amputations present with increased rate of depressive symptoms as compared to persons with non-traumatic amputations (Livneh et al., 1999). The researchers further indicated that young adults with traumatic amputations are at risk of developing major depression as compared to the elderly people with amputation. Similarly, Canserver et al. (2003) reported that most people with traumatic amputations have an increased rate of psychological problems. The researchers further indicated the prevalence of depressive symptoms among 34.7% of persons with traumatic limb amputations and 54% among people with surgical amputation. It has been reported that in traumatic amputation, depression is only associated with time since amputation while in surgical amputations depression is associated with age, education level, marital status, economic status, time since amputation and prosthetic use. However, an old study which was conducted by Williamson and Walters (1996) found that there is no relationship between the cause of amputation and psychological symptoms. Similarly, Singh et al. (2009) highlighted that there is no association between vascular cause of amputation and the psychological symptoms.

In terms of gender, females with lower limb amputations show high levels of depression symptoms as compared to males (Hawamdeh et al., 2004; Williams et al., 2004). Similarly, Pezzin et al. (2000) reported that more females are at risk

of suffering from depression symptoms compared to males. Age of the client has also been reported as a factor which influences the depression symptoms. The age of an individual with amputation is related to the state of his/ her mental status (Mohammed & Shebi., 2014; Shabban, Fosbury, Kerr & Cavan., 2006). Similarly, Dunn (1996) reported that young persons with lower limb amputation are at risk of developing psychological symptoms as compared to the elderly people with amputation. According to Horgan and MacLachlan (2004), depression symptoms manifest in young people in the early days' post surgery while in elderly the symptoms appear later.

2.5.4 Social participation and community re-integration challenges

Amputation being a change in body structure has a significant impact on many participation activities and quality of life of an individual (Burger & Marincek, 2007). Persons with LLA face changes in life style, social interactions, and identity (Horgan & MacLachlan, 2004). Participation refers to being involved in activities of life while participation problems are problems that an individual may experience in the involvement in life activities (WHO, 2001). Therefore, social participation in persons with amputations entails the extent to which an individual participates in social activities within the community (Williams et al., 2004). According to International Classification of Functioning, Disability and Health (ICF), an individual is expected to participate in the following social activities at community level: - community gatherings like church, festivals, recreation activities like sports, and participation in the local community events (WHO, 2001).

The social participation in persons with LLA may be affected by the following factors: social discomfort (Horgan & MacLachlan, 2004), physical and environmental barriers like accessibility to buildings, roads, transportation resources, and society attitudes (Gallagher et al., 2011; WHO, 2002). According to Sjudahl et al. (2004), problems in social participation may also arise due to social isolation. This may in turn affect the physical well-being and psychological function of an individual.

Most persons with LLA experience more challenges in sports recreations (78.6%), leisure and cultural activities (54.1%) (Gallagher et al., 2011). In addition, social participation of persons with lower limb amputations may be limited by problems in mobility as it is reported that only 26-62% of persons with lower limb amputations are able to ambulate outdoors (Van velzen et al., 2006). According to William et al. (2004), there are high levels of social integration following LLA within two years post surgery.

Community re-integration includes participation in social activities, independent living, employment or engagement in productive activities within the community (Sander, Clark & Pappudus, 2010). According to International Classification of Disability and Health (ICF), a successful community integration is characterized by activity and participation (WHO 2001). The most reported participation restrictions which people with LLA meet are restrictions in intimate relationships and sexuality (Geertzen et al., 2009a; Geertzen et al., 2009b; Kohler et al., 2009) and re-employment (Pezzin., 2000; Burger & Marincek., 2007). Similarly, activity limitation and participation have also been reported to be influenced by personal factors like functional abilities, balance

confidence, social discomfort, emotional impact, changes in goals and priorities, and external factors like accessibility, climate change, and transportation issues (Gallagher et al., 2011; Miller et al., 2002; Donovan-Hall, Yardley & Watts, 2002). In addition, emotional distress has also been reported to have an impact on participation restrictions (Cardol, De Jong & Ward, 2002).

Returning to previous work or ability to find employment back in the community is also another factor which contributes to effective community integration. Some persons with LLA are unable to return to their previous work because of the energy which is required to do the work and this result into change of jobs (Burger & Marincek, 2007). There are different factors which affect returning to work post amputation and these include presence of co-morbidities, level of amputation, age, as well as restrictions in mobility (Burger & Marincek, 2007). Gallagher et al. (2011) reported that about 53% of persons with LLA experience problems in finding employment post –amputation. However, in general, persons with lower limb amputation show good job participation as compared to persons with other disabilities / conditions (Schoppen et al., 2001; Schoppen et al., 2002).

2.5.4.1 Factors affecting social participation and community integration

Body image is one of the factors affecting participation and integration into the community. Body image is defined as the combination of an individual's psychosocial adjustment experiences, feeling, and attitude that are related to the form and function, appearance and desirability of one's own body which is influenced by personal and environmental factors (Horgan & MacLachlan., 2004). Body image is also explained as a dynamic phenomenon which is

influenced by feelings and perceptions of a person's own body that keeps on changing (Flanery & Faira, 1999). The image of one's body is an important element on the perception of one's self (Klapheke, Marcell, Taliaferro & Creamer, 2000). Therefore, a disruption of body image will have a long lasting impact on an individual's sense of identity (MacLachlan, 2004), personal relationships and interaction with others (Desmond & MacLachlan 2002; Rybarczyk et al., 1995). According to Jacobsen (1998), an individual with limb amputation may experience a negative body image and loss of social acceptance as a result of the disfigurement secondary to amputation.

Perception of body image is expressed differently depending on an individual. Some people tolerate the impact of body image with minimal distress while others may result into long-lasting negative self-identity (Rybarczyk & Behel, 2008). According to a study which was conducted by Prince & Fisher (2002), about 31% of people with lower limb amputation presents with body image problems.

The level of independence has been reported to influence the sense of body image and esteem (Liu, Williams, Liu & Chien, 2010). The relationship is in such a way that people with severe disabilities and less independent have low levels of body esteem and negative body image (Taleporis & Mc cabe, 2005; Sjodahl et al., 2004; Rybarczyk et al., 1995). To minimize body image problems in people with limb amputations, Liu et al. (2010) suggested improvement of the cosmetic aspect of the prosthesis, and minimizing the visual aspect of the amputation to be very important. Similarly, Gallagher and MacLachlan (2001) indicated that appearance of the prosthesis is an important element in

establishing self-image. The researchers further indicated that after limb loss people are more concerned with body appearance and desires to look normal. Therefore, the use of a prosthesis is considered an essential element in restoration of lives of people with limb amputation to normal life (Gallagher & MacLachlan, 2001).

Social discomfort has been reported as one of the perceptions experienced by persons with limb amputation and this is related to the problem of body image (Gallagher & MacLachlan, 2001). Problems with social discomfort and body image are reported to be associated with poor adjustment to amputations and in return may result into greater activity restrictions, depression as well as anxiety (Horgan & MacLachlan, 2004; Davidson, 2002). The researchers further indicated common adjustment problems which are reported by people with limb amputations and these include concerns of body image, social isolation, loss of sense of wholeness, anxiety and reduced sexual activity).

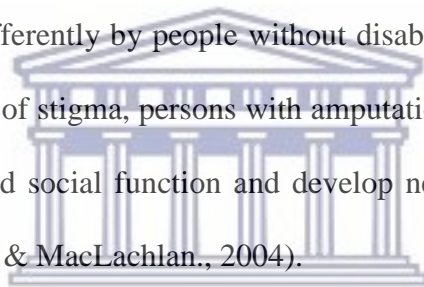
Social isolation is also one of the experiences of persons with limb amputation in the community (Williams et al., 2004). According to a study which was conducted by Liu et al. (2010), many participants preferred to stay indoors and did not want to go outside and meet any visitor because of being afraid of the reaction of people when they see them. In addition, people with lower limb amputation experience a feeling of embarrassment in their appearance and make assumptions that people will reject them. In this case, they end up isolating themselves from the society. Social isolation is opted in order to avoid risking society rejection (Liu et al., 2010; William et al., 2004; Sjodahl et al., 2004). The

researchers further indicated that social isolation has an impact on physical, psychological and social participation of an individual.

Society attitude is also one of the factors which affect community integration and participation (Gallagher et al., 2011). An attitude is a set of emotions, beliefs and behaviour towards a particular person, object or an event (Cherry & Gans, 2018). Attitudinal barriers are the main barriers to improvement of the lives of people with disabilities. A negative attitude towards people with disabilities include a belief that people with disabilities have a lesser position in the society or that they cannot contribute much to the society due to their impairments (Deal, 2007). These beliefs will lead to people maintaining social distance from them and are excluded from social networks (Deal, 2007). According to Clement and Bigby (2008), people with disabilities have the same rights to achieve their personal goals and ambitions like any other person in the community/ society. This is in line with the United Nations Conventions Rights of People with Disabilities report (UNCPWD) (2006), which indicates that people with disabilities have same rights as anyone in the society. The attitude of the society towards disability rather than existence of the impairments negatively affects the feeling of wellbeing among people with disabilities (Green, 2007). According to a study which was conducted by Ghallagher et al. (2011), one in every four participants' experiences peoples' attitude as an environmental barrier.

Social stigma is also one of the factors which affect social participation and community integration. According to Goffmans theory (1963), social stigma is defined as an attribute, behavior, or reputation which is socially discrediting in a particular way (Frost, 2011). Social stigma result into an individual to be

classified by others in undesirable rejected stereotyped rather than in an accepted normal way (Frost, 2011). Sometimes people with lower limb amputations perceive themselves as people who are not fit to live in the society anymore and also see themselves as a stigmatized group. In return, the society also view them as a group which is stigmatized (Wald & Avaro, 2004). This is because an individual's body image provides sense of self and affects how someone thinks about him/herself, act as well as relate to other people around them (Wald & Avaro, 2004). Similarly, Horgan and MacLachlan (2004) indicated that people with amputation perceive themselves on how the society see them, therefore, the perception of being stigmatized in people with limb amputation may influence that they should be treated differently by people without disabilities. Therefore, in order to reduce perceptions of stigma, persons with amputations need to adapt to the changes of physical and social function and develop new sense of self-identity (Green, 2007; Horgan & MacLachlan., 2004).



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Labeling also affects participation and integration in the community in people with disabilities. People see that disability is a sign of personal failure, or people with disabilities are considered as people of less value comparing to other people in the society (Green, 2007). To reduce the perceptions of being stigmatized, adjustment and acceptance of the amputation are the best solutions (Mugo, 2010). Similarly, Green (2007) reported that adaptation to changes in physical and social function is essential in persons with limb amputations and this should be incorporated with new self-identity. Once an individual adapts to new self and new identity, it helps to prevent the mind from labelling (Green, 2007).

Physical barriers such as designs of buildings are some of the factors which affect participation in community life (Burger, 2012). As reported by Ghallager et al. (2011), climate, physical environment and income are the most common environmental barriers in community participation. Climate becomes a barrier in community participation because the residual limb is sensitive to climate changes. For example, when the weather is hot, perspiration of the stump will result into physical discomfort. In cold weather, wet leaves and snow will affect mobility of an individual with lower limb amputation thereby affecting community participation (Ghallager et al., 2001). The researchers further indicated that community participation requires sufficient mobility and the ability to gain access easily within community environment. Similarly, Ephraim et al. (2006) reported physical/ structural environment as the greatest barrier perceived by persons with lower limb amputation in the community.

2.5.4.2 Cultural stigmatization

Cultural beliefs explain how people interact and associate themselves with the world, and how they behave towards certain situations (Omu & Reymond, 2012). Cultural beliefs are considered as a combination of religious, social and traditional beliefs (Omu & Reymond, 2012). Perceptions of the causes of disability and diseases differ according to communities (Legg & Penn, 2013). A study which was conducted in the rural area of South Africa indicated that most people believe that the cause of disability is associated with spiritual or mystical origin (Wegner & Rhoda, 2015). As a result of cultural stigmatization, persons with disabilities face challenges in accessing public transport like taxis. This is because people are sometimes not willing to offer transport to a person with a disability and this in turn affects accessibility of medical and rehabilitation

services (Wegner & Rhoda, 2015). Segregation, stigmatization, and labeling in persons with amputations affect social participation, re-integration into the community and may also result into psychological disorders (Green, 2007).

2.5.4.3 Factors facilitating social participation and community integration

Social support is an exchange of resources between two individuals perceived by the provider or recipient to be intended to promote the wellbeing of the recipient (Shumaker & Brownell 1984). Support from the family members and friends is very important in facilitating post amputation recovery (Schoppen et al., 2003). Social support assist people with limb amputation to adapt to limb amputation in such a way that a person, with adequate social support, may benefit from the assistance offered in an attempt to negotiate to their physical and social environment (Schoppen et al., 2003). Furthermore, social support is also associated with adjustment to limb loss (Oaksford, Frude & Cuddily, 2005). According to William et al. (2004), people with limb amputation, who receive social support, have more time out of bed, out of their houses and in the communities. In return, these people have increased social participation, leisure, vocational and other activities within the community.

Increased social support helps to enhance psychological wellbeing. Perceived social support is a predictor of both physical and mental health outcomes including depression effect (Rybarcyck et al., 1995). In addition, increased social support also predicts the outcome of quality of life (Asano et al., 2008), and activity restriction (Williamson & Walters, 1996). Similarly, Bosse et al. (2002) indicated that perceived social support at one-month post amputation predicts the improvement of pain and depression, while the reduction in levels of

social support has a prediction of poor self-reported health status. People with limb amputation, who have negative mentality to social support are reported to present with increased levels of emotional distress and have difficulties in adjustment to limb loss (Liu et al., 2010; Oaksford et al., 2005).

Peer support has been reported to be beneficial to people with lower limb amputation (Liu et al., 2010). Peer support will allow people with LLA to share their feelings with their friends of the same experiences. This helps to reduce emotional distress, sense of isolation, and in turn, provide new sense of perspective (Liu et al., 2010). Furthermore, it has been indicated that people with limb amputation are able to view things more positively and bravely face their problems after attending peer support groups or interact with their peers (Sjodahl et al., 2004; Oaksford et al., 2005).

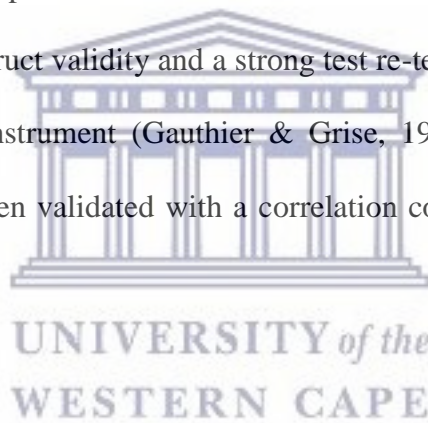
In conclusion, the existing literature shows amputation has a significant impact on an individual's life. Regardless of the cause and level of amputation, people with amputation require early rehabilitation to overcome functional and psychological challenges which may inturn enhance effective participation and intergration into the community. The literature proves that people with lower limb amputation have different experiences in the community which affects their community participation and intergration. However, no information could be found on community experiences of persons with lower limb amputation in Malawi.

2.6 Outcome measures in lower limb amputations

Several outcome measures are used in lower limb amputations apart from the outcome measures which have been used in this study. Some of these include;

2.6.1 A locomotor capabilities index.

This instrument was developed by Gauthier and Grise (1994). It is a self rating 14-point scale used to evaluate the level of independence of a person with lower limb amputation when performing ambulatory activities and it provides the scores on the basic as well as advanced activities. It is rated zero to three depending on degree of independence of an individual. A locomotor index demonstrates a face and construct validity and a strong test re-test agreement has shown that it is a reliable instrument (Gauthier & Grise, 1994; Grise et al., 1993). The instrument has been validated with a correlation coefficient of 0.95 (Gaugon & Grise, 1994).



2.6.2. Berthel index.

A berthel index scale is an outcome measure used in people with amputations, neurological conditions, burns as well as cardiac problems. It is used to determine the functional abilities and capabilities (Finch et al., 2002). The instrument is reliable, valid and is used widely to evaluate eight self care activities and two mobility activities (Beck et al., 2008). It has a correlation coefficient which ranges from 0.7- 0.88 (Finch et al., 2002).

6.2.3. Orthotics and prosthetics users survey (OPUS).

OPUS is one of the outcome measures used in people with LLA. The instrument has four modules and one of the modules include; health related quality of life (HRQOL). HRQOL is a self -reporting scale consisting of 23 items. (Heinemann, Bode & O'Reilly, 2003). Each of the OPUS's sections has been tested for validity and reliability, and can be used independently of each other. HRQOL has a positive strong correlation coefficient of 0.88 in the measurement of health-related quality of life following lower limb amputation (Heinemann, Bode & O'Reilly, 2003).

2.7 Conceptual framework.

The study adopted an International Classification of Functional, Disability and Health (ICF) concept. ICF was developed with an aim of revising the International Classification of Impairment, Disability and Handicap (ICIDH). The International Classification of Impairment, Disability and Handicap was developed in 1980s and focused on the consequences of diseases instead of the disease constituents (WHO, 2001). Unlike ICIDH, ICF concept provides a classification with neutral components rather than using negative terminologies (WHO, 2001). The ICF is in line with the biopsychosocial disability model which explains that disability is not only the consequent of a disease or health condition but is also determined by physical environment, availability of services within the society, attitude and legislation (Dahl, 2002). ICF provides an international classification and a universal language for comparing human functioning (Cieza & Stucki, 2005; WHO, 2001).

The concept of ICF deals with description of a person's level of function as a dynamic interaction between health condition, environmental and personal

factors (WHO, 2001). Therefore, the function and disability in ICF are described across the domains of body structure and body function, activity and participation, environmental factors and the personal factors which are not included in the current version of ICF (WHO, 2001). The environmental factors include some of the following; social attitudes, legal and social structures, architectural characteristics, climate and terrain. The personal factors include the following; age, gender, coping styles, education, profession, past and current experiences, overall behavior pattern, character and other factors that influence how disability is experienced by an individual (WHO, 2001). The ICF has been tested internationally and is available in different languages (Ustun, Chatteji & Bickenbach, 2003). Therefore, ICF is very essential in categorizing functional impairments which persons with lower limb amputations meet worldwide (Burger, 2011; Burger, 2012). Health condition/ disorder affects an individual's body function or structure which in turn result into activity limitation and participation restriction. The activity limitations and participation restrictions are not only the resultant of the health condition as they may also be influenced by environmental factors and personal factors which may either negatively affect or facilitate participation and activity performance (figure 2.1)

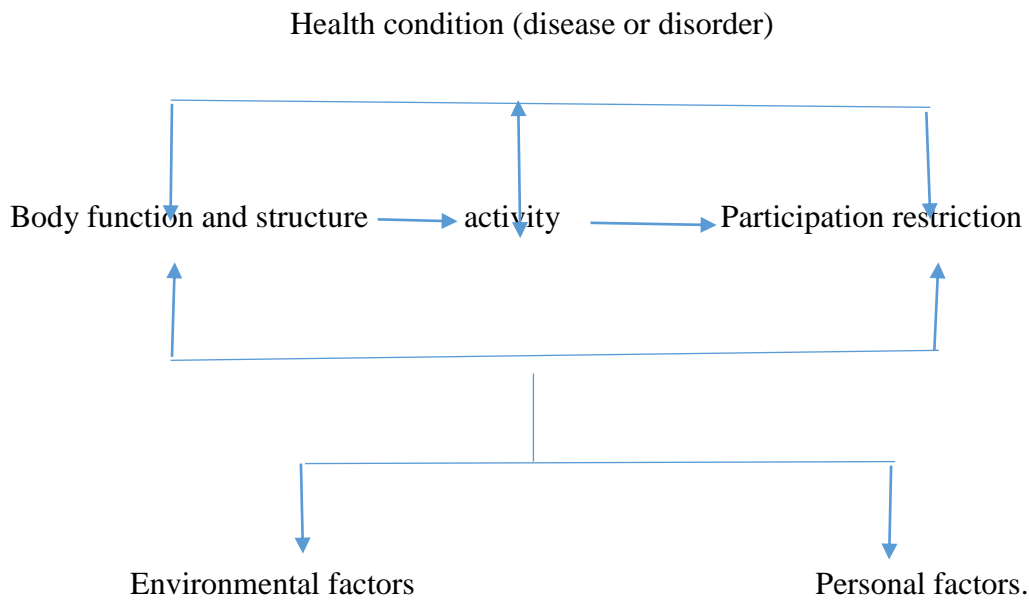


Figure 2.1. ICF concept.

2.8. Summary of chapter.

The review of literature included the incidences and prevalences of limb amputations, etiological factors and the importance of early rehabilitation following limb amputation which has been found to facilitate good functional status and in turn improves community participation. Literature review also included the functional and psychological status following limb amputation and factors which hinder or facilitate community participation and integration. A theoretical framework of ICF concept was adopted at the end.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

Chapter three describes the two study approaches which were used to address the aims and objectives of this study: quantitative and qualitative approach. The chapter also explains the study design, study setting, the sampling of participants, data collection instruments and data analysis procedures. The chapter also describes the process of verification and trustworthiness of the data. Finally, the ethical considerations that were applied in the study are explained.

3.2 Study Setting

The study was conducted in Malawi. Malawi is a sub-Saharan country which borders with Mozambique, Zambia and Tanzania. The country measures 118,484 square kilometers. Malawi has a population of over 17 million people (National statistics office, 2010). A survey which was conducted in the year 2008 by the WHO indicated that about four percent of the population of Malawi is living with disabilities. There are more people living with disabilities in rural areas as compared to urban areas. The most common disabilities are mobility and visual impairment (National statistical office, 2010).

Participants were recruited from Queen Elizabeth Central Hospital (QECH) and Kamuzu Central Hospital (KCH) (500 miles) orthopedics centers' outpatient clinics. The 500 miles' orthotics and prosthetics center is a private institution which fabricates orthotics and prosthetics. It is located within the premises of Kamuzu Central Hospital. Queen Elizabeth Central Hospital (QECH) is a referral hospital found in the southern region of Malawi. QECH has a bed

capacity of over 1100 (Browning, 2011) and serves the population of the southern region of the country and sometimes receive referrals from the rest of the central hospitals in Malawi. Kamuzu Central Hospital is the referral hospital found in the central region of Malawi. KCH has a bed capacity of over 780 and serves the population of the central region of the country (WHO, 2016). QECH and KCH are both teaching hospitals where medical students, nurses, physiotherapy, pharmacy, radiology and medical laboratory students are trained. The hospitals comprise of the following departments: surgical, medical, pediatrics, oncology, gynae and obstetrics, pharmacy, laboratory, radiology, physiotherapy and orthopedics (orthotics and prosthesis). The orthopedic centers have workshops which manufacture/ fabricate orthotics and prosthesis. People with lower limb amputations are referred to the orthotic and prosthetic centers after discharge from the hospital for prosthetic assessment and fitting. The orthotic and prosthetic center at QECH is funded by the government and clients are required to pay a certain percentage for the prosthesis while the orthotic and prosthetic center at Kamuzu Central Hospital is a private institution which is owned by an individual and clients are required to pay full amount of the prosthetic (Milanzi, 2016). QECH and KCH (500 miles) are the main orthotic and prosthetic centers in Malawi and practically provide prosthetic services to most of the country.

3.3 Research Approach and Study Design

The study applied a mixed method approach, where both quantitative and qualitative methods were used. (Creswell, 2013). The approach assisted to bring together the weaknesses and strengths of the experiences of the participants on social participation and community re-integration and those of psychological and

functional level (Patton, 1990). A cross-sectional concurrent approach was applied where both qualitative and quantitative studies were implemented at the same time (Johnson, Onwuegbuzie & Tuner, 2007). The approach was appropriate for this study because the participants of the study lived far apart and this helped to save time and funds. Data relating to physical and psychological function (through the use of questionnaires) was collected concurrently with data relating to community re-integration and social participation through interviews. This was done separately and on a single visit. Data were analyzed separately and the results were compared or related during interpretation



Figure 3.2 Mixed method research approach.

3.4. Section A: Quantitative Component

This section outlines step by step the process that was undertaken in order to achieve the objectives of the quantitative component. In the quantitative phase, data pertaining to social demographic and medical background information, information concerning the function of the lower limb and the psychological status of the participants were collected.

3.4.1 Study population, sampling strategy and sample size

The participants of the study were persons who had undergone major lower limb amputation surgery at Queen Elizabeth and Kamuzu central hospitals more than three months but less than two and a half years ago (from the month of June 2014 to September 2017). The total size of the population was 195.

The study utilized whole population sampling whereby the whole population of clients who had undergone surgery for LLA at QECH and KCH more than three months but less than two and a half years ago were utilized. Levin (2006) argues that when the population is small, the whole population can be taken as a sample because it is best to estimate the prevalence of outcome of interest especially when using cross sectional designs. A report from the orthopedic centers' registry indicated a total number of 195 clients who had undergone surgery in the indicated period (Milanzi, 2016). Therefore, the whole population of 195 was included in the quantitative component as the study sample upon their willingness to participate. Based on the inclusion criteria described below, 180 participants from the two orthotics and prosthetic centers participated in the quantitative study.

3.4.2 Inclusion criteria

The following participants were included: males and females over the age of 18 years with unilateral trans-tibial, trans-femoral and knee disarticulation amputations, and no other neurological or communication challenges, people who underwent surgery more than three months but less than two and half years ago (from the year 2014). Only individuals with a unilateral amputation were included as a person with bilateral amputations would potentially have a much lower functional status when compared to a unilateral amputation. The period was selected according to a report from Horgan and MacLachlan (2004) which indicated that some of the psychological symptoms are worse within the first two years following amputation. Adult persons with amputations were selected considering that they were on the majority in the population with lower limb amputations.

3.4.3 Data Collection procedure

Ethical clearance for this study was obtained from the University of the Western Cape's Biomedical Research Ethics Committee (Appendix 13) and the College of Medicine Research Ethics Committee in Malawi (Appendix 14). Permission to collect data was obtained from the hospital director of the Queen Elizabeth Central Hospital (Appendix 15), chief executive officer of 500 miles at KCH (Appendix 16) and the heads of departments of QECH and KCH 500 miles' orthotics and prosthetic centers. Two research assistants were identified (one from each prosthetic and orthotic center) to assist in administering the questionnaires to the participants. The nature of the study was explained to the assistants and they were trained on how to administer the questionnaires. The research assistants were monitored frequently in order to make sure that the

whole process was done according to the set standards. The inclusion criteria were clearly explained to the research assistants. Participants were identified from the orthopedics centers' data registry book. Participants were contacted telephonically and an appointment was scheduled at the prosthetic center at an appropriate time. All participants were reimbursed for their transport costs. Necessary arrangements were made with the orthotic and prosthetic technicians of QECH and KCH to schedule participants who were included in the study through phone calls. As participants arrived at the center, they were introduced to the research assistant who collected the data, and they were taken to a private room. The questionnaires were administered by the researcher and /or research assistant either in Chichewa or English language depending on patients' preference. After seeking consent from the participant, an information sheet was provided to the participants to read and sign the consent form if they agreed to participate. Each participant was then asked to complete three surveys namely: 1) a socio-demographic (Appendix 9), 2) the lower limb functional measure section of the Orthotics and Prosthetic user's survey (OPUS) (Appendix 5), and 3) Beck's depression inventory (Appendix 7). A completed questionnaire was then reviewed if there were any gaps. Soon after administering the questionnaires, if the participant was selected to participate in the qualitative component of the study, the semi-structured interviews were then conducted using a semi structured interview guide. In total, duration of data collection was approximately 60 minutes per participant.

3.4.4 Instrumentation

Two instruments were utilized to achieve the objectives of the study. The questionnaires were translated from English to Chichewa as a medium of communication.

The researcher also developed a socio demographic and medical co-morbidity questionnaire (Appendix 9) based on similar studies in literature (Mohammed & Shebl, 2014; Godlwana et al., 2008). The questionnaire was divided into two sections and comprised of closed ended questions.

Section one included demographic details and aimed at capturing data on the following: age, marital status, gender, occupation, level of education, area of residence, nationality, history of smoking and drinking.

Section two of the questionnaire included medical background and the following questions were included: when was the amputation done? What was the cause of the amputation, level of amputation, side of the body amputated, presence of co-morbidities and history of medical rehabilitation services received whilst in the hospital and after discharge?

3.4.4.1 Orthotics and prosthesis user's survey (OPUS) (Appendix 5)

The first instrument that was used is an orthotics and prosthesis user's survey (OPUS). This study utilized one of the OPUS modules - lower limb functional measure (LLFM). LLFM is a self-reporting instrument containing 20 items (Heinemann, Bode & O'Reilly, 2003). The instrument allows evaluation of effectiveness and quality of rehabilitation services offered to prosthetic and orthotics users (Jarl, Heinemann & Hermansson, 2012). Each of the OPUS's

sections has been tested for validity and reliability and can be used independently of each other (Heinemann et al., 2003). LLFM's validity is demonstrated by providing results that are consistent with clinical practice e.g. running is scored lower than walking, and it has a positive strong correlation coefficient of 0.88 in the measurement of lower limb function (Heinemann et al., 2003). The contents of the instrument include body function, activity and participation as well as the environmental factors of the ICF (Lindner, Natterlund & Hermansson, 2010). LLFM's was appropriate in this study to collect data on the functional status of the lower extremity following amputation of the lower limb.

3.4.4.2 Beck's depression inventory scale (Appendix 7)

The second instrument that was used is a Beck's depression inventory scale. Beck's depression inventory scale is a 21-item self-administered questionnaire which is utilized both in clinical and research studies (Beck, Steer & Brown, 1996). The scale covers cognitive and affective components of depression and is reliable for assessment of both depressed and non-depressed older persons and people of other ages (Farinde, 2013). Beck's depression inventory scale has been validated with coefficient alpha of 0.91 and above (Farinde, 2013) and has a very good and strong correlation of between 0.93 and 0.84 (Sprinkle et al., 2002). The Becks' depression inventory scale was appropriate in this study to collect data on the psychological function (especially depression status) of the participants following LLA.

3.4.5 Validity and reliability

To ensure the face and content validity of the newly developed socio-demographic questionnaire, experts in the field or those with experience on the area under study (an experienced physiotherapist at College of Medicine (COM) and orthopedic technologist at Queen Elizabeth Central Hospital) were asked about their opinion on clarity and content of the questionnaire (Polit & Beck, 2003). Some changes were suggested on the questionnaire especially on phrasing of the words. For example, a medical background question asking about the level of amputation in the local Chichewa version was modified to be clear to the participants. Otherwise all the questions were clear. To ensure reliability of the translated instruments (OPUS & Beck's depression inventory scale), the questionnaires were translated from English to Chichewa language by an English speaking physiotherapist and later, the same questionnaires were translated back into English language by an independent second translator, and a comparison was made with the original version to determine if there were any differences. To ensure reliability and stability of the translated questionnaires, a test-retest reliability study was conducted whereby the translated questionnaires were distributed to ten people to answer the questions, and after a week the same questionnaires were also re-distributed to the same group to assess if the results were similar or the same as the first test (Polit & Beck, 2003).

3.4.6 Pilot study

After permission to conduct the study was obtained from the relevant authorities, a pilot study was conducted on the demographic questionnaire (Appendix 5), and the translated versions of the OPUS mode of lower limb function measure (Appendix 3) and Becks' depression inventory scale (Appendix 4). The

questionnaires were piloted at Queen Elizabeth Central Hospital orthotics and prosthetic centers. The questionnaires were administered to ten participants with LLA to test their objectivity and feasibility as well as their clarity and applicability after translation (Olsen & St. George, 2004). The participants were identified from the data registry book. Identification of the participants was based on the inclusion criteria, i.e. males and females, unilateral amputations, trans-tibial and trans-femoral and knee disarticulation amputations and those who were 18 years and above. Participants were randomly selected from the list based on the inclusion criteria and their willing to participate. Participants were contacted telephonically and recruited to participate in the pilot study at the orthotics and prosthetic center. Prior to the completion of the questionnaires, informed consent was obtained in writing. Three questionnaires were administered to the participants. Based on the results of the pilot study, modifications of the questions were made where necessary (Polit & Beck, 2003).

The questionnaires were re-administered after seven days to assess the reliability and stability of the questionnaires. This was done in order to assess the accuracy of the translated questionnaires from English to Chichewa version.

Data was analysed using chi-square and T-test. Descriptive statistics were expressed as frequencies, mean, standard deviation and standard error of mean at 95 % confidence interval. To assess if there were any statistical differences between the responses of the first and second test, OPUS (LLFM) questionnaire revealed that there was no statistical significance on the differences between the first and second tests which was evidenced by alpha being >0.05 ($p = 0.682$). The first and second test were also tested for Cronbach alpha to assess if the

responses were consistent. It was revealed that the results of both tests were more reliable this was evidenced by Cronbach alpha being greater than 0.7 thus it was 0.78 and 0.83 respectively. The same tests were repeated on beck questionnaire and revealed no statistically significant differences on the translated questionnaires evidenced by alpha >0.05 ($p= 0.418$) and correlation coefficient was 0.74 on the first test and 0.81 on the second test.

After piloting the questionnaires, the problematic questions were noted and modified as explained below.

3.4.6.1 Opus questionnaire

Question 1 was modified to suit the Malawian environment. Instead of going into and out of the bath tub, bathing using a basin was added because most of the participants do not possess a bathing tub at home.

Question 15 was asking about going up and down the escalator. Considering the Malawian environment, the question was removed because most of the participants have never used an escalator since they are not locally found.

Question 19 the follow up question for question 19a which was question 19b, was considered not applicable because the question 19a was asking about how easy or difficult is it to put on and off the prosthesis yet the follow up question (19b) was asking about whether the client needs to put on the prosthesis in order to perform the activity or not.

3.4.6.4.2 Beck's depression inventory questionnaire

Question 19 was modified for clients' better understanding. The question indicated loss of weight in pounds which brought about confusion to most of the

participants. Therefore, the pounds were converted into kilograms for participants' easy understanding.

3.4.6.4.3 Demographic questionnaire

Question 1.2 a. The answers were not clear to the participants i.e. the answers read; through the leg, through the thigh (Chichewa version) therefore the knee was used as a reference point instead of through the leg, below the knee was used, and above the knee instead of through the thigh.

The period taken to fill the questionnaires on the first test was between 30- 40 minutes. While on the second test the duration was shortened to 20 to 35 minutes.

3.4.7. Data management and analysis

Data were analyzed using Stata version 14.0 (Stata Corp, Texas, USA). Means and standard deviation (SD) were computed for continuous variables that were normally distributed. For variables with skewed distribution, median and inter-quartile range were computed and reported. Proportions and 95% confidence intervals (CI) were computed for categorical variables. Chi-squared test and t-test were used for testing association between binary outcome variables with categorical explanatory variables and continuous variables, respectively. Alternatively, due to small samples, Fisher's Exact test or Mann-Whitney U-test was used for categorical and continuous variables, respectively. Unadjusted risk ratios (RR) and 95% CIs were computed using simple binomial regression. Risk ratios were computed throughout given that the primary outcome was common (>15%) and upon confirming that odds ratios (OR) did not correctly estimate the RR.

We fit multivariate binomial regression models to adjust for any imbalance on baseline characteristics. Age and sex were included in the multivariate model *a priori* as natural confounders as well as any other variable with $p=0.200$. Functional status scores were normally distributed (Figure 4.1) with mean of 36.5 (SD: 10.99). Therefore, the binary variable used in the rest of the analysis including statistical modelling were generated using the mean as a cut-off coded 1 for people with good functional status and 0 for those with suboptimal functional status. Psychological status scores were skewed to the right (Figure 4.2) with a median of 7 (IQR: 3-14); mean 10.6 (SD: 10.06). Thus, a binary variable was generated using the median as the cut-off coded 1 for people with good psychological status and 0 for those with suboptimal psychological status.

3.5 Section B: Qualitative component of the study

This section explains the process that was undertaken to conduct interviews and obtain information concerning the participants' feelings and experiences on community integration and social participation.

3.5.1 Sampling method and sample size

The participants of the qualitative component of the study were selected through purposeful maximum variation sampling in order to maximize the depth of understanding of data (Creswell, 2013; Patton, 2002). Fourteen participants were purposively selected from the quantitative sample of 180 participants based on pre-identified characteristics such as level of amputation, cause of amputation and age. The final sample size was controlled by the saturation of data and this is the point whereby there is repetition of responses and or when no new information is arising from the participants (Creswell, 2013; Streubert &

Carpenter, 2003). The sampling of participants was as follows: based on gender, seven participants were females and seven were males, ten participants were presenting with trans-tibial amputations and 4 participants had trans- femoral amputations. This imbalance was due to the increase of the population with trans-tibial amputations. The age range was between 23 years to 65 years of age. Eight participants had traumatic amputations while six participants were presenting with non-traumatic amputations.



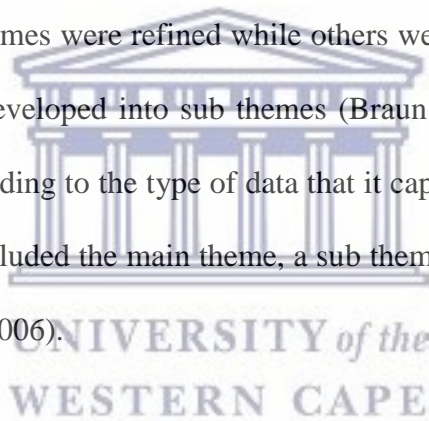
3.5.2. Data Collection

In-depth interviews were conducted using a pre-determined semi-structured interview guide (Appendix 11) to collect data on the participant's feelings and experiences relating to social participation and community integration. The interviews consisted of open-ended, predetermined questions and some probing questions that arose during the interview (Meriam, 2009). Therefore, the questions had no specific order and this allowed the researcher to react to the participant's answer (Meriam, 2009). The interviews were conducted by the researcher. Prior to the interviews, permission was obtained from the participants for this phase of the data collection. The participants were informed about the purpose and nature of interview. Participants were informed that interviews were to be audio recorded in order to capture all the data that was reported by the participants to avoid missing out some information. Therefore, the researcher also seek permission to record the interview. After the interview, the audio recorder was re-played to the participant to verify if what was captured was indeed what the participant wanted to report. Clarifications were made wherever necessary. In-depth interviews were appropriate in this study in order to maximize the depth of data collected (Patton, 2002). Interviews were conducted for the period of 20-30 minutes for an individual participant and all interviews were audio recorded and field notes were taken (Creswell, 2013).

3.5.3 Data analysis

Data was analysed using thematic analysis where an inductive approach was applied (Braun & Clark, 2006). The analysis was done in phases whereby after data collection the interviews were transcribed into written form ((Braun & Clark, 2006). The trnscription included both verbal and non verbal data in order

to have a deep understanding of the meaning of data. During the process of transcription, the researcher started to familiarise with data. The process of familiarisation of data continued after transcription of data into written form which involved reading data for several times to understand the content and searching for meanings and patterns of data. During the process notes were taken to mark some ideas for coding (Braun & Clark, 2006). After data familiarisation, open and axial coding of data was done whereby important statements were extracted from the text and data of similar ideas, words and phrases were organized and grouped together to form codes (Braun & Clark, 2006). After coding of data, different codes were sorted out into potential themes. Later the potential themes were refined while others were collapsed into each other and others were developed into sub themes (Braun & Clark, 2006). The themes were named according to the type of data that it captures. At the end a report was written which included the main theme, a sub theme and supporting data extract (Braun & Clark, 2006).



3.5.4 Trustworthiness of data

To ensure credibility of data, pre-determined, semi-structured questions were reviewed and analyzed by experts in the field (a physiotherapist and an orthotics and prosthetic technologist) in order to ensure that the questions were clear, relevant and applicable (Polit & Beck, 2003). The interviews were audio recorded and field notes were taken. At the end of the interview, member checking was done whereby an audio recorder was replayed to the participant in order to verify and clarify whether the data captured was indeed what had been reported and to make sure that all the information had been captured (Polit & Beck, 2003). Participants were allowed to make some clarifications and changes

wherever necessary (Creswell, 2013). To ensure dependability of data, the researcher had to read the transcripts few times to ensure that she was well acquainted with the data (Polit & Beck, 2003). To ensure transferability, the research supervisor checked the codes, themes and categories and the results were examined and compared (Polit & Beck, 2003). To ensure confirmability, an external physiotherapist with experience in qualitative research verified the research process and the interpretation of the results (Polit & Beck, 2003).



3.6 Ethics Consideration

Ethics clearance was obtained from the Biomedical Research Ethics Committee of the University of the Western Cape. The approval in Malawi was requested from the College of Medicine Research Ethics Committee (COMREC). Permission to conduct the study was obtained from the hospital directors of QECH and KCH (500 miles), and permission to collect data was obtained from the heads of the orthopedic centers of QECH and KCH (500 miles). Participants were briefed about the study using an information sheet that was translated into the local language (Chichewa). Participants willing to participate were given either an English or Chichewa (depending on their preference) consent form to sign. Participants had a right to withdraw from the study at any point, and no penalties were given for withdrawing because the process was voluntarily (Shenton, 2004). To ensure confidentiality, no names of the participants were disclosed instead codes were used. The collected data was kept in a secure cabinet to make sure that its accessibility was appropriately restricted. Therefore, only the researcher, research supervisor and research assistant had access to the data collected. Electronic data and recordings were stored on a password protected computer. During interviews, participants who were emotional were assisted accordingly and referred to a psychologist for counseling.

3.7 Summary of the chapter

The chapter has explained in detail the methodology used to conduct the study. It has described the study design, method, setting, analysis process and trustworthiness of both the quantitative and qualitative data.

CHAPTER FOUR

RESULTS

4.1 Introduction

In this chapter, the results are presented according to the objectives of the study. Quantitative data are presented first and include demographic details, functional level and psychological status. The qualitative data include the experiences on social participation and community integration.

4.2. Quantitative results

4.2.1. Demographic details

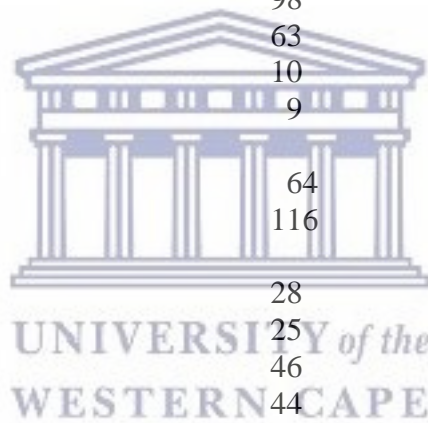
The age range of the participants was between 18 and 88 years of age. The mean age being 40.9 (SD +- 18.2 years) years of age while the median age was 40.5 years of age. The majority (55%; n = 99) of participants were between 20 and 49 years of age at the time of data collection. Of the 180 participants, the majority (n= 112; 62%) were males. The majority (54%; n = 98) of participants were married. Of the 180 participants, 116 (65%) were from the rural areas and 26% (n=46) of the participants were farmers. Of the 180 participants, 52%(n = 93) were presenting with right sided amputation. Trauma was the leading cause of amputations in this setting. Of the 180 participants, 108 participants (60%) had amputations secondary to trauma. The majority (31% n=57) of the participants had their amputation surgery done within the year 2017. Of the 180 participants, 125 (70%) reported to have received in-patient rehabilitation. The majority (64% n=115) did not receive out-patient rehabilitation. There is limited rehabilitation follow-up of people with lower limb amputations after discharge

from the hospital. Of the 180 participants, 109 (60%) reported that they had no rehabilitation follow up after discharge. The majority (80%; n=114) were prosthetic users. The majority (86%; n=156) of the participants do not smoke tobacco nor (81% n=146) drink alcohol (Table 4.1).



Table 4.1 Socio-demographic details of persons with lower limb amputations
(N=180)

Characteristics	Frequency (n)	Percentage (%)
Gender		
Male	112	62
Female	68	38
Age range;18-88; mean 40.9 (SD. +/-18.2)		
18-19	25	14
20-29	41	23
30-39	22	12
40-49	36	20
50-59	23	13
60-69	16	9
70 and above.	14	8
Missing	3	1
Marital status		
Married	98	54
Single	63	35
Divorced	10	6
Widow	9	5
Location of the participants		
Urban	64	35
Rural	116	65
Occupation		
Employed	28	16
Unemployed	25	14
Farmer	46	26
Business	44	24
Student	36	20
Level of amputation (LOA)		
Trans-tibial	117	65
Trans-femoral	49	27
Knee disarticulation	14	8
Side of the body amputated (SOBA)		
Left	86	48
Right	94	52
Cause of amputation		
Traumatic	106	59
Non-traumatic	74	41
Period of amputation		
2014	26	14
2015	45	25
2016	52	30
2017	57	31
In-patient rehabilitation		
Received	125	69
Did not receive	55	39



Out-patient rehabilitation		
Received	64	36
Did not receive	116	64
Duration of rehabilitation follow-up		
No follow-up	109	60
1-3 months	64	36
4-7months	3	2
8-12months	4	2
Prosthetic use		
Prosthetic user	144	80
Non prosthetic user	36	20
Tobacco smoking		
Smokes	25	14
Does not smoke	156	86
Drinking alcohol		
Drinks alcohol	34	19
Does not drink alcohol.	146	81



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4.2.2 Characteristics of participants according to gender

The majority of the 180 participants in the study were men (n = 112; 62.2%). The median age of the study sample was 40.9 (IQR: 24.0; 54.0; SD +/- 18.2 years) years (Table 4.2). Men were more likely to report that they were married (n = 70; 71.4%) compared to women (n = 28; 28.6%; p=0.003). Overall, prevalence of smoking was low in this patient population with only 26 (14.4%) participants reporting that they were smokers. Significantly more men than women (n = 25; 96.2% vs. n = 1; 3.8%; p<0.001) reported that they were smokers. Similarly, men were more likely to report consuming alcohol (n = 32, 94.1%) compared to women (n = 2; 5.9%; p<0.001). Men (n = 78, 73.6%) were significantly (p<0.001) more likely to have suffered a traumatic amputation when compared to women (n = 28, 26.4%). Overall, two thirds of patients received in-patient rehabilitation with a comparable proportion of men and women (p=0.482). Only a third of participants received out-patient rehabilitation with no significant differences in reporting between men and women (p=0.388). Most participants reported using a prosthesis with no significant differences between men and women (p=0.318).

Table 4.1 Participant characteristics by gender (N = 180)

Variable	Category	Male - n (%)	Female-n (%)	Overall-N (%)	p-value*
Total	N	112 (62.2)	68 (37.8)	180	NA
Age (years)	Median (IQR)	43.0 (25.5; 54.5)	36 (22.5; 53.5)	40.5 (24.0; 54.0)	0.156
Marital status	Married	70 (71.4)	28 (28.6)	98 (54.4)	0.003
	Single	36 (57.1)	27 (42.9)	63 (35.0)	
	Widowed/Separated/Divorced	6 (31.6)	13 (68.4)	19 (10.6)	
Occupation	Employed	18 (64.3)	10 (35.7)	28 (16.1)	
	Unemployed	14 (56.0)	11 (44.0)	25 (14.4)	
	Farmer	32 (69.6)	14 (30.4)	46 (26.4)	
	Business	28 (63.6)	16 (36.4)	44 (25.3)	
	Student	17 (54.8)	14 (45.2)	31 (17.8)	
Smoking	Yes	25 (96.2)	1 (3.8)	26 (14.4)	<0.001
	No	87 (56.5)	67 (43.5)	154 (85.6)	
Alcohol	Yes	32 (94.1)	2 (5.9)	34 (18.9)	<0.001
	No	80 (54.8)	66 (45.2)	146 (81.1)	
Level of amputation	Trans-tibial	70 (59.8)	47 (40.2)	117 (65.4)	0.473
	Trans-femoral	31 (63.3)	18 (36.7)	49 (27.4)	
	Knee disarticulation	10 (76.9)	3 (23.1)	13 (7.2)	
Side of the body amputated	Left	50 (58.1)	36 (41.9)	86 (48.0)	0.305
	Right	61 (65.6)	32 (34.4)	93 (52.0)	
Cause of amputation	Traumatic	78 (73.6)	28 (26.4)	106 (59.6)	<0.001
	Non-traumatic	33 (45.8)	39 (54.2)	72 (40.4)	
Prosthetic use	Yes	87(60.4)	57 (39.6)	114 (62.2)	0.318
	No	25 (69.4)	11 (30.6)	36(37.8)	
In-patient rehabilitation	Yes	74 (59.2)	51 (40.8)	125 (69.8)	0.238
	No	37 (68.5)	17 (31.5)	54 (30.2)	
Duration of rehabilitation†	Median (IQR)	1 (1; 1)	1 (1; 1)	1 (1; 1)	0.482
Out-patient rehabilitation	Yes	37 (57.8)	27 (42.2)	64 (35.8)	0.388
	No	74 (64.4)	41 (35.6)	115 (64.2)	

* Fisher's Exact test for categorical variables and Mann-Whitney U-test for continuous variables. NA: not applicable; IQR: inter-quartile rang

Table 4.2. Frequencies of prosthetic use and amputation level.

Level of amputation	Prosthetic use	Non prosthetic use	Total	p-value
Trans-tibial	99 (84.6)	18 (15.4)	117 (100)	
Trans-femoral	34 (69.4)	15 (30.6)	49 (100)	0.069
Knee disarticulation	10 (76.9)	3 (23.5)	13 (100)	

The majority of the participants were prosthetic users (Table 4.3). There were no statistically significant differences between the number of prosthetic users based on the levels of amputation (trans-tibial, trans-femoral and knee disarticulation) (P=0.069).



4.2.3 Functional status

Of the 180 participants, (55.0 %; n = 99) reported good functional status based on having a mean functional score of the OPUS questionnaire being greater than or equal to the mean of 36.5. In unadjusted analysis, having knee disarticulation was associated with 72.0% increased risk of having suboptimal functional status compared to a trans-tibial amputation (RR 1.72, 95.0% CI: 1.13; 2.63; p=0.012) (Table 4.4). Patients who received in-patient rehabilitation had a 39.0% decreased risk of having sub-optimal function compared to those who did not receive in-patient rehabilitation (RR 0.61, 95.0% CI: 0.40; 0.94; p=0.026). Not using a prosthesis exposes an individual to substantially worse functional status as compared to using a prosthesis (RR 2.61, 95.0% CI: 2.02; 2.37; p = <0.001).

In adjusted analysis (the following variables were adjusted: gender, consuming alcohol, level of amputation, cause of amputation, in-patient rehabilitation and out-patient rehabilitation), not consuming alcohol was now protective from sub-optimal function adjusted RR (aRR 0.62, 95.0% CI: 0.53; 0.71; P<0.001) (Table 4.5). A person with a knee disarticulation type of amputation was now associated with 98.0% increased risk of having suboptimal functional status compared to a person with a trans-tibial amputation (aRR 1.98, 95.0% CI: 1.74; 2.25; p<0.001). If the cause of amputation was non-traumatic, this was associated with 23.0% increased risk of sub-optimal function compared when the cause was traumatic (aRR 1.23, 95.0% CI: 1.06; 1.43; p=0.007). The protective effect of in-patient rehabilitation was stronger in adjusted analysis (a RR 0.53, 95% CI: 0.36; 0.78; p=0.001). Furthermore, not receiving out-patient rehabilitation was associated with an 85.0% increased risk of having sub-optimal function (aRR 1.85,95% CI: 1.63; 2.10; p<0.001).

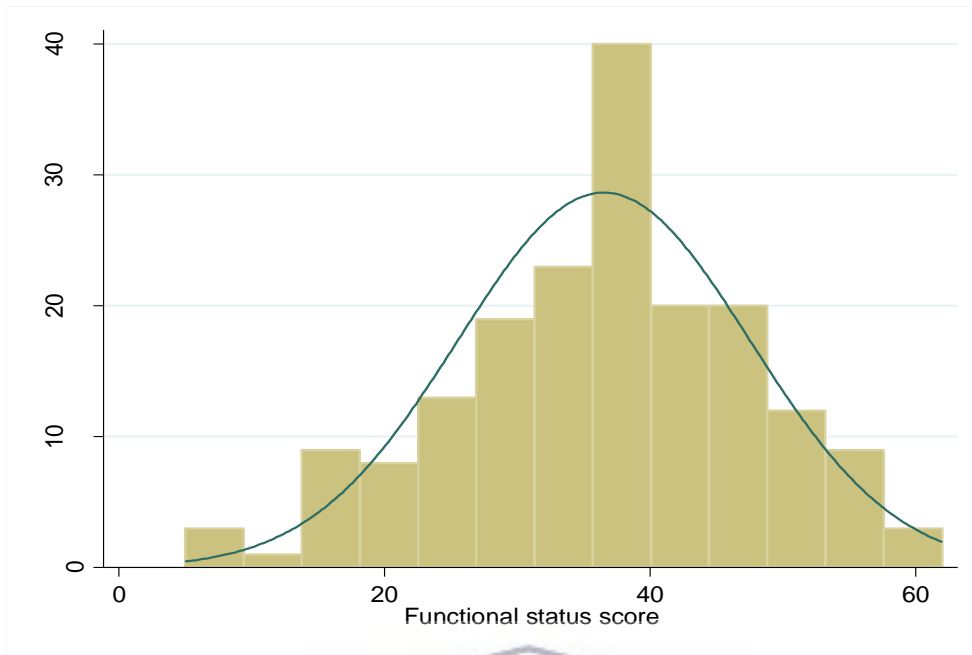


Figure 4.1 Distribution of functional status score

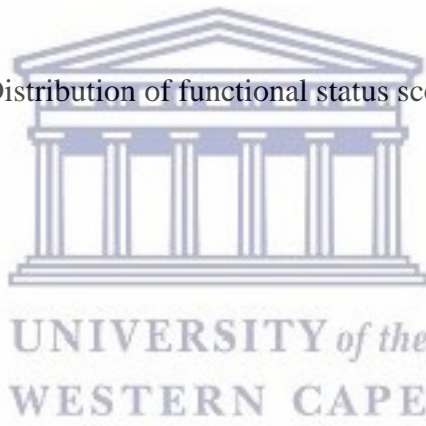


Table 4.3 Unadjusted association between functional status and demographic and other variables

Variable	Category	Functional status		RR	95% CI	p-value*
		Good n (%)	Suboptimal n (%)			
Total	N	99 (55.0)	81 (45.0)	NA		
Age (years)**	Median (IQR)	37 (23; 53)	44 (26; 56)	1.00	0.99; 1.01	0.468
Sex	Male	59 (52.7)	53 (47.3)	ref		
	Female	40 (58.8)	28 (41.2)	0.87	0.62; 1.23	0.429
Marital status	Married	53 (54.1)	45 (45.9)	ref		
	Single	38 (60.3)	25 (39.7)	0.86	0.60; 1.25	0.443
	Widowed/Separated/Divorced	8 (42.1)	11 (57.9)	1.26	0.81; 1.96	0.301
Occupation	Employed	17 (60.7)	11 (39.3)	ref		
	Unemployed	11 (44.0)	14 (56.0)	1.42	0.81; 2.54	0.228
	Farmer	23 (50.0)	23 (50.0)	1.27	0.74; 2.19	0.385
	Business	26 (59.1)	18 (40.9)	1.04	0.58; 1.86	0.891
	Student	18 (58.1)	13 (41.9)	1.07	0.57; 1.98	0.836
Smoking	Yes	15 (57.7)	11 (42.3)	ref		
	No	84 (54.6)	70 (45.4)	1.07	0.66; 1.74	0.770
Alcohol	Yes	15 (44.1)	19 (55.9)	ref		
	No	84 (57.5)	62 (42.5)	0.76	0.53; 1.08	0.128
Level of amputation	Trans-tibial	70 (59.8)	47 (40.2)	ref		
	Trans-femoral	24 (49.0)	25 (51.0)	1.27	0.89; 1.81	0.184
	Knee disarticulation	4 (30.8)	9 (69.2)	1.72	1.13; 2.63	0.012
Side of the body amputated	Left	46 (53.5)	40 (46.5)	ref		
	Right	52 (55.9)	41 (44.1)	0.95	0.69; 1.31	0.744
Cause of amputation	Traumatic	63 (59.4)	43 (40.6)	ref		
	Non-traumatic	34 (47.2)	38 (52.8)	1.30	0.95; 1.79	0.104
Prosthetic use	Yes	95 (66)	49 (34)	ref		
	No	4 (11.1)	32 (88.9)	2.61	2.02; 2.37	<0.001
In-patient rehabilitation	Yes	61 (48.8)	64 (51.2)	ref		
	No	37 (68.5)	17 (31.5)	0.61	0.40; 0.94	0.026
Duration of rehabilitation†	Median (IQR)	1 (1; 2)	1 (1; 1)	0.93	0.79; 1.11	0.422
Out-patient rehabilitation	Yes	39 (60.9)	25 (39.1)	ref		
	No	59 (51.3)	56 (48.7)	1.25	0.87; 1.78	0.229

RR: risk ratio; CI: confidence interval; NA: not applicable; IQR: inter-quartile range

* Simple binomial regression

** For every additional year

† For every additional month in rehabilitation

Table 4.4 Adjusted association between functional status, demographic and other variables

Variable		Unadjusted			Adjusted		
		RR	95% CI	P-value*	RR	95% CI	P-value‡
Age **	Years	1.00	0.99; 1.01	0.468	1.00	1.00; 1.01	0.659
Sex	Male	ref			ref		
	Female	0.87	0.62; 1.23	0.429	0.88	0.68; 1.12	0.292
Alcohol	Yes	ref			ref		
	No	0.76	0.53; 1.08	0.128	0.62	0.53; 0.71	<0.001
Level of amputation	Trans-tibial	ref			ref		
	Trans-femoral	1.27	0.89; 1.81	0.184	1.32	0.95; 1.82	0.094
	Knee disarticulation	1.72	1.13; 2.63	0.012	1.98	1.74; 2.25	<0.001
Cause of amputation	Traumatic	ref			ref		
	Non-traumatic	1.30	0.95; 1.79	0.104	1.23	1.06; 1.43	0.007
In-patient rehabilitation	Yes	ref			ref		
	No	0.61	0.40; 0.94	0.026	0.53	0.36; 0.78	0.001
Out-patient rehabilitation	Yes	ref			ref		
	No	1.25	0.87; 1.78	0.229	1.85	1.63; 2.10	<0.001

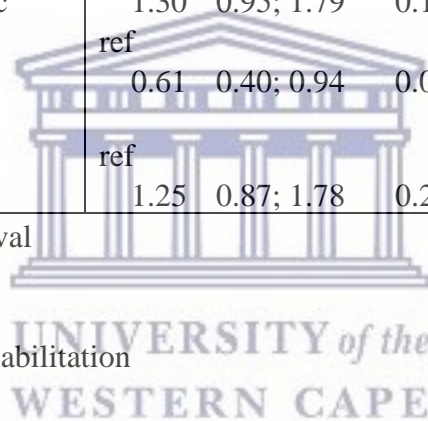
RR: risk ratio; CI: confidence interval

* Simple binomial regression

** For every additional year

† For every additional month in rehabilitation

‡ Multivariate binomial regression



4. 2.4 Psychological status

Of the 180 participants, (51.7%; n= 93) reported good psychological status based on having a median psychological status score greater than or equal to the median of 7.0. In unadjusted analysis, consuming alcohol was associated with 74.0% increased risk of having sub-optimal psychological status (a RR 1.74, 95% CI: 1.05; 2.88; p=0.033) (Table 4.6). Receiving in-patient rehabilitation was significantly protective from having sub-optimal psychological status (a RR 0.60, 95% CI: 0.41; 0.89; p=0.011).

In adjusted analysis, consuming alcohol was strongly associated with having sub-optimal psychological status (a RR 2.00, 95% CI: 1.153; 3.50; p<0.015) (Table 4.7). The protective effect of in-patient rehabilitation was stronger in adjusted analysis with (a RR 0.53, 95% CI: 0.35; 0.79; p=0.002). However, not receiving out-patient rehabilitation was associated with increased risk of having sub-optimal psychological status (a RR 1.38, 95% CI: 1.04; 1.85; p=0.028).

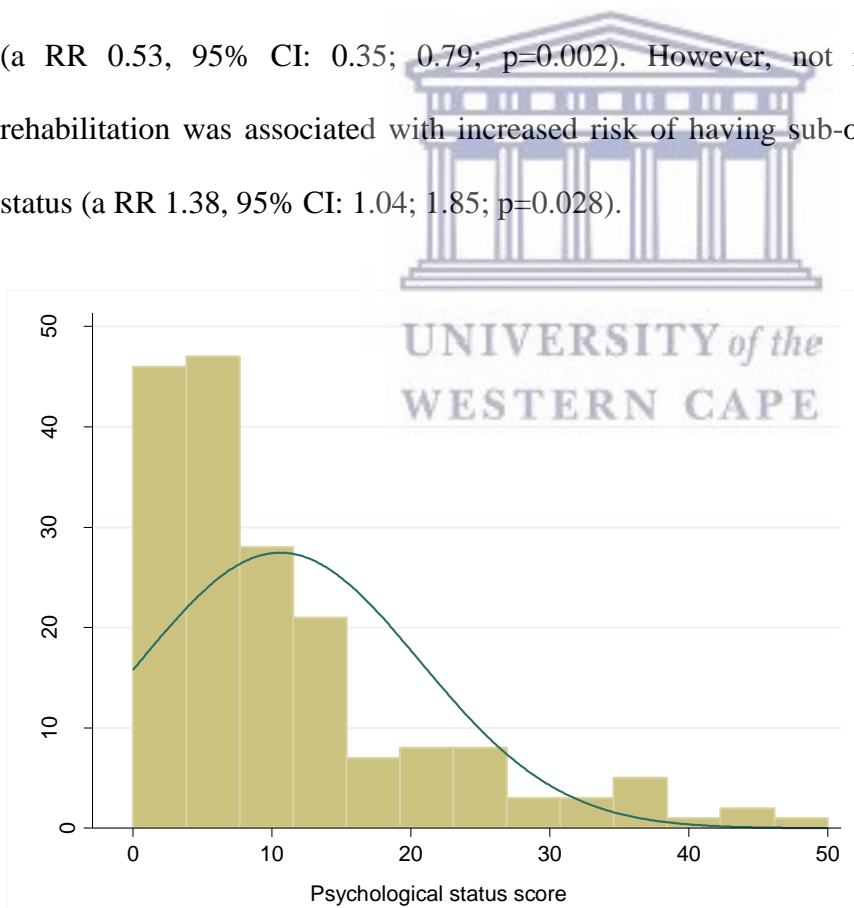


Figure 4.2 Distribution of psychological status scores.

Table 4.5: Unadjusted association between psychological status and demographic and other variables

Variable	Category	Psychological status		RR	95% CI	p-value*
		Good n (%)	suboptimal n (%)			
Total	n	93 (51.7)	87 (48.3)	NA		
Age (years)**	Median (IQR)	44 (27; 57)	39 (20; 50)	0.99	0.99; 1.00	0.111
Sex	Male	58 (51.8)	54 (48.2)	ref		
	Female	29 (42.7)	39 (57.3)	1.19	0.90; 1.58	0.226
Marital status	Married	52 (53.1)	46 (46.9)	ref		
	Single	25 (39.7)	38 (60.3)	1.29	0.96; 1.72	0.091
	Widowed/Separated/Divorced	10 (52.6)	9 (47.4)	1.01	0.61; 1.70	0.973
Occupation	Employed	13 (46.4)	15 (53.6)	ref		
	Unemployed	9 (36.0)	16 (64.0)	1.19	0.76; 1.88	0.442
	Farmer	26 (56.5)	20 (43.5)	0.81	0.50; 1.31	0.391
	Business	21 (47.7)	23 (52.3)	0.98	0.62; 1.52	0.914
	Student	13 (41.9)	18 (58.1)	1.08	0.69; 1.71	0.730
Smoking	Yes	16 (61.5)	10 (38.5)	ref		
	No	71 (46.1)	83 (53.9)	1.40	0.84; 2.33	0.193
Alcohol	Yes	23 (67.6)	11 (32.4)	ref		
	No	64 (43.8)	82 (56.2)	1.74	1.05; 2.88	0.033
Level of amputation	Trans-tibial	58 (49.6)	59 (50.4)	ref		
	Trans-femoral	22 (44.9)	27 (55.1)	1.09	0.80; 1.49	0.575
	Knee disarticulation	7 (53.9)	6 (46.1)	0.92	0.50; 1.69	0.777
Side of the body amputated	Left	38 (44.2)	48 (55.8)	ref		
	Right	49 (52.7)	44 (47.3)	0.85	0.64; 1.13	0.256
Cause of amputation	Traumatic	57 (53.8)	49 (46.2)	ref		
	Non-traumatic	30 (41.7)	42 (58.3)	1.26	0.95; 1.68	0.108
Prosthetic use	Yes	68 (47.2)	76 (52.8)	ref		
	No	19 (52.8)	17 (47.2)	0.89	0.61; 1.31	0.564
In-patient rehabilitation	Yes	52 (41.6)	73 (58.4)	ref		
	No	35 (64.8)	19 (35.2)	0.60	0.41; 0.89	0.011

Duration of rehabilitation†	Median (IQR)	1 (1; 1)	1 (1; 1.5)	0.94	0.81; 1.10	0.441
Out-patient rehabilitation	Yes	34 (53.1)	30 (46.9)	ref		
	No	53 (46.1)	62 (53.9)	1.15	0.84; 1.57	0.378

RR: risk ratio; CI: confidence interval; NA: not applicable; IQR: inter-quartile range

* Simple binomial regression

** For every additional year

Table 4.6 Adjusted association between psychological status, demographic and other variables

Variable		Unadjusted			Adjusted		
		RR	95% CI	p-value*	RR	95% CI	p-value‡
Total	n	NA					
Age (years)**	Years	0.99	0.99; 1.00	0.111	1.00	0.99; 1.00	0.426
Sex	Male	ref			ref		
	Female	1.19	0.90; 1.58	0.226	1.06	0.82; 1.38	0.657
Smoking	Yes	ref			ref		
	No	1.40	0.84; 2.33	0.193	0.72	0.51; 1.02	0.063
Alcohol	Yes	ref			ref		
	No	1.74	1.05; 2.88	0.033	2.00	1.15; 3.50	0.015
Cause of amputation	Traumatic	ref			ref		
	Non-traumatic	1.26	0.95; 1.68	0.108	1.20	0.92; 1.55	0.172
In-patient rehabilitation	Yes	ref			ref		
	No	0.60	0.41; 0.89	0.011	0.53	0.35; 0.79	0.002
Out-patient rehabilitation	Yes	ref			ref		
	No	1.15	0.84; 1.57	0.378	1.38	1.04; 1.85	0.028

RR: risk ratio; CI: confidence interval

* Simple binomial regression

** For every additional year

† For every additional month in rehabilitation

‡ Multivariate binomial regression

4.3 Qualitative results

4.3.1 Introduction

This section outlines the findings of the semi-structured interviews with the participants. After the analysis of the interviews, the findings are categorized into themes which are defined according to ICF.

4.3.2 Demographic details

The age of the participants in the qualitative component of the study ranged from 23-65 years of age. The mean age of the participants was 37 years old at the time of data collection. Seven participants were females and the other seven were males. Eight participants had an amputation secondary to trauma while six participants had non-traumatic amputation. Five participants had a trans-femoral amputation while nine participants had a trans-tibial amputation. Ten participants were prosthetic users and three participants were non-prosthetic users.

Table 4.7. Demographics of the participants in the qualitative study

Participant number	Gender	Age	Level of amputation	Cause of amputation	Prosthetic use
1	Male	35	Trans-tibial	Traumatic	Yes
2	Female	65	Trans-tibial	Non-traumatic	No
3	Female	56	Trans-tibial	Traumatic	Yes
4	Female	36	Trans-tibial	Non-traumatic	Yes
5	Male	25	Trans-femoral	Non-traumatic	Yes
6	Male	38	Trans-tibial	Non-traumatic	Yes

7	F	23	Trans-femoral	Traumatic	Yes
8	M	28	Trans-tibial	Traumatic	Yes
9	F	35	Trans-tibial	Non-traumatic	No
10	M	28	Trans-tibial	Traumatic	No
11	F	35	Trans-femoral	Traumatic	Yes
12	M	38	Trans-tibial	Traumatic	No
13	F	32	Trans-femoral	Non-traumatic	Yes
14	M	47	Trans-femoral	Traumatic	Yes

4.3.3 Themes identified from the analysis of interviews

The themes were identified from the responses of the participants and they are categorized as barriers to social participation and community integration, and the facilitators to social participation and community integration.



Table 4.8 An overview of the main themes and categories.

Theme	Category	Supporting quote
Barriers to social participation and community integration	Problems with body-image -Social discomfort -Social isolation	<i>“people will look at the way am walking and this makes me feel uncomfortable and shy” (P 7)</i>
	Social stigmatization -Discrimination -Societal attitudes -Feeling of not being respected	<i>“There is a time that I applied for a job at a certain company (I: mmm) but I was told that I cannot manage to do the work because of my condition” (P 9)</i>
	Physical and environmental challenges -Accessibility problems. -Functional challenges. -Financial constraints	<i>“like the way my school is (chancellor college) for me to move around especially using steps (I; mmm) they are hard to climb in that way, I feel like I am a failure unless there could be an elevator.” (P 5)</i>
	Emotional problems	<i>“Life with amputation is very disappointing, because am not able to leave in peace and chart with my friends..... because most of the time I am worried” (P 7).</i>
Facilitators to social participation and community integration	Family and community support	<i>“when I am having problems with food or money they would contribute and assist me including the transport money that I used for rehabilitation</i>

		<i>checkups”. (P 9).</i>
	Access to a prosthesis	<i>“There is no difference. It is the same when I had my natural leg and this artificial leg because I can walk long distances and do my businesses and come back (I: mmm)” (P 4).</i>

4.3.3.1 Barriers to social participation and community integration

4.3.3.1.1 Problems with body image

In this study, participants reported numerous challenges with their body image. Some participants reported having problems with their appearance and felt that they are completely different from other people and some think that they are not even worthy to be among their friends because of how they appear. The majority indicated that being self-conscious about their appearance has affected them greatly in community participation.

“...people will look at the way I am walking and this makes me feel uncomfortable and shy” (P 7)

“It appears ...as if we are not the same as other people.” (P 1)

Social discomfort. Due to problems with body image, participants reported feelings of social discomfort when they are among the community. The participants reported not feeling comfortable exposing their prosthetic limb among the people surrounding them.

They would try to hide the amputated limb as well as the prosthesis so that people would not be aware that they are using an artificial limb.

“...sometimes I am able to hide my artificial limb in a way that people are not able to notice that I am having a disability.” (P 1)

“(I; mmm) for example if I go to church meetings where I will spend some days, it becomes a bit difficult. My friends know that I am disabled but they don’t know the extent of my disability. So am like a slave for the whole period, during the night I have to wait for everyone to sleep in order for me to take off my artificial limb and I would wake up early in the morning while everyone is still asleep to put it on. I normally do this till the end of the meeting, this is because I do not want to divert peoples’ minds and focus on my condition”. (P13)

“I cannot walk with a short, I need to always put on trousers” (P13).

Social isolation. Some participants indicated that because of the problems of body image, they decided to isolate themselves from their friends and community activities. Some reported that they resolved to social isolation because they feel shy and uncomfortable when they are among their friends, while others resolve to social isolation because of the attitude of the society.

“Since I had this amputation, I have never been with my friends or do community things or whatever. Am always at home. They are the ones who come to visit me”.
(P 2)

“I decided to withdraw myself from my friends because of the way they talk or behave about my condition”. (P 7)

4.3.3.1.2. Social stigmatization

Some participants reported that they experience challenges with social stigmatization. Participants experience social stigmatization when they are looking for a life partner or during courtship or within the marriage which result into being divorced. Some experience stigmatization when they are seeking for employment. Within social stigmatization participants reported problems with the attitude of the society and they somehow feel that they are not respected within the society.

“(Eeeeh). Only that my wife and her parents did not listen to what people were saying because some people were asking them that how can they allow their daughter to marry a disabled person?” (P 14)

“When my husband proposed to me some people were telling him that why did you propose to that lady (I: mmm) can't you see good women”. (P 9).

” Before I bought the artificial limb, and when I was going to the market some people would say andichi, meaning a disabled person” (P 4).

Discrimination. Participants reported of being discriminated against in different community activities. Some of these activities are like community programs where the leaders have to choose beneficiaries of certain activities like social cash transfers or if they are to benefit from certain government programs like receiving fertilizer subsidies.

Participants feel that this affects their effective participation and integration into the community.

“You will find out that community leaders who are given the task to register beneficiaries of other community programs discriminate against me and my name does not appear in all the programs.” (P14)

“I am discriminated against in many community activities for example when people are receiving something from the government my name is not included or registered, People are not even concerned that there is a disabled person here and they do not care”. (P 13).

Societal attitudes. Some of the participants reported that they meet challenges in social participation and community integration because of the attitude of the society towards their condition. According to the participants, the societal attitudes included the way people talk to them, others laugh at the way they walk and some even reported that they receive abusive words from the society.

“When I go out for a walk I receive a lot of insults like people will say, (I: mmh) she was proud when she was walking properly today she is not walking because her leg was cut, and all the pride is gone.” (P 12).

“When am riding a bicycle, the other leg does not reach down the pedals properly. People laugh at me in the streets even when I am walking, children imitate me (I: mmm) and some laugh. And this include women as well they also laugh at me”. (P 11).

One of the participants reported of feeling vulnerable due to the attitude of the society. She is threatened that the remaining stump will be cut whenever she has an argument with friends.

“When am among a group of my friends and we differ on something, they talk about my amputated leg (I: mmm) they say, we will remove the remaining part of your amputated leg.” (P 7).

Feelings of not being respected. One of the participants reported that as a person with disability, he feels that he is not respected amongst his peers. People talk to him as if he is a young person. In that way he feels that people with disabilities are not respected in such a way that there is no difference whether someone is old or young.

“For example when a person is old, he is given respect like he is not my age..... But for us when someone wants to talk to us, whether he is young, he talks to you like his age mate. Even your fellow grownups or children, they talk to you like a disabled person who has less value.” (P 13)

4.3.3.1.3 Physical and environmental challenges

Accessibility problems. Some participants reported having physical as well as environmental challenges such as accessibility problems. Participants reported experiencing problems in accessing certain areas in the community due to the environment surrounding them. The main concerns with accessibility were problems in climbing stairs and inadequate space in the minibus taxis.

“like the way my school is (chancellor college) for me to move around especially using steps (I; mmm) they are hard to climb in that way, I feel like I am a failure unless there could be an elevator.” (P 5)

” When am boarding public transport where there are a lot of people, I do find problems to find enough space to sit, I have to look for a car which does not have a lot of people” (P 5).

“When am boarding the minibus and if there is some one sitting on the front seat, he/she changes the seat in order to provide enough space for me to sit”. (P 3)

Functional challenges. Other participants reported that they experience challenges participation in the society due to their physical functional challenges. These challenges included walking long distances and performance in activities of daily living.

“I am having problems with walking, and am just sitting at one place without doing anything.” (P 3).

And some of the activities I can't even manage them because this time I don't have enough strength and there are some activities that require someone to assist e.g. washing clothes, drawing water, (P 11).

“This operation has disturbed me in a lot of things, like the issue of standing, toileting, and doing other things.” (P 12).

One of the participants also reported that because of functional restrictions she is experiencing restrictions to participate in leisure activities

“like I used to play netball, and I can no longer do that”. (P 12).

Financial constraints. As a result of functional challenges like mobility, most participants reported that they are not able to continue with their work/ businesses to earn a living as they used to do before the amputation and this has affected their financial status.

“My 99% of life has been affected by amputation (I: mmm) I was doing my business but now I can’t go out to do my businesses as I used to do.” (P2).

Due to financial problems, some of the participants reported that they are unable to raise resources to manage their homes, inability to participate in some of the community activities due to lack of transport problems.

“I face a lot of problems in my home e.g. the way to find food and other necessities like soap, it’s very hard.” (P6)

“Am living like a child because am no longer doing business and am given everything including money for airtime for my cell phone.” (P 12).

4.3.3.1.4 Emotional problems

As a result of the challenges which people with lower limb amputations experience in the community, some participants expressed emotional problems as they are failing to achieve what they had planned. Others expressed emotional problems because of the way the society treat them.

“I feel so touched that I would have achieved everything that I had planned in my life, and my books, as of now the future of my children and family is gone” (P 6).

“I feel like am not worthy because when I mix with other people they do not look at me” (P 7).

4.3.3.2 Facilitators to social participation and community integration

4.3.3.2.1 Family and community support

Family and community support have been reported by most of the participants as some of the factors which assist them to adjust and participate in the community. Almost all the participants reported that their family members have been of the greatest help since the amputation. The support has been in different forms like psychological, financial and physical such as performance of ADLS.

“when am having problems with food or money they would contribute and assist me including the transport money that I used for rehabilitation checkups”. (P 9).

“(I: mmm) as am saying, up to now if I could say bring my clothes I want to wash they will stop me and assist to wash my clothes.”. (P3).

Community support. Some participants reported that they receive support from the community. The support has been expressed in terms of financial, social and physical help. Some of the participants have expressed that the support which they receive from the community has assisted them to settle down.

“I have discovered love from the public, one day when I was coming from the review clinic, as I was trying to cross the road one of the minibus call boys rushed and told the driver to open the front seat door for me, the driver welcomed me and asked him to assist me to enter the minibus”. (P 2)

“the transport that I have used to come here it’s a contribution from the church members”. (P 9).

4.3.3.2.2 Access to a prosthesis

Two participants reported that though they are living with an amputation, they are living happily and are very satisfied with their prosthetic limbs. In these instances, having a prosthesis was a facilitator to community integration.

“Am very happy comparing to the way I was before the artificial limb, when I was using crutches my life was so hard because (I: mmm) I could not even go to the maize mill.....There is no difference. It is the same when I had my natural leg and this artificial leg because I can walk long distances and do my businesses and come back (I: mmm)” (P 4).

4.4. Summary of chapter

The results of quantitative study show that some people (45.0%; n= 81) with lower limb amputations present with difficulties in executing functional activities. This has been substantiated by the qualitative results. Participants with a knee disarticulation type of amputation presented with an increased risk (98.0%) for suboptimal functional as compared to participants with a trans-tibial amputation ($p < 0.001$). The participants with non-traumatic amputations had a significantly increased risk (23.0%) of developing suboptimal function as compared to those with traumatic amputations ($p = 0.007$). The participants who received in-patient rehabilitation significantly reported good functional status as compared to participants who did not receive in-patient rehabilitation ($p = 0.001$). However, the participants who did not receive out-patient rehabilitation reported a worse

functional status as compared to those who received out-patient rehabilitation ($p = <0.001$). Non-prosthetic users presented with worse functional status as compared to prosthetic users ($p = <0.001$).

In the study, depression has been found to be present among (48%; $n = 87$) of people with lower limb amputations. These results are also consistent with qualitative findings of the study where some participants reported emotional problems as one of the experiences that they encounter in the community. Receiving in-patient and or out-patient rehabilitation both served as statistically significant protecting factors from developing depression symptoms. The results show that consuming alcohol predisposed participants to a worse functional and psychological status.

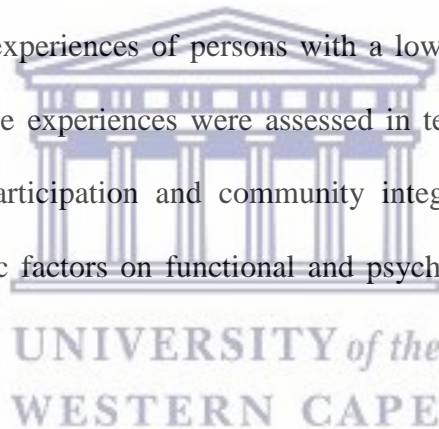
The results show that people with lower limb amputations have different experiences in their communities. Some of these experiences are reported as barriers to social participation and community integration while others were facilitators to community integration and social participation. The barriers identified in this study included problems with body image, social stigma, physical and environmental challenges and emotional challenges. The facilitators include community and family support and access to a prosthesis.

CHAPTER FIVE

DISCUSSION

5.1 Introduction

This chapter will discuss the main findings of the study in relation to the relevant literature and will also highlight the potential clinical implications. Living with disability in a developing country like Malawi presents significant challenges to persons with lower limb amputations. The community experiences of persons with a lower limb amputation were investigated in the study. These experiences were assessed in terms of functional status, psychological status, social participation and community integration. Furthermore, the influence of socio-demographic factors on functional and psychological status were also explored in the study.



A person who suffered a lower limb amputation's life is changed drastically. Living with an amputation affects a person's physical and psychological status, and in turn, their participation in ADLS, social participation and integration into the community is also affected. These challenges affect full participation in the community. The results of the study will be discussed under the following headings: functional status, psychological status and barriers and facilitators to community participation and integration.

5.2 Functional status

Some of the participants in the study (45%; n=81) presented with sub-optimal functional status (functional difficulties) as measured by the OPUS lower limb functional measure survey. These results are supported by the studies of Kohler et al. (2009) and Burger et al. (2005) which both indicated that people with lower limb amputations present with problems in mobility and performance of ADLS. Difficulties in mobility and performance of functional activities may result in dependency on others in performing ADL's which, in turn, might result in frustration and depression. Consequently, depression may restrict participation in the community. Participants who did not receive in-patient as well as out-patient rehabilitation were significantly more at risk for sub-optimal functional status as well as worse psychological status. Therefore, rehabilitation should be a priority in order to improve mobility and subsequent psychological status. More specifically, rehabilitation should emphasize gait training. Rehabilitation should also be focused on functional training in order to ensure that patients are able to ambulate independently in their communities.

The level of lower limb amputation was found to directly affect functional status of persons with lower limb amputation. Persons with a trans-tibial amputation, presented with a better functional status when compared to persons with knee disarticulation type of amputations. There were, however, no statistically significant difference between the functional status of persons with trans-tibial and trans-femoral amputations. This finding is contrary to the results reported by Hogan MacLachlan (2004), which indicated a significant difference in functional status of people with trans-tibial and trans-femoral amputations. The reason

could be because there was no statistically significant difference on the number of prosthetic users between people with trans-tibial and trans-femoral amputations. Therefore, the use of prosthesis might mitigate the differences in the functional status of persons with trans-tibial and trans-femoral amputations. The study found that having a knee disarticulation predisposed participant to having 98.0% chance of developing suboptimal function as compared to trans-tibial amputation ($p < 0.001$). This could be because there was a large percentage of persons with through-knee amputations who were non prosthetic users as compared to the percentage of persons with trans-tibial amputations (Table 4.3). Furthermore, another reason could be that persons with knee disarticulation are less likely to have a prosthesis as compared to their counterparts. This shows that having a knee disarticulation amputation might affect physical function of an individual. Therefore, intensive rehabilitation of people with knee disarticulation amputation could be important in improving their function in the community. Surgeons should also be made aware about the most appropriate stump length in order to maximize the function of a person with lower limb amputation. More research is required to explore why people with a knee disarticulation type of amputation present with worse functional status.

The cause of amputation also influenced the functional status of an individual. In this study, persons with non-traumatic amputations have a significant risk of developing suboptimal function as compared with those with traumatic amputations ($p = 0.007$). These results are similar to the results of the study which was conducted by Zidarov et al. (2009) and Schoppen et al. (2003) who reported that people with amputations secondary to DM and vascular diseases have reduced function as compared to those with traumatic amputations. The reason behind this could be because of the fact that non traumatic

amputations present with additional comorbidities which may reduce their functional status. Patients who suffered traumatic amputations are often also younger than those who suffer non-traumatic amputations, so they might have had a better baseline functional status. Therefore, more emphasis on functional performance training should be considered in the rehabilitation of people with non-traumatic amputation in order to improve their functional status. If there is any presence of other comorbidities, they should be managed thoroughly.

People with lower limb amputations who had received in-patient rehabilitation reported to have statistically significant good functional status as compared to those who did not ($p=0.001$). These results are supported by the findings of the study which was done by Pezzin et al. (2000) who reported that in-patient rehabilitation significantly improves the physical function, pain and vocational outcomes. Lack of in-patient rehabilitation may negatively affect the physical function (mobility, and ADLS performance) of people with lower limb amputation. This may in-turn result into activity limitations and participation restrictions within the communities. It is, therefore, recommended that people with lower limb amputations should be provided with in-patient rehabilitation services (both pre- and post-operative) in order to achieve good functional status.

The results of the study show that participants who had not received out-patient rehabilitation presented with statistically significant worse function as compared to those who received out-patient rehabilitation ($p < 0.001$). These results are in line with the report from the study which was conducted by Collins and Timmons (2018), which highlights that receiving out-patient rehabilitation enhances good functional outcome

following lower limb amputation. The reasons why the majority could not have accessed out-patient rehabilitation in Malawi might be due to inadequate access to rehabilitation services. This is evidenced by the study which was conducted by Chimatiro (2012) in Malawi, where some people with stroke reported limited rehabilitation services countrywide which had contributed for them to remain inactive and not fully participate in the community. Furthermore, another reason for inability of people with lower limb amputation to attend out-patient rehabilitation services could be due to poor referral systems. Most patients are discharged from the hospital wards without being referred for Physiotherapy Management. As reported in Ennion and Johannesson (2017), lack of an adequate referral system may contribute to greater challenges in rehabilitation/physiotherapy management. Failure to receive out-patient rehabilitation can affect an individuals' physical performance which may in turn result into activity limitation and participation restrictions. Therefore, awareness of patients as well as other medical personnel's is very important in-order to facilitate that people with lower limb amputation should attend the services to improve the physical function and as well as community participation and integration.

The use of a prosthesis in people with lower limb amputation has been found to have a statistically significant good functional status as compared to people who are non-prosthetic users ($p = <0.001$). These results are supporting the qualitative findings of the study where some people reported good functional status with the use of the prosthesis as compared to when they had no prosthesis. Similarly, Ennion and Rhoda (2016) indicated that participants reported improved function with the use of prosthesis. Fredricks and Visage (2013) emphasized prosthetic rehabilitation and training to be very important in

improving in-door as well as outdoor mobility. The researchers further reported that addressing community mobility during prosthetic rehabilitation has a significant impact on the aspects of community mobility like going up and down stairs, walking on bad weather and different terrain. Without a prosthesis, people with lower limb amputations could face many challenges in physical function, mobility and performance of ADLS. Therefore, use of prosthesis and prosthetic rehabilitation should be emphasized in order to improve functional performance of people with lower limb amputation.

The study shows that two thirds of the participants were not followed up post- amputation discharge as it is reported that the majority did not receive out- patient rehabilitation. According to WHO report (2008), part of comprehensive rehabilitation is to provide a comprehensive discharge follow-up for as long as necessary. Lack of follow up of people with lower limb amputations may result into different problems in the community like the physical well-being of the clients may be affected. For example, patients with other comorbidities need frequent monitoring to avoid more complications. Physical function, psychological as well as community participation and integration may also be affected because a person with difficulties in ADLS performance and mobility may develop psychological symptoms and will be restricted in participation. This in turn may worsen the disability and sometimes may increase mortality rate. It is recommended that the government should train and recruit more physiotherapists (rehabilitation personnel in district hospitals as well as rural hospitals) to enable people with lower limb amputations to access the services within their communities' post discharge.

Not consuming alcohol has been reported to have a statistically significant improved function as compared to those who were consuming alcohol ($P < 0.001$). This could be

because when someone is drunk, balance and coordination may be affected, and this could affect mobility and prosthetics use in the community. This information is new in literature, therefore, more research is required to confirm the findings. Rehabilitation of the people with lower limb amputation should include counselling on behavior change for those people who indulge themselves in alcohol and smoking.

5.3 Psychological status

Some of the participants (n=87; 48%) in the study presented with suboptimal psychological function (signs of depression). These results are supported by the qualitative findings of the study where quite a number of participants reported that they struggled emotionally after losing their limb. The prevalence of signs of depression in the current study sample was lower than what was reported in a study which was conducted by Ghallagher et al. (2011) and Ide (2010) where depression was present among 60-69% of people with lower limb amputation. Conversely, it was almost double the prevalence that was reported in the studies done by Darnall et al. (2005) and Siedel et al. (2006) who reported presence of depression signs among 21-35% of people with lower limb amputations. These differences may be attributed to the differences in the instruments of data collection. For example, Ide (2010) used Zung self –rating depression scale and Darnall et al. (2005) used a Centre for Epidemiological Study Depression Scale (CES-D 10 item). Depression signs in people with lower limb amputation might appear because of the changes in the body image and difficulties in adjustment and coping with the impairment (Desmond & MacLauchlan, 2006). In this study, people reported that changes in their body image negatively influenced their participation in the communities, which in turn, could lead to feelings of isolation and depression. Multidisciplinary management of people with lower limb amputations is very

necessary in order to reduce effects of depression. People with lower limb amputation should be referred for psychological counselling pre- amputation as well as post – amputation with the aim of reducing or preventing post-amputation depression.

The study found that there was no stastically significant difference between the psychological function (depression) of people with traumatic and non- traumatic amputations ($p= 0.172$). Although most studies reported that persons with traumatic amputations present with high risk of psychological dysfunction (Canserver et al., 2003; Linveh et al., 1999). However, the results of the study are in line with the findings of an older study which was conducted by Williams and Waters (1996) who reported that there is no relationship between cause of amputation and psychological function of an individual. Similarly, Singh et al. (2009) reported that there is no relationship between the cause of amputation and psychological symptoms.

The level of amputation has been found to have no influence on psychological function of a person with lower limb amputation. There was no statistically significant difference between the psychological function of the trans-tibial, trans-femoral and through knee amputation. These results are contrary to the findings of the study which was conducted by Hawamdeh et al. (2004) in middle east /Asia, which indicated that people with trans-tibial amputations present with high prevalence of depression symptoms as compared to other levels. The differences in the results could be attributed to different social factors and cultural beliefs such as believing that amputations make an individual to be in-complete.

Receiving in-patient rehabilitation is reported to have a stastically significant positive effect on psychological status as compared to those who did not ($p=0.002$). On the other hand,

not receiving out-patient rehabilitation is reported to have a statistically significant increase in psychological symptoms (depression) as compared to those who received out-patient rehabilitation ($p= 0.028$). These results highlight the importance of rehabilitation (both in-patient and out-patient) in patients with lower limb amputation to prevent psychological symptoms. Therefore, in-patient and out-patient rehabilitation is very important to improve psychological function of a person with lower limb amputation. Multidisciplinary rehabilitation of people with lower limb amputation should be emphasized to prevent psychological symptoms.

Not consuming alcohol has been found to have a statistically significant good psychological status as compared to consuming alcohol ($p=0.015$). This could be related to the fact that people with lower limb amputation who consume alcohol present with suboptimal functional status as reported in the results. Reduction in functional status may contribute to depression and frustrations. This is new information which requires more research. Therefore, rehabilitation of people with lower limb amputation should include counselling on behavior change for those people who indulge themselves in alcohol and smoking.

5.4. Barriers to social participation and community intergration.

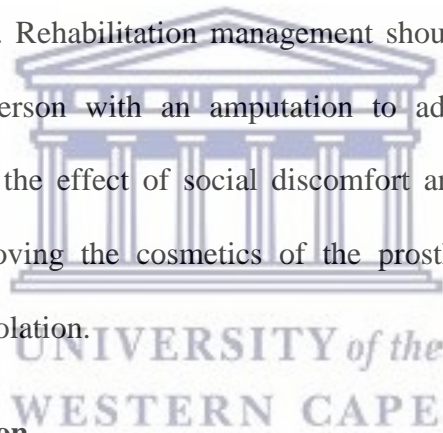
The following were reported as barriers to community participation and intergration: problems with body image, social stigmatization, physical and environmental challenges and emotional challenges.

5.4.1 Problems with body image.

Problems with body image were reported by some of the participants as a barrier to social participation and community integration. Participants reported having problems with their appearance and some of them felt that they are completely different from other people. Due to changes in body image, they become shy and did not want to go out. These results are echoed by Zidarov et al. (2009) and Courture (2012) indicated that a disturbance in body image becomes a major problem after amputation of the lower limb. As reported in MacLachlan (2004), disruption of body image has a negative impact on self-identity. A problem with body image may affect the social participation and psychological function of an individual resulting in participation restriction. Therefore, rehabilitation management should include post-amputation counselling in order to assist persons with lower limb amputation to adjust to the new sense of identity and be able to live successfully.

Due to the problems of body image, participants reported experiencing social discomfort such that they developed strategies to make sure that they should not expose their amputated limb/prosthesis. Others preferred to hide the artificial limb by always wearing long dresses or trousers instead of shorts. In addition, some people reported that they become very conscious about the way they walk so that people should not notice that they are using an artificial limb. These results are similar to the findings of the study which was conducted in Johannesburg (South Africa) by Goldwana and Stewart (2013). The study findings indicated that participants were self-conscious about their appearance and image especially in public places. These participants had a perception that people think that they are different instead and they opt to put on long pants when they are going out so that people should not notice them.

As a result of the problems with body image and social discomfort, participants opted to withdraw/ isolate themselves from community activities and the public. Participants opted to withdraw themselves because they felt shy and uncomfortable when they were among their friends. These results are consistent with the results of the study which was conducted in Taiwan by Liu et al. (2010), which reported that many participants preferred to stay indoors and did not want to go outside to meet visitors because they were afraid of the reaction of people when they see them or society rejection. Similarly, Karmel (2000) reported that social isolation may result from the following reasons: either the person is worried, depressed, anxious as well as sad about their condition. Social discomfort and isolation may have an impact on the psychological as well as social functioning of an individual. Rehabilitation management should include psychological counselling in order to assist the person with an amputation to adjust and cope with the amputation. This may in turn reduce the effect of social discomfort and isolation. In addition, according to Liu et al. (2010) improving the cosmetics of the prosthesis may also improve problems with social discomfort and isolation.



5.4.2 Social stigmatization

Social stigmatization has also been reported in the study as one of the barriers to participation and integration into the community. Participants reported that they experience stigmatization when seeking employment and they were turned down because of their physical impairment. These findings are similar to what is reported in a study which was conducted in South Africa by Naidoo and Ennion (2018). In this study, participants were excluded and not allowed to join certain groups due to their disability or the fact that they had an artificial limb. Similarly, Wegner and Rhoda (2015) in South Africa reported that people with disabilities face stigmatization in accessing public transport because there is a perception that people with disabilities are cursed. Social

stigmatization of people with a lower limb amputation may result in depression and reduced social participation in the community. Therefore, rehabilitation of people with amputations should include raising public awareness about amputations so that they should be given equal opportunities for employment and be allowed to participate in different roles in the society.

Discrimination has also been reported as one of the barriers to social participation and integration. The participants experienced discrimination in accessing government programs like receiving social cash transfers or fertilizer subsidy program. They reported that community leaders do not include their names on the list of beneficiaries. These results are similar to the report from Wegner and Rhoda (2015), which indicated that people with disabilities are perceived to be of less value in the community. This was evidenced when the participants were not included on the disability grant.

Negative societal attitudes were also reported by some of the participants as a barrier to participation and integration. Participants reported being insulted and mocked and others laughed at when they are in the community. These results are supported by the report from Andregard and Magnusson (2016) in Sierra Leone, which highlighted that participants were mocked and provoked, laughed at when they are participating in the society. Some participants reported that they are not being respected in the society by their peers. These results are similar to reports from Deal (2007) and Green (2007) that indicated that people with disabilities are perceived as people with less value in the society and that cannot contribute anything to the society because of the impairment. One of the participants of the study reported feeling of being vulnerable when she is among her friends because of the way they treat her. They threaten her that they will cut off the remaining stump whenever they have an argument. In support of this experience, Williams et al. (2004) reported that feelings of being vulnerable is common after limb amputations. Social

stigmatization, discrimination, societal attitudes, feelings of not being respected and feelings of being vulnerable may affect the psychological function (depression, anxiety) of an individual with lower limb amputation and this will have a negative impact on social participation and integration in the community. Therefore, rehabilitation should include community awareness on disability. The community should be informed about the rights of people with disabilities, emphasize on equal rights on people with disabilities and others.

5.4.3 Physical and environmental challenges

Problems with physical function have been reported as a barrier to community participation and integration. The physical challenges included mobility problems and performance in ADLS. These results are supported by the quantitative findings of the study which indicated that 45% (n = 81) of the participants reported suboptimal functional status (difficulties in functional activities). Similarly, Amoah et al. (2018) reported that participants with limb amputations had difficulties to perform daily functional activities independently to the extent that they had to depend on others. In addition, Naidoo and Ennion (2018) highlighted that participants were dependent on family and paid care givers to assist them in ADLS and participating in the community. Difficulties in performance of functional activities may result into social and psychological problems (frustrations, depression, anxiety and anger). This is because the person becomes dependent on others. In addition, restrictions in mobility may affect community participation. Rehabilitation should involve the multidisciplinary team and include ADLS and mobility training where patients will be trained on how to ambulate in the community like walking on an even ground (different terrain) and going up and down the stairs before discharge.

Due to problems with physical function, participants reported that they are not able to return to their previous employment. As a result, they become financially challenged. Some men reported

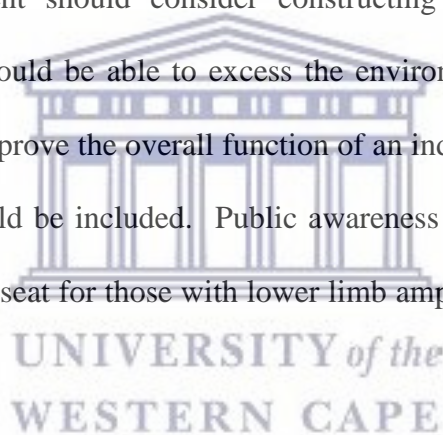
that they were not able to support their families. As a result, they depend on assistance from other people to manage their homes. These results are similar to the findings of Amoah et al. (2018) who reported that participants experienced economic challenges due to their inability to work, failure to return to employment or conduct their business. Consequently, financial challenges may result in psychological problems like depression, anxiety and frustrations and loss of independence in people with lower limb amputations. Therefore, there is need for vocational training for people with limb amputations to promote financial independence in the community. The government should assist with the provision of loans so that people with lower limb amputations can start small scale businesses in order to provide for themselves and their families.

Due to financial challenges, transport was reported to be a problem for people to attend prosthetic review clinics. These results are supported by a report from Naidoo and Ennion (2018), where financial constraints hinder the participants to attend rehabilitation services. Reduced functional level also restricts an individual to participate in leisure activities as reported by one of the participants of this study. One of the participants reported having challenges to play netball as she used to before amputation. Physical challenges may have a great impact in an individual's life with lower limb amputation as reported in the study. Therefore, rehabilitation management should work on improving management of people with lower limb amputations to make sure that they achieve optimal function that can enable them to participate fully in the community.

Accessibility problems were also noted as a barrier to social participation and integration in the community. Participants reported experiencing problems in walking up and down stairs to access the school environment and other infrastructures. In that case, they become frustrated and feel that other people think that they are failures. These results are in line with the findings of a study which was conducted in Sierra Leone by Andregard and Magnusa (2013). The study reported that

participants were unable to go to school because they could not physically access school buildings due to inability to climb stairs.

Boarding public transport like minibuses was also reported as one of the challenges in the community. This was due to inadequate space within the minibus hence participants prefer to use the front seat. If the front seat is already filled, they have to wait for another minibus. This is supported by the findings of the study which was conducted by Naidoo and Ennion (2018), where participants reported experiencing difficulties when accessing public transport such as taxi services as they could only use the front seat. Failure to access the surrounding may bring frustrations and depression. Therefore, the government should consider constructing user friendly buildings whereby a person with a disability should be able to access the environment. The rehabilitation program should also be intensive to improve the overall function of an individual. Gait training on stairs, uneven ground and slopes should be included. Public awareness is also necessary for the minibus drivers to provide appropriate seat for those with lower limb amputation in order for them to sit comfortably.



5.4.4 Emotional challenges

Emotional problems were also reported as a barrier to community participation and integration in people with lower limb amputation. The emotional problems came as a result of failure to achieve what they had planned to do and because of the way the society treat them. One of the participants reported of feeling unworthy and disappointed with her condition. These results are in support of the quantitative findings which indicated that suboptimal psychological status is present among (48 %; n=87) of the participants. These results are similar to the findings of the study which was conducted by Amoah et al. (2018), which indicated that amputation has a psycho- emotional impact on an individual with lower limb amputation such that people with amputation feel like

they are a burden to others, unimportant as well as useless. Emotional / psychological problems may seriously worsen an individual's disability (physical function) and restrict participation in the community. Therefore, it is recommended that management of persons with limb amputations should include multi-disciplinary approach where a psychologist or a counselor should be involved from the pre-amputation rehabilitation to post –amputation rehabilitation in order to prevent or manage the emotional and psychological issues post- amputation.

5.5 Facilitators to community participation and intergration

Community support, family support and access to prosthesis were categorized as facilitators to community participation and integration.

5.5.1 Community and family support

Community and family support were reported by most of the participants as a facilitator to community participation and integration. The community (friends) and family members provided assistance to people with lower limb amputation in different ways like providing psychological support (encourage them to forget about their condition and live a normal life), assistance in ADLS performance and financial support. Some people with lower limb amputation reported that their spouses and children have been of a great help. While others reported that their church members sometimes could contribute for their transport money when they are going for prosthetics review. These results are supported by Amoah et al. (2018) and Goldwana and Stewart (2013) who indicated that support from the family members, spouse, children and friends in form of advice and financial assistance assisted people with amputations to manage their homes. Lack of community and family support to people with lower limb amputations may induce stress and depression and this may affect the functional performance and community participation. Therefore, it is recommended that rehabilitation of people with amputations should include information to the

family members and community on how they can accommodate and assist people with limb amputations to adjust and cope with their condition in the communities where they live. This will facilitate effective social participation and integration into the communities.

5.5.2 Access to prosthetic use

Accessibility to prosthetic use has been reported to facilitate community participation and integration. Some participants reported that their lives have not been affected negatively in any way after the loss of their limb, because they are using a prosthesis. They reported that the prosthesis assists them to perform their ADLS normally. They are no longer discriminated against in the community, because people are not able to notice that they are using an artificial limb. With the use of a prosthesis, participants reported that they are able to walk long distances unlike when they had no prosthesis. These results are in line with the findings of Ennion and Rhoda (2016) who reported that the use of prosthesis improves function of people with lower limb amputations. In addition, participants felt that though they had difficulties with the prosthesis at times, it helped them to become more functional and independent. Similarly, Andregard and Magnusson (2016) reported that the use of a prosthesis enabled the people with lower limb amputation to do their work and provide for their families. Participants were satisfied that they are able to walk long distances and the prosthesis had reduced the impact of negative attitude from the society. The use of the prosthesis could assist to bring acceptance of one's condition. This may assist people with lower limb amputation to adjust and cope with their present condition. This, in turn, may increase community participation and integration. Rehabilitation should include the referral and provision of a functional prosthesis, and clients should receive adequate rehabilitation with their prosthesis.

5.6 Summary of the chapter

People with lower limb amputations under go different experiences in the community. Some of the experiences include functional and psychological challenges. The following factors were found to negatively influence functional status of an individual following limb amputation: non-traumatic amputation, through- knee amputation, consuming alcohol, not receiving in-patient or out-patient rehabilitation and non-prosthetic use. Psychological status was negatively influenced by the following factors: consuming alcohol and not receiving in-patient or out -patient rehabilitation. People with lower limb amputations presented with different experiences which negatively affected community participation and integration. These included 1). Problems with body image, ii). Social stigmatization, iii). Physical and environmental challenges and iv). emotional problems. However, there were also some positive experiences which assisted them to participate and intergrate into the community and these included community and family support and accessibility to prosthetic use. The discussion included similarities of the findings to relevant literature, clinical relevance and the recommendations. The following were some of the recommendations made based on the results of the study: multidisciplinary management of people with limb amputation which includes referal to psychologist/ counsellor pre and post- amputation, comprehensive rehabilitation and follow-up post discharge, public awareness on disability and how they can assist people with lower limb amputations to cope and adjust post amputation.

CHAPTER SIX

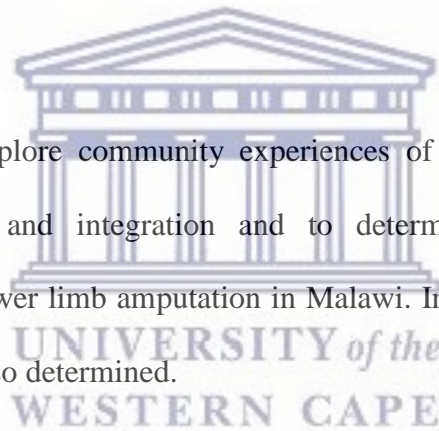
SUMMARY OF THE STUDY, LIMITATIONS AND RECOMENDATIONS, CONCLUSSION

6.1 Introduction

This chapter serves to draw conclusions from the findings of the study. It provides limitations and recommendations for future research based on the results and the challenges encountered in the study.

6.2 Summary of the study

The purpose of the study was to explore community experiences of people with lower limb amputations in social participation and integration and to determine the functional and psychological status of people with lower limb amputation in Malawi. In fulfilling the purpose of the study, demographic details were also determined.



The age range of the participants of the study was 18-88 years of age with a mean of 40.9 (SD+/- 18.2) years of age. The majority of the participants were between 20-49 years of age. There were more men as compared to women. Trauma was the leading cause of amputation and the majority of people with traumatic amputations were men. More than two thirds of the participants received in-patient rehabilitation. About two thirds of the participants did not receive out-patient rehabilitation and were not followed-up post- discharge.

A large percentage of participants (45%; n = 81) reported having difficulties in performing functional activities (suboptimal functional status) assessed by using the OPUS (Lower limb

functional status). People with knee disarticulation type of amputation presented with higher risk of suboptimal function as compared to people with trans-tibial amputations ($p < 0.001$). There was no statistically significant difference between the functional status of the people with trans-tibial and trans-femoral amputations. People having non-traumatic amputations had a significant risk of developing suboptimal function as compared to people with traumatic amputations. There was no statistically significant difference on the functional status between males and females. People who received in-patient rehabilitation significantly reported good functional status as compared to those who did not. However, people who did not receive out-patient rehabilitation reported worse functional status as compared to those who did ($p < 0.001$). Consuming alcohol has been found to predispose people with lower limb amputation to have difficulties in performing functional activities. Non-prosthetic users reported worse functional status as compared to prosthetic users ($p < 0.001$).

A high number of participants presented with symptoms of depression. There was no statistically significant difference between the psychological status of people with non-traumatic and those with traumatic amputation. The level of amputation did not have any influence on the psychological status of the people with lower limb amputation. Receiving in-patient rehabilitation has been found to improve psychological status. Not receiving out-patient rehabilitation has also been found to worsen the psychological status. People who were consuming alcohol were found to have increased chances developing psychological symptoms.

Different community experiences on social participation and integration were reported among people with lower limb amputations. These experiences were analyzed into two themes: barriers and facilitators to community participation. The following sub-themes emerged from the main theme 'barriers to community participation and integration': problems with body image, social

stigmatization, physical and environmental challenges, and emotional challenges. Under the main theme ‘facilitators to community participation and integration’ the following sub-themes emerged: community and family support and access to prosthetic use.

6.3 Study limitations

A number of challenges were experienced during data collection for this study. Firstly, there was a limitation in record keeping which brought a challenge to trace some contacts of the would be participants in the registry book. This was because the registry book had inadequate information on the clients’ details like missing address and contact numbers or in some cases the address was in-complete. Due to this problem, some would be participants could not be reached because there were no contacts for them. This reduced the available sample size of the study.

Due to low levels of literacy, some of the questionnaires could not be self-administered and required the assistance of a research assistant to complete. This could bias the study results as the assistant could have mis-interpreted the participants’ responses.

Due to the large geographical area that the orthopaedics (orthotics and prosthetics) centers, serviced, participants who stayed too far away were not willing to participate in the study due to prolonged travel time and cost. This meant that only participants who lived close enough to the centers participated in the study. This could bias the study sample and might mean that the findings are not generalizable to the entire setting.

Some of the participants selected for both qualitative and quantitative study were not willing to participate in the qualitative part. After the completion of the questionnaires, they were complaining that they had to return to their homes since they travelled long distances. This was a

challenge because it required to identify other eligible participants for the interviews and this prolonged period of data collection.

6.4 Recommendations

Comprehensive rehabilitation of people with lower limb amputations is key to enhancing community participation and integration. Based on the findings of the study, multidisciplinary management of people with lower limb amputations is very important to reduce challenges in the community. The nurses, clinicians and surgeons should refer patients with amputations to the rehabilitation personnel (pre- and post –amputation) for in- patient and out-patient management. Likewise, the rehabilitation personnel should also work in collaboration with the psychologist or counsellor to manage psychological symptoms. Rehabilitation management should emphasize ADLS training, community mobility training like going up and down stairs and walking on different terrain. This could improve community mobility and ADLS performance. Vocational rehabilitation should be prioritized to facilitate return to employment. Furthermore, the physiotherapists and occupational therapists should also work hand in hand with the prosthetist in management of people with lower limb amputation post- discharge. This might improve general function and community mobility.

Based on the findings of the study, which indicate that without a prosthetics a person might have worse functional status, the government should provide enough financial support to the prosthetic departments for them to purchase enough materials for fabrication of the prosthetics. In addition, there is need for establishing more prosthetic centers as at present the country is only having two centers which fabricates and sells the prosthetics to the clients. Some people with lower limb amputation reported that they could not afford to buy a prosthetics or else they have to seek donors to assist them. Enough support of the centers could assist to increase fabrication of the prosthetics.

These prosthetics could be supplied for free or at a reduced price which everyone could afford. This could improve function of people with lower limb amputation. This, in turn, would facilitate community participation and integration.

With an aim of improving out-patient rehabilitation services and follow-up, the government should decentralize the services in the district hospitals and the rural hospitals in order to maximize access of the services in the communities. The society should be aware of the available rehabilitation services which are found within their localities, and if they are not available, they should be able to demand for them.

To reduce some of the community participation barriers, awareness should be carried out to inform the society on how they can assist people with amputation to integrate back in the community. The society should be aware that people with amputations have equal rights like any other person in the society and they have rights to participate in all community activities. This could assist people with lower limb amputations to adjust and cope with their amputation in the community. In addition, public infrastructures like schools should be built in such a way that they are user friendly. The family members and the community (friends) should be aware about the facilitators that may assist people with amputation to participate fully in the society. For instance, the support rendered to people with amputation could facilitate effective participation and integration.

Future research to be conducted to explore the reasons why the majority of participants did not receive rehabilitation management and follow-up post discharge in Malawi. More research should also be conducted to explore the influence of knee disarticulation type of amputation on functional status, and influence of alcohol on functional and psychological status.

6.5 Conclusion

The study provides a pre-liminary evidence on community experiences that people with lower limb amputations encounter in Malawi. The study was conducted to contribute to the evidence based on the challenges of living with amputations in Malawi, and help to highlight gaps in rehabilitation of people with lower limb amputations. The results have proved that people with lower limb amputations experience a lot of challenges in the community and these included physical functioning like mobility problems and ADLS performance and psychological challenges. These challenges provided a barrier to community participation and integration. Furthermore, these people also encounter other barriers to social participation and integration. However, despite the barriers, there were also some facilitators to community participation and integration. The results highlight that there is need for multidisciplinary approach in management of people with lower limb amputation and the involvement of the government stake holders to improve community participation and integration of people with lower limb amputation. Not receiving rehabilitation management (in-patient and out-patient) and non-prosthetic use was found to influence worse functional status. This highlights the need for comprehensive rehabilitation which will include community mobility training, prosthetic rehabilitation and ADLS training. The government stake holders should provide funding for prosthetics fabrications in order to increase the production thereby increasing access of prosthetics to all people with amputations. Rehabilitation services should be decentralized in district and rural hospitals so that people with LLA should have access to rehabilitation services within their localities. In addition, having non-traumatic amputation and through-knee amputations have been found to be closely associated with difficulties in functional status. This highlights the need of close monitoring of non-traumatic amputation for the presence of comorbidities and provide appropriate management. The surgeons

should consider the level of amputation when performing surgery. This might assist to prevent functional challenges. Due to the presence of psychological symptoms, people with lower limb amputation should be referred for psychological counselling and support.

Barriers affecting community participation and integration in Malawi included problems with body image, social stigmatization, physical and environmental challenges and emotional challenges. These barriers need to be reduced in order to improve community participation and integration of people with lower limb amputations in Malawi. To reduce the barriers, community awareness should be conducted to inform people about the rights of people with disabilities as stipulated by UNCRPD. The government should emphasize on implementation of the policies on rights of people with disabilities. Furthermore, the community and family members should assist people with lower limb amputation to participate and integrate into the community. In addition, people with lower limb amputation should be assisted to cope and adjust to the new sense of identity.

Several recommendations on how to improve community participation and integration of people with lower limb amputations were highlighted. A multidisciplinary approach is paramount to improve physical and psychological status following LLA. Furthermore, availability of rehabilitation services in the communities and accessibility of prosthetics may also improve function of people with lower limb amputations. To reduce the barriers, people with lower limb amputations should be counselled on how to cope and adjust to the amputations. The society should be aware about the rights of people with disabilities. In addition, the community and family members should be informed on how to assist people with lower limb amputations to participate fully in the society.

The rehabilitation team, government stake holders, the community, family members and people with lower limb amputations themselves, have a role to play in order to improve function and psychological status of people with lower limb amputations and reduce the barriers to community participation and integration. This may in turn improve participation and integration following lower limb amputations.



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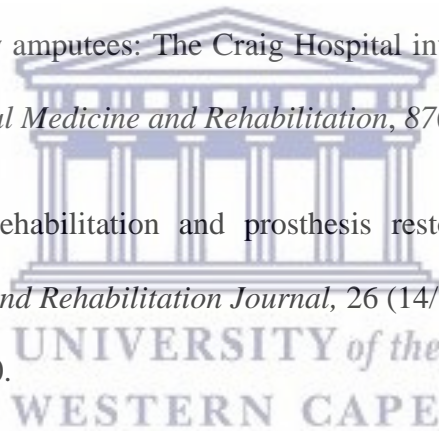
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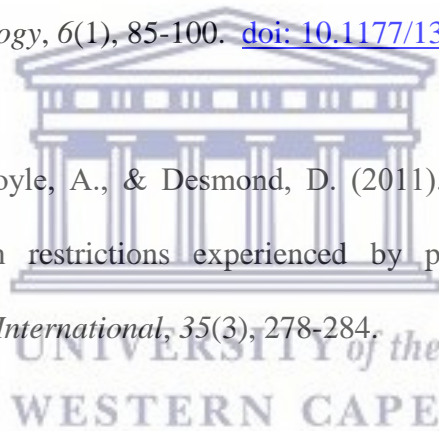
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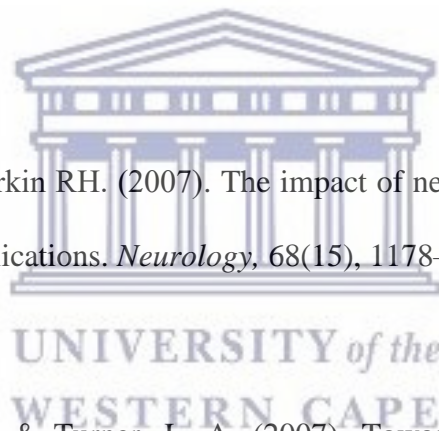
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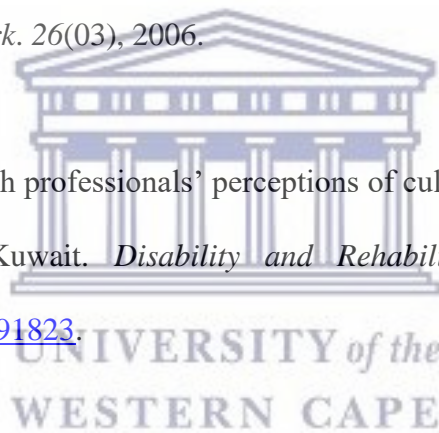
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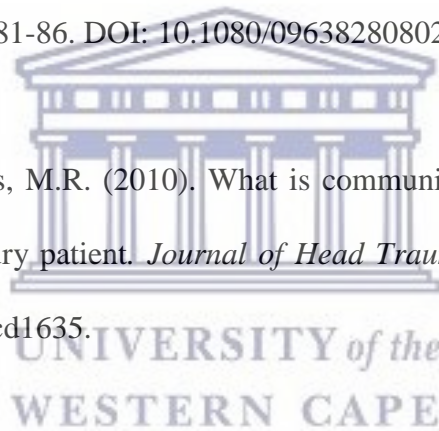
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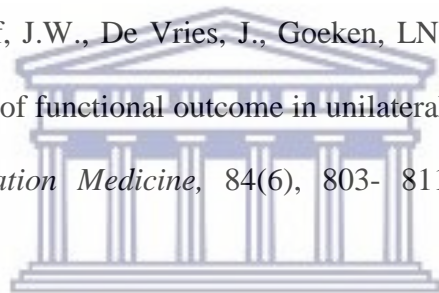
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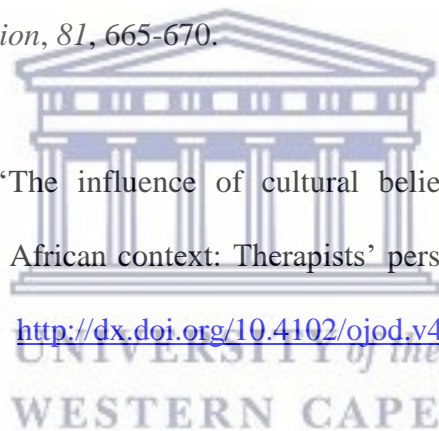
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APPENDICES

Appendix 1



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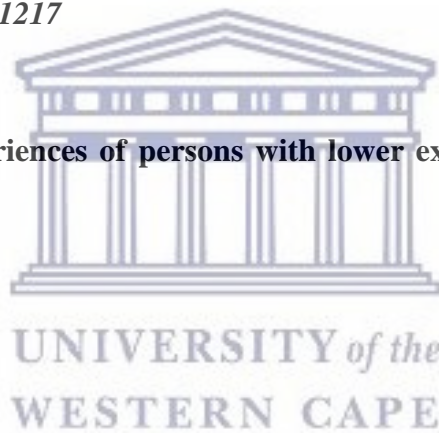
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INFORMATION SHEET

Project Title: Community experiences of persons with lower extremity amputations in Malawi.

Study investigator; Stella Mpezeni

Study Supervisor; Dr Liezel Ennion



What is this study about?

This is a research project being conducted by Stella Mpezeni at the University of the Western Cape. We are inviting you to participate in this research project because you are the one who we think has enough knowledge on experiences following lower extremity amputation in the community and therefore qualify for this research. The purpose of this research project is to explore community experiences following lower extremity amputation. Exploring experiences will highlight some gaps in rehabilitation of persons with lower extremity amputations and this will assist rehabilitation personnel to improve on the delivery of services.

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

You will be asked to sign the consent form upon agreement. Before answering the questionnaires, the researcher will ask permission from you whether you would like to participate on the surveys or not. You will be free to refuse to participate and no penalties will be given. Later you will be asked to answer three questionnaires, one questionnaire will be asking about your personal details and medical history like; age, area of residence, occupation, side of amputations, level of amputation, cause of amputation and presence of other conditions like; hypertension, diabetes etc. The second questionnaire will be asking about how you are able to function in the community following amputation and some of the questions are; how long are you able to walk without experiencing problems, are you able to come up from the floor to standing position without problems etc. and the last questionnaire is assessing the presence of signs and symptoms of depression following lower limb amputation. The survey will take place at the rehabilitation clinic setting and this will take a period of 30 - 45 minutes in total. You might also be asked to take part in the interviews. Before interviews permission will be asked from you whether you want to take part or not and you are free to refuse and no penalties will be granted for that. Interviews will be recorded using audio tapes and before audio recording, permission will also be asked from you. Interviews will take approximately 45 minutes in total.

Would my participation in this study be kept confidential?

We will do our best to ensure confidentiality in the whole process. To ensure your anonymity, the surveys will be anonymous and will not contain information that may personally identify you. Your name will not be included in the surveys and other collected data; instead a code will be used on all the collected data. The researcher will be able to link your survey through the identification key and only the researcher will have access to the identification key.

This research project involves making audiotapes of you. This is necessary for the researcher to be able to remember everything that you have said. The audio tapes will be kept at the secure place i.e. will be locked in the cabinet where only the researcher and the research supervisor will have access. The tapes will be destroyed after the information has been well captured and is no longer needed.

To ensure your confidentiality, data will be stored in a secure place (locked in the cabinet) where only the researcher, research supervisor and research assistant will have access. Electronic data will be stored using password –protected computer files.

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

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

What are the risks of this research?

There may be some risks from participating in this research. In case there are some risks in participating in this study, we will nevertheless minimize such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention. For instance, if you experience psychological discomfort, you will be referred to the psychologist for appropriate intervention.

What are the benefits of this research?

The benefits of this study to you include; improved community rehabilitation care wherever necessary. The results may also help to highlight some gaps in the rehabilitation process and we hope that in future other people might also benefit from this study through improved rehabilitation care of persons with lower extremity amputation after understanding what they are going through.

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

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

What if I have questions?

This research is being conducted by Stella Mpezeni at the University of the Western Cape. If you have any questions about the research study itself, please contact Stella Mpezeni at: The University of the Western Cape, private bag X17 Bellville, South Africa. E- mail; stellampezeni@gmail.com / 3621159@myuwc.ac.za.

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

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Prof José Frantz

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This research has been approved by the University of the Western Cape's Senate Research Committee and college of medicine research ethics committee in Malawi.



Appendix 2

Information sheet Chichewa version.



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CHOFOTOKOZA ZAKAFUKUFUFU

Mutu Wakafukufuku: Zomwe anthu omwe adulidwa mwendo ku Malawi amadutsamo akakhala pakati pa anthu kwawo.

Wopanga kafukufuku; Stella Mpezeni

Woyang'anira kafukufuku; Dr Liezel Ennion



Kodi kafukufuku ameneyu ndiwokhudza chani?

Uyu ndi kafukufuku yemwe akupangidwa ndi Stella Mpezeni ku Yunivesite ya Western Cape. Tikukupemphani kuti mutenge nawo mbali pakafukufuku ameneyu chifukwa tikuganiza kuti ndi inuyo omwe mukudziwa zambiri zomwe anthu omwe adulidwa mwendo amadutsamo akakhala pakati pa anthu kwawo kotero ndinu oyenera kutenga nawo mbali pakafukufuku uyu. Cholinga cha kafukufuku amaneyu ndi kufufuza zomwe anthu amadutsamo akadulidwa mwendo. Kufufuza zomwe anthu omwe adulidwa mwendo amadutsamo kuthandiza kuti zinthu zomwe sizimachitika bwino pa ntchito yothandiza anthu omwe adulidwa mwendo kuti azitha kuzipangira zinthu paiwo

wokha zidziwike ndipo zikadziwika zidzathandiza kuti anthu omwe amathandiza anthu omwe adulidwa mwendo kuti azitha kuzipangira okha zinthu azigwira ntchito yawo mwaluso.

Ndidzafunsidwa kuchita chani ndikavomera kutenga nawo mbali pakafukufuku ameneyu?

Mukavomera mudzafunsidwa kusayina fomu yowonetsa kuvomera kwanu kuti mutenga nawo mbali pakafukufuku uyu. Musanayambe kuyankha mafunso amene ali mu ndandanda wa kafukufukuyu mudzayamba kaye mwa pemphedwa ngati nkutero. Mudzakhala ndi ufulu ovomela kapena kukana ndipo simudzapasindwa chilango chilichonse chifukwa chokana. Kenako mudzafunsidwa kuyankha mafunso omwe ali pamindandanda yamafunso itatu, mndandanda wamafunso umodzi uli ndi mafunso omwe cholinga chake ndikudziwa za inu ngati munthu komanso za umoyo wanu ndi kudulidwa kwanu kwa mwendo, uli ndi mafunso ngati awa; zaka zanu, komwe mumakhala, ntchito yomwe mumagwira, mbali yomwe anakudulani mwendo, anakudulani gawo lalikulu bwanji, chomwe chinapangitsa kuti akuduleni komanso ngati mulinso ndi mavuto ena monga kuthamanga kwa magari, matenda okhudzana ndi shuga ndi ena otero. Mndandanda wamafunso wachiwiri ufunsa ngati mumantha kuchita zinthu zina kwanu mutatha kudulidwa mwendo ndipo uli ndi mafunso monga awa; mumantha kuyenda mtunda wautali bwanji osawona vuto, kodi mumatha kudzuka kuchoka pansi ndikuyimirira popanda vuto lina lili lonse ndi mafunso ena otero ndipo mndandanda wamafunso womalizira wukufufuza ngati muli ndi zizindikiro zowonetsa kuti ndinu wokhumudwa komanso wamantha kapena wodandaula. Kuyankha mafunso olembedweratu kutenga mphindi zapakati pa 30 ndi 45. Mukamaliza kuyankha mafunso olembedweratu mudzapemphedwa kuti muyankhe mafunso omwe tikufunsensi kuti mufotokoze mwatsanetsatane zomwe inu mumadutsamo mukamatenga nawo mbali pazochitika zagulu komanso momwe anthu ena ndi apabanja lanu amakulandirirani pazochitika za gulu komanso zapabanja. Mufunsidwanso kuti mulongosole mwatsanetsatane ngati kudulidwa kwanu kwa mwendo kumakupangitsani kuti muzilephera kuchita zinthu zina za moyo wanu watsiku ndi tsiku. Zomwe muziyankha zidasungidwa kugwirisa ntchito chosungira mau ndipo mudzafunsidwa ngati muli ololera kuti mau anu asungidwe mu chosungira mauchi ndipo muli ooledwa ku kana ngati simukufuna kutero potero sumadzapasidwa chilango chili chonse. Kufunsidwa kwa mafunsoku kutenga mphindi zapakati pa 30 ndi 45.

Kodi pakhala chinsinsi chokhudza kutenga nawo mbali kwanga pakafukufuku uyu?

Tiyesetsa kuti tikusungireni chinsinsi mumadongosolo onse akafukufuku uyu. Kuti inu musadziwike, mindandanda yamafunso sipalembedwa mayina komanso sipalembedwa mfundo zina zomwe zingapangitse kuti inu mudziwike. Dzina lanu sililembedwa pa mindandanda yamafunso komanso pamfundo zina zomwe inu mupereke, mmalo mwa dzina lanu nambala yina igwiritsidwa ntchito pa mfundo zonse zomwe inu mupereke. Wochita kafukufuku uyu adzatha kuzindikira kuti munayankha mindandanda wamafunsowo ndinu pogwiritsa ntchito cholembedwa chodziwitsa kuti nambala yikuyimira ndani komanso ndiwochita kafukufuku yekha yemwe adzakhale ndi cholembedwa chodziwitsachi.

Mbali ina ya kafukufukuyi ikukhudzana ndi ku jambula zomwe mulankhule kugwirisa ntchito chotengera mau. izi ndizofunikira chifukwa wopanga kafukufukuyi akuyenera kusunga zonse zimene munene, ndipo kuti athe kutero, akuyenera ku jambula zimene mulankhule.

Kuti tiwonesetse kuti takusungiraninso chinsinsi, mfundo zomwe inu mupereke zidasungidwa pamalo otetedzeka (tidzazitsekera mukabati) ndipo omwe adzakhale ndi mwayi wowona mfundo zomwe inu mwapereka ndi wochita kafukufuku yekha, womutsogolera pakafukufuku uyu ndi womuthandizira okha basi. Mfundo zolembedwa pamakina oyendera magesi zidasungidwa pogwiritsa ntchito dzina lachinsinsi – mafayilo otetedzedwa apakompyuta.

Ngati titalembe lipoti kapena cholembedwa choti chitsindikidzidwe chokhudza kafukufuku uyu dzina lanu silidzatchulidwapo.

Molingana ndi zofunikira mwamalamulo kapena mulingo wantchito zaukachenjede, tidzawauza anthu kapena mabungwe oyenerera tikapeza mfundo zowonetsa kuti ana amachitidwa nkhanza kapena samasamaliridwa kapena ngati pali china chake chomwe chikupereka chiwopsezo kwa inu kapena kwa anthu ena. Pakakhala zoterezi tidzakuwuzani kuti tikuyenera kuphwanya chipangano chosunga chinsinsi kuti tikwaniritse udindo wathu mwamalamulo kuti tinene kwa anthu kapena mabungwe oyenerera.

Kodi pali chiwopsezo chotani chokhudzana ndi kafukufuku uyu?

Pakhoza kukhala chiwopsezo china chake chifukwa choti mwatenga nawo mbali pakafukufuku uyu. Patakhala kuti pali chiwopsezo chifukwa choti mwatenga nawo mbali pakafukufuku uyu, tidzayesetsa kuti tichepetse chiwopsezocho ndipo msangamsanga tidzakuthandizani mutakhala

kuti muli ndi mantha, mukuvutika mmaganizo kapena zina zotero nthawi yomwe inu mukutenga nawo mbali pakafukufuku uyu. Zikakhala kuti ndi zofunika kutero, tidzakutumizani kwa akachenjede kuti akakuthandizeni. Mwachitsanzo ngati mungakumane ndi vuto lokhumudwa, mudzatumizidwa kwa akachenjede okhudzana ndi kuona zamavuto akukhumudwa.

Kodi phindu la kafukufuku ameneyu ndi chani?

Inu mupindula ndi kafukufuku uyu motere; zinthu zidzasintha pomwe zikusowekera kutero ndipo nchito yothandiza anthu omwe adulidwa mwendo kuti akhale ozichitira zinthu okha idzakhala yapamwamba. Zotsatira zakafukufuku uyu zikhoza kuwonetsa madera ena omwe ntchitoyi siyikuyenda bwino komanso tikuyembekedzera kuti anthu ena mtsogolomu adzapindula ndi kafukufukuyu chifukwa choti adzatha kumvesetsa kuti anthu omwe adulidwa mwendo amadutsa muzinthu zotani akakhala pakati pa anthu.

Kodi ine ndikuyenera kutenga nawo mbali pakafukufuku uyu komanso kodi ndikhoza kusiya kutenga nawo mbali nthawi yina ili yonse?

Mutenga nawo mbali pakafukufuku uyu mwakufuna kwanu. Mukhoza kusankha kusatenga nawo mbali. Mukasankha kutenga nawo mbali pakafukufuku uyu, mukhoza kusiya kutenga nawo mbali nthawi yina yili yonse ndipo simuzalandira chirango chamtundu wina uli wonse kapena kutaya mwayi wina wuli wonse womwe inu mukuyenera kukhala nawo.

Nanga ndikakhala ndi mafunso?

Kafukufuku uyu akupangidwa ndi Stella Mpezeni ku Yunivesite ya Western Cape. Ngati muli ndi mafunso okhudzana ndi kafukufuku ameneyu, chonde muwalembere kalata a Stella Mpezeni ku adiresi iyi: University of the Western Cape, Private Bag X17, Bellville, South Africa. Imelo; stellampezeni@gmail.com / 3621159@myuwc.ac.za.

Mukakhala ndi mafunso okhudza kafukufuku uyu komanso maufulu anu ngati munthu wotenga nawo mbali kapena ngati mukufuna kunena za vuto lina lili lonse lomwe mwakumana nalo lokhudzana ndi kafukufuku uyu, chonde lumikizanani ndi:

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Kafukufuku uyu wavomeredzedwa ndi komiti yowona za kafukufuku ya Yunivesite ya Western Cape yotchedwa Senate Research Committee komanso komiti yowona za kafukufuku ku Malawi.



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CONSENT FORM

Title of Research Project; Community experiences of persons with lower extremity amputation in Malawi.

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

Participant's name.....

Participant's signature.....

Date.....

Appendix 4.



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FOMU YOWONETSA KUVOMERA

Mutu Wakafukufuku: Zomwe anthu omwe adulidwa mwendo ku Malawi amadutsamo akakhala pakati pa anthu ena.

Ndafotokozeredwa zakafukufuku ameneyu muchiyankhulo chomwe ine ndimamva. Mafunso omwe ndinali nawo okhudza kafukufuku ameneyu ayankhidwa. Ndikumvetsetsa kuti kutengapo mbali kwanga kukhala motani ndipo ndikuvomera mwakufuna kwanga ndi kusankha kwanga komanso mosakakamidzidwa kutenga nawo mbali pakafukufuku ameneyu. Ndikuvomereza kuti ndidzayankha ma funso amene ali mundandanda wakafukufukuyi. Ndikuvomereza kuti chotengera mau chidzagwiridwa ntchito pakafukufukuyu kutenga zonse zimene ndilankhule. Ndikumvetsetsa kuti dzina langa silikatchulidwa kwa wina aliyense. Ndikumvetsetsa kuti ndikhoza kusiya kutenga nawo mbali pa kafukufuku ameneyu nthawi yina yili yonse ndipo popanda kupereka chifukwa china chili chose komanso sindikhala ndi mantha kuti ndilandira chilango china chake kapena kutaya mwayi wina wake.

Dzina la wotenga nawo mbali.....

Siginecha ya wotenga nawo mbali..... Tsiku.....

Appendix 5

OPUS: Lower Extremity Function measure.

--	--	--	--	--

Client ID.

--

63125

difficult, or easy, is it for you to:	Very easy	easy	Slightly difficult	Very difficult	cannot do this activity	do you typically use an orthotic or prosthetic device to perform this activity	
Getting into shower							
Getting in and out of a bathtub using a basin							
Using a wheelchair or a walker to dress your lower limbs							
Getting on and off the toilet							
Getting up from the floor							
Walking on uneven surfaces while carrying a load							
Walking for one-half hour							
Picking up something from the floor while carrying a load							
Getting up from the floor							
Getting into and out of a car							
Walking around the house							
Walking outside in an open area (e.g., a park or around a building)							
Walking in bad weather (e.g., rain, snow, or wind)							
Walking for two hours							
Walking up in a steep hill							
Walking up one flight of stairs without a handrail.							

climb one flight of stairs without a rail							
climb one block of stairs							
carry a plate of food while walking							
climb on or off a bus or prosthesis.							



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OPUS CHICHEWA VERSION.

Nambala Yomuzindikiritsa Wotenga Nawo Mbali

OPUS: Kuwunika Momwe Mwendo Ukugwirira Ntchito

diphwekerani a kukuvutani kuchita izi:	diphwekera piri	diphwekera kwani	divuta piri	gapange	i mumachita vala nsapato yothandizira rika mwendo malo mwake ena mwendo hita kupanga uthe kuchita zinthu izi?	
lowa kutuluka beseni mbiramo kubafa						
dziveka gawo la i la thupi						
khala ndi pamtondo mbuzi mbuzi.						
dzuka kunyamuka kera pansa						
yima bwino ndima						
khala muli ire mphindi na makumi						
tola chinthu mutayimirira						

dzuka a kunyamuka ndo							
ukwera ndi a galimoto							
uyenda malo asiyana nba							
uyenda pamalo azika							
uyenda o koti o siyiri (mvula, u, kuwomba o)							
uyenda awiri							
uyenda era pamalo eka biri omwe angidwa kuti nasitepe							
ukwera pe okhala sulo fira							
ukwera pe opanda fira							
uthamanga a mdadada i wa mba							
unyamula yachakudya yenda							
uyikirira a kuchotsa o dizira i mwendo o mwake							



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amwendo a kupanga							
----------------------	--	--	--	--	--	--	--

Note;

Question 15 from the original questionnaire has been removed because it is not applicable to the environment where the research will be conducted.



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Appendix 7

Beck's Depression Inventory.

This depression inventory can be self-scored. The scoring scale is at the end of the questionnaire.

Circle the appropriate answer according to how you fill.

1.

0. I do not feel sad.

1. I feel sad

2. I am sad all the time and I can't snap out of it.

3. I am so sad and unhappy that I can't stand it.

2.

0. I am not particularly discouraged about the future.

1. I feel discouraged about the future.

2. I feel I have nothing to look forward to.

3. I feel the future is hopeless and that things cannot improve.

3.

0. I do not feel like a failure.

1. I feel I have failed more than the average person.

2. As I look back on my life, all I can see is a lot of failures.

3. I feel I am a complete failure as a person.

4. 0. I get as much satisfaction out of things as I used to.

1. I don't enjoy things the way I used to.

2. I don't get real satisfaction out of anything anymore.

3. I am dissatisfied or bored with everything.

5. 0. I don't feel particularly guilty

1. I feel guilty a good part of the time.

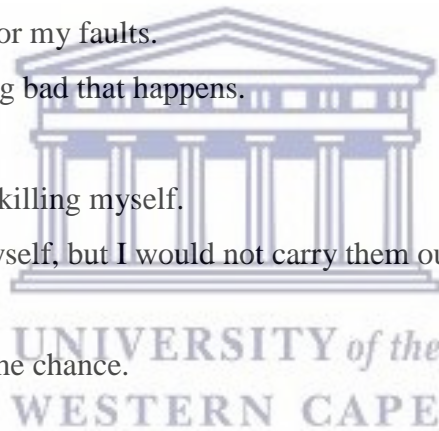
2. I feel quite guilty most of the time.

3. I feel guilty all of the time.



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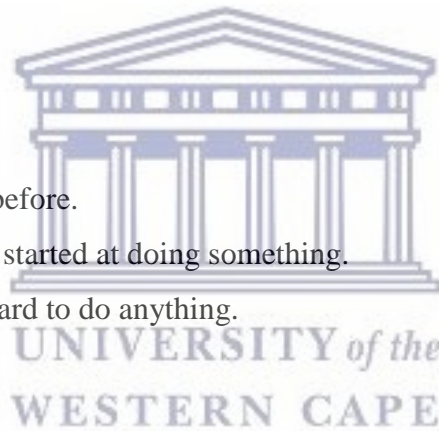
6. 0. I don't feel I am being punished.
1. I feel I may be punished.
2. I expect to be punished.
3. I feel I am being punished.
7. 0. I don't feel disappointed in myself.
1. I am disappointed in myself.
2. I am disgusted with myself
3. I hate myself.
8. 0. I don't feel I am any worse than anybody else.
1. I am critical of myself for my weaknesses or mistakes.
2. I blame myself all the time for my faults.
3. I blame myself for everything bad that happens.
9. 0. I don't have any thoughts of killing myself.
1. I have thoughts of killing myself, but I would not carry them out.
2. I would like to kill myself.
3. I would kill myself if I had the chance.
10. 0. I don't cry any more than usual.
1. I cry more now than I used to.
2. I cry all the time now.
3. I used to be able to cry, but now I can't cry even though I want to.
11. 0. I am no more irritated by things than I ever was.
1. I am slightly more irritated now than usual.
2. I am quite annoyed or irritated a good deal of time.
3. I feel irritated all the time.
12. 0. I have not lost interest in other people.



1. I am less interested in other people than I used to be.
 2. I have lost most of my interest in other people.
 3. I have lost all of my interest in other people.
- 13.
0. I make decisions about as well as I ever could.
 1. I put off making decisions more than I used to.
 2. I have greater difficulty in making decisions more than I used to.
 3. I can't make decisions at all anymore.
- 14.
0. I don't feel that I look any worse than I used to.
 1. I am worried that I am looking old or unattractive.
 2. I feel there are permanent changes in my appearance that make me look

Unattractive

3. I believe that I look ugly.
- 15.
0. I can work about as well as before.
 1. It takes an extra effort to get started at doing something.
 2. I have to push myself very hard to do anything.
 3. I can't do any work at all.
- 16.
0. I can sleep as well as usual.
 1. I don't sleep as well as I used to.
 2. I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
 3. I wake up several hours earlier than I used to and cannot get back to sleep.
- 17.
0. I don't get more tired than usual.
 1. I get tired more easily than I used to.
 2. I get tired from doing almost anything.
 3. I am too tired to do anything.
- 18.
0. My appetite is no worse than usual.



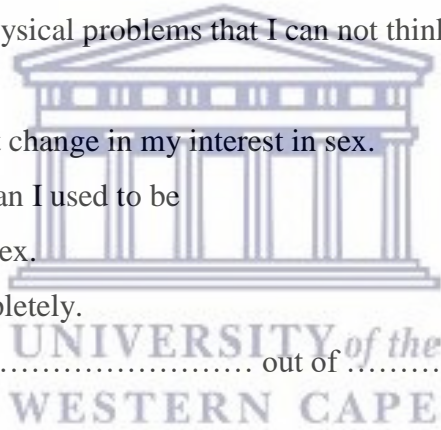
- 1. My appetite is not as good as it used to be.
- 2. My appetite is much worse now.
- 3. I have no appetite at all anymore.

19. 0. I haven't lost much weight, if any, lately.
- 1. I have lost more than five pounds.
 - 2. I have lost more than ten pounds.
 - 3. I have lost more than fifteen pounds.

20. 0. I am no more worried about my health than usual
- 1. I am worried about physical problems like aches, pain, stomach upset or constipation
 - 2. I am very worried to think of physical problems and its hard to think of much less.
 - 3. I am so worried about my physical problems that I can not think of anything.

21. 0. I have not noticed any recent change in my interest in sex.
- 1. I am less interested in sex than I used to be
 - 2. I have almost no interest in sex.
 - 3. I have lost interest in sex completely.

Total score out of



Interpretation

- 1-10.....normal
- 11- 16.....mild mood disturbance
- 17-20..... borderline clinical depression
- 21-30.....moderate depression
- 31-40.....severe depression
- Over 40.....extremity depression.

Appendix 8

Muyezo owonetsa kukhumudwa pa umoyo wamunthu wolembedwa ndi Beck

Munthu akhoza kudziyesa yekha kuonetsela kukhumudwa kumene iye mwini alili.

Chonde zungilizani nambala immene ikufotokozero mmene inu muli.

1. 0. Ndimakhala wosangalala
 1. Ndimakhala wosasangalala
 2. Ndimakhala wosasangalala nthawi zonse ndipo zimandivuta kupeza chimwemwe
 3. Ndimakhala wosasangalala komanso wosakondwa ndipo zimandisowetsa mtendere
2. 0. Sindimakhumudwa kwenikweni polingalira za tsogolo langa
 1. Ndimakhumudwa ndi tsogolo langa
 2. Ine ndimaona kuti ndiribe chiyembekezo chilichonse chokhudza tsogolo langa
 3. Ndimona kuti ndiribe chiyembekezo ndiponso palibe chilichonse chingasinthike
3. 0. Sindimadzimva kuti ndine wolephera
 1. Ndimadzimva kuti ndine wolephera kuposa amzanga
 2. Ndikayang'a zamoyo wanga kumbuyoku zonse ndimazona zolephera zokhazokha
 3. Ndimadzimva kuti ndine munthu wolephera kwambiri

4. 0. Ndimakhutitsidwa ndipo sindiona kusiyanitsa kwa zinthu ngati mmene zinalili kale
 1. Sindimasangalatsidwa ndi zinthu ngati mmene ndimkachitila kale
 2. Sindimakhutitsidwa kwenikweni ndi zinthu panopa
 3. Ndimakhala wosakhutitsidwa komanso woipidwa ndi zinthu zina zilizonse

5. 0. Sindimadzimva ngati wolakwa kwenikweni
 1. Ndimadzimva ngati wolakwa nthawi zina
 2. Ndimadzimva ngati wolakwa nthawi zambiri
 3. Ndimadzimva wolakwa nthawi zonse

6. 0. Sindimadzimva kuti ndilandila chilango
 1. Ndimamva kuti mwina ndingalandile chilango
 2. Ndikuyembekezera kulangidwa
 3. Ndimadzimva kuti ndikulandila chilango

7. 0. Mwaine ndekha sindimadzimva kukhumudwitsidwa
 1. Mwaine ndekha ndikudzimva kukhumudwa
 2. Ine ndekha ndimadzimva kunyamsidwa
 3. Ndimadzida ndekha



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8. 0. Sindimadzimva kuipa kuposa anthu ena onse
 1. Ndimona kuti zonse zofooka komonso zolakwika zanga ndichifukwa cha ine mwini
 2. Ndimadziloza chala ndekha nthawi zonse chifukwa chazolakwa zanga
 3. Ndimadziloza chala ndekha pa zonse zoipa zimene zimandichitikira

9. 0. Ndiribe maganizo wofuna kudzipha ndekha
 1. Ndiri ndimagano wozipha ndekha koma sindingathe kutero
 2. Ndikufuna ndidziphe ndekha
 3. Ndikadakhosa kudzipha ndekha ndikadakhala ndi mpata kuti kutero

10. 0. Sindimaliranso tsopano ngati mmene ndimkachitira poyamba
 1. Ndimalira kwambiri kuposa mmene ndimkachitira kale
 2. Panopa ndimalira nthawi zonse
 3. Ndimkalira kale koma panopa sindingalire ngakhale nditafuna kutero

11. 0. Panopa sindimakwiyitsidwa ngati mmene ndimkachitira kale
 1. Ndimatha kukwiyitsidwako pang'ono panopa kuposa kale
 2. Ndimakwiyitsidwa komonso kuipidwa kwambiri nthawi zambiri
 3. Ndimakhala wokwiya nthawi zonse



12. 0. Ndili ndi chidwibe ndi anthu
 1. Chidwi changa pano ndichochepelako pa anthu kuyelekeza ndi mmene ndinalili kale
 2. Ndiliba chidwi chmbiri pa anthu ena
 3. Chidwi changa chonse chinatha pa anthu ena

13. 0. Ndimatha kupanga ziganizo ngati ndinayenera kutelo
 1. Sindimatha kupanga ziganizo zanga moyenelela ngati ndimkachitila kale
 2. Ndimavutika kupanga ziganizo ngati mmene ndimkachitila kale
 3. Ndingakwanitsiletu kupanga ziganizo panopa

14. 0. Sindikudzimva kuti ndikuoneka molakwika kuyelekeza ndi mmene ndinalili kale
 1. Ndili ndi nkhwana kuti ndikuoneka wokalamba komanso wosapatsa chidwi kapena chikoka
 2. Ndimadzimva kuti pali kusintha kwachikhalile pa maonekedwe anga, zomwe zikuchititsa kuti ndidziona wosapatsa chikoka.
 3. Ndikukhulupirira kuti ndikuoneka wosakongola.

15. 0. Nditha kugwira ntchito ngati mmene ndimagwirila kale
 1. Zimatengela khama la padeladela kuti ndikwaniritse kuchita china chake
 2. Ndimayenela kudzikakamiza kwambiri kuti ndikwanilitse kuchita china chake
 3. Sindingathe kugwila ntchito ina iliyonse

16. 0. Ndimatha kugona bwinobwino ngati mwanthawi zonse
1. Sindimagona bwino ngati mmene ndimkagonela kale
 2. Ndimatha kudzukilapo mofulumila kwa nthawi yokwana ola limodzi kapena awiri kuyelekeza ndimmene ndimkachitila kale ndipo zimandivuta kuti ndigonenso
 3. Ndimatha kudzukilapo kwa nthawi ya maola ambiri kuyelekeza ndimmene ndimkachitila kale ndipo sindigonanso
17. 0. Sinditopa kwambiri ngati kale
1. Ndimatopa kwambiri mwansanga kusiyana ndi kale
 2. Ndimatopa pafupifupi popanga china chilichonse
 3. Sindingakwanitse kupanga china chilichonse chifukwa ndimadzimva kutopa kwambiri
18. 0. Chilakolako changa chofuna kudya chili bwino
1. Chilakolako changa cha chakudya sichili bwino kuyelekeza ndi kale
 2. Panopa chilakolako changa cha chakudya chachepe kwambiri
 3. Sindilakalanso chakudya panopa
19. 0. Kulemela kwa thupi langa sikunatsike kuyelekeza ndi mmene ndinalili kale
1. Kulemela kwa thupi langa kwatsika ndi muyeso wa makilogram oposa awiri
 2. Kulemela kwa thupi langa kwatsika ndi makilogram oposa anayi



3. Kulemela kwa thupi langa kwatsika ndi makilogram oposa asanu ndi imodzi.

20. 0. Ndilibe nkhawa zokhudza thanzi langa

1. Ndili ndi nkhawa chifukwa chamavuto athupi langa; kupweteka kwa thupi, vuto lammimba, komanso kudzimbidwa

2. Ndili ndi nkhawa kwambiri zokhudza mavuto athupi langa ndipo ndizovuta kuiwala.

3. Ndili ndi nkhawa kwambiri zokhudza mavuto athupi langa ndipo sindingathe kuganiza zinthu zina

21. 0. Chidwi changa chogonana sichinasinthe

1. Ndili ndi chidwi pang'ono pankhani yogonana kuyelekeza ndi mmene ndinalili kale

2. Panopa ndili ndi chidwi chogonana chochepa kwambiri

3. Chidwi changa pankhani yogonana inathelatu.

kuphatikiza zonse pa.....



kutanthauzira kwa muyezo wa kukhumudwa.

1 - 10----- palibe kukhumudwa kulikonse.

11-16----- kusokonezeka pang'ono kwa mmene munthu akuganizira

17-20----- chiyambi cha kukhumudwa kofunikira chithandizo

21-30----- kukhumudwa kocheperako

31-40----- kukhumudwa kwa mbiri.

kupitilira 40----- kukhumudwa kwambiri koposera.

SOCIO-DEMOGRAPHIC

Code

Please tick the correct answer in the box or write an appropriate answer on the space provided.

Date; day month year

a. How old are you?

b. Gender: Male Female

c. Marital Status: Married Single Widow Divorced

d. Area of living: Urban Rural

e. Country of origin:

f. Level of education: Illiterate Primary Secondary Tertiary

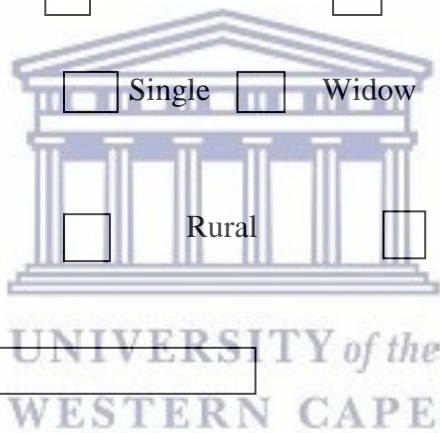
g. Occupation: Farmer employed self -employment other

h. Have you ever smoked tobacco in your life? Yes No

If yes, how many cigarettes in a day?

i. Have you ever taken alcoholic drinks in your life? Yes No

If yes, how many bottles a day?



MEDICAL BACKGROUND

a. Level of amputation: below the knee above the knee through knee

b. Side of the body amputated: left right

c. Cause of amputation:

d. Date of amputation:

e. Co-morbidities: hypertension

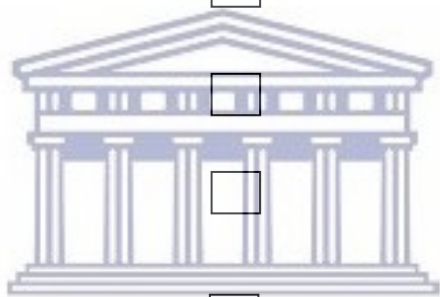
Cardiac diseases

Diabetes

Renal problem

Visual impairment

Other specify.....



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F. Did you receive any rehabilitation in the hospital after you had an amputation?

Yes No

g. Did you receive any rehabilitation after discharge from the hospital? Yes, No

if yes, how long did you continue with rehabilitation?

Appendix 10

Social demographic questionnaire Chichewa version

Mbiri Yanu

Nambala

Chonde chongani yankho yolondola mu kabokosi mwapasidwa kapena lembani yankho yolondola mu mipata imene mwapasidwa.

Tsiku Mwezi Chaka

a. Muli ndi zaka zingati?

b. Ndinu wa; mwamuna kapena mkazi

c. Mumakhala; ku Tauni kapena kumudzi

d. Ndinu; wokwatiwa wosakwatiwa ukwati unatha

Mkazi wa masiye /bambo wamasiye

e. Dziko lochokera

f. Maphunziro munaimba mpaka pati? Simunapite ku sukulu Pulayimale

sekondale sukulu ya ukachenjede

g. Mumagwira ntchito yanji? Kulima yapatikiti business

Ntchito zina monga;

h. Munayamba mwasutapo fodya mmoyo wanu? Inde ayi

Ngati inde mumasuta ndudu zingati pa tsiku?

i. Munayamba mwamwapo zakumwa zoledzeletsa pa moyo wanu? Inde ayi

Ngati inde mumamwa ma botolo angati pa tsiku?

Mbiri ya kudulidwa Kwa mwendo wanu.

a. Mwendo wanu unadulidwa pati? Mushi mwa bondo m'mwamba mwa bondo
pakati pa bondo

b. Mwendo wanu unadulidwa mbali iti ya thupi lanu? ku manzere ku manja

c. Chimene chinachitika kuti mwendo udulidwe ndi chiyani?

d. mwendo wanu unadulidwa liti?

d. Matenda ena amene muli nawo kuonjezerapo kudulidwa kwa mwendo ndi ati?

i. Matenda othamanga magazi

ii. Nthenda ya shuga

iii. Nthenda ya mtima

v. Vuto lakusaona bwino maso

vi. Nthenda ya impsyo

vii. Matenda ena monga.....

e. Mudakali mchipatala munalandilapo thandizo lina lililonse la fizo? inde

F. Nanga mutatuluka mchipatala, munalandirapo thandizo la fizo? Inde

ngati munalandilapo, munalandindila thandizoli kwa nthawi yaitali bwanji?



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Appendix 11.

SEMI – STRUCTURED INTERVIEW GUIDE.

Introduction.

I would like to thank you for accepting that we can meet today. My name is Stella Mpezeni a physiotherapy student at the university of the western cape in south Africa. I would like to ask your experiences of living with an amputated limb in the community, especially your experiences on the integration and social participation in the community. The interview will take less than 45 minutes. The interview will be audio recorded because we don't want to miss any information that will be reported. Although I will be taking notes during the interview, but still I cannot write as fast enough to capture everything that you will be reporting. Therefore, you are required to speak loudly enough so that I should not miss any information that you will provide. All your responses will be kept confidential and the information will only be shared with the research team members. I will make sure that all the information included in the report does not identify you as a respondent. Remember that if you don't want to talk about something that you are not comfortable with you are allowed to do so and you can also decide to end the interview anytime. Do you have any questions regarding what I have explained?
Are you willing to participate in this interview?

Questions.

1. Please share your experiences of living with amputation in your everyday life in the community.
 - What challenges do you meet?
 - Explain how do you manage these challenges.
2. Has amputation affected you in any way - please explain more?
 - How does amputation affect your functional performance?
3. Please explain how your family members feel towards you since you had an amputation?
 - How does your husband/wife, parents, and others react towards your amputation?
 - Explain how your family members accommodate you during family gatherings.
4. How does the community feel about your condition?
 - Explain how the community accommodate you in the following;
 - i. Social gatherings
 - ii. When accessing public transport
 - iii. at church.
5. Are there any other issues that you want to share?

Appendix 12

INTERVIEW GUIDE CHICHEWA.

MNDANDANDA WAMAFUNSO OTI AFUFUZIDWE MWATSATANETSATANE

Introduction.

Ndathokoza kwambiri povomereza kutenga nao mbali pa kafukufuku uyu. Ine dzina langa ndine Stella Mpezeni wophunzira wa physiotherapy ku sukulu ya western cape ku south africa. Ndikufunana ndiyankhule nanu pa nkhani yokhudzana ndi zinthu zomwe inu mumakumana nazo mukakhala kudela la kwanu pamane munaduludwa mwendo kufikira tsiku la lero. Makamaka ndikufuna ndidziwe za mmene anthu aku dera la kwanu anachilandilira kuti inuyo munadulidwa mwendo komanso mmene amakulandilirani mu ma gulu osiyanasiyana.

Kufunsidwaku kutenga mphindi zosapitilira makumi anayi kudza mphamvu zisanu. Mafunso komanso ma yankho anu adzajambulidwa ndi chotengera mau ndicholinga choti tisalakwise china chili chonse chomwe inu mutanene. Ngakhale kuti ndizakhala ndikulemba china chili chonse chimene inu muta dzalankhule komabe sindingakwanitse kulemba zinthu zonse chotero mukupemphedwa kuyankhula mokweza mau kuti zidzamveke bwino.

Zokambirana zathu zidasungidwa mwa chinsinsi. Izi zikutanthauza kuti zonse zimene inu mulankhule zidzagwiritsidwa ntchito ndi anthu okhao amane atenga nao mbali pa kafukufuku uyu. Komanso simudzazindikiridwa kuti munatenga nawo mbali. Musaiwale kuti muli ndi ufulu osafotokoza zimene inu simukufuna kuti mutero komanso muli ndi ufulu oyimitsa kafukufukuyi nthawi ina iliyonse imene inu mungafune.

Kodi muli ndi mafunso pa zimene ndalongosolazi.

Nanga kodi mukuvomereza kuti mutenga nao mbali?

Mafunso

1. Chonde fotokozani mwatsatanetsatane zomwe inu mumadutsamo tsiku ndi tsiku kuyambira pomwe munadulidwa mwendo, mukakhala pakati pa anthu.
 - Ndi zobetchera zotani zimene inu mumakumana nazo.
 - Fotokozani za mmene mumachitira pothana ndi zobetchera zimenezi.
2. Kodi kudulidwa kwanu kwa mwendo kunapangitsa kuti moyo wanu usinthe munjira ina yake? – Chonde fotokozni mwatsatanetsatane.
 - Zimakukhudzani bwanji pa kagwiridwe kanu ka ntchito
3. Kodi anthu amubanja lanu amamva bwanji za inu chidulidwireni mwendo? Chonde fotokozani.
 - Kodi makolo anu, amuna anu, komanso ena onse amamva bwanji za vuto limene inu muli nalo.
 - Fotokozani za mmene anthu akubanja kwanuwa komanso anzanu anachilandilira kuti inu munadulidwa mwendo.
 - Fotokozani mmene amakulandilirani mukakhala zochitika mmbanja la kwanulo.
4. Kodi anthu ena kudera kwanuko anachilandira motani kuti inu munadulidwa mwendo?
 - Amakulandirani motani kukakhala muzochitika za mmudzimo kapena kuderako
 - Mukakhala mumagulu azochitika zina
 - Mukamakwera mabasi kapena matola
 - Ku chalichi.
5. Pomaliza kodi mulinso ndi zina zimene mukufuna mugawane nafe?

Appendix 13



OFFICE OF THE DIRECTOR: RESEARCH RESEARCH AND INNOVATION DIVISION

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

16 August 2017

Ms S Mpenzeni
Physiotherapy
Faculty of Community and Health Sciences

Ethics Reference Number: BM17/6/12

Project Title: Community experiences of persons with lower extremity amputations in Malawi.

Approval Period: 15 August 2017 – 15 August 2018

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

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

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

A handwritten signature in black ink, appearing to read 'Patricia Josias'.

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

PROVISIONAL REC NUMBER -130416-050

Appendix 14



Telephone: (265) 01 874 333 /877 333
Facsimile: (265) 01 876928
Email: queenshosp@globemw.net



In reply please quote No. QEC/GEN/2

QUEEN ELIZABETH CENTRAL HOSPITAL
P.O. BOX 95
BLANTYRE
MALAWI

All communications should be addressed to:
The Hospital Director

25TH AUGUST, 2017

The Chairman
COMREC
Private Bag 360
Chichiri
BLANTYRE 3

Dear Sir/Madam

**RE: PERMISSION TO CONDUCT A RESEARCH STUDY AT QUEEN ELIZABETH
CENTRAL HOSPITAL**

Reference is made to Mrs Stella Mpezeni requesting to conduct study titled
"Community experience of persons with lower extremities amputations in
Malawi" at Queen Elizabeth Central Hospital.

This letter serves to inform you that Management has no objection for her to
conduct the said study. She should remember to provide us with a copy of the
results after the study.

Yours faithfully,
The Hospital Director
Queen Elizabeth Central Hospital

Ms Linly Chewere
2017-08-25
P.O. Box 95
Blantyre
Ms Linly Chewere
DEPUTY HOSPITAL DIRECTOR

Stella Mpezeni
Malawi against Physical Disabilities
P.O. Box 256
Blantyre



getting people moving

15th August 2017

Dear Ms Mpezeni,

**Community experiences of persons with
lower extremity amputations in Malawi**

I refer to your application dated 10th August for approval to conduct research at the 500 miles Prosthetic and Orthotic Centre at Kamuzu Central Hospital together with a copy of the protocol.

We consent to the research subject to the terms and conditions discussed in our email exchange on 14th and 15th August.

Yours faithfully

On behalf of 500 miles



UNIVERSITY of the
WESTERN CAPE



Olivia Giles, Chief Executive Officer



PRINCIPAL
Richard Tambulasi, B.A.(Pub Admin), BPA(Hons),MPA, Ph.D

Our Ref.:
Your Ref.:

CHANCELLOR COLLEGE
P.O. Box 280, Zomba, Malawi
Telephone: (265) 524 222
Fax: (265) 524 046
E-mail: principal@chanco.unima.mw

26th October, 2018

PROOFREADING/EDITING OF THE THESIS TITLED
COMMUNITY EXPERIENCES OF PERSONS WITH LOWER
EXTREMITY AMPUTATION IN MALAWI

I write to confirm that I have proofread and edited the thesis titled
Community Experiences of Persons with Lower Extremity Amputation in
Malawi written by Stella Mpezeni.

Yours Sincerely

A small, handwritten signature in blue ink, appearing to be 'Mervis'.

Mervis Kamanga, PhD

Lecturer- Department of African Languages and Linguistics