

**BARRIERS AND FACILITATORS TO UTILISATION OF REHABILITATION  
SERVICES AMONGST PERSONS WITH LOWER-LIMB AMPUTATIONS IN A  
RURAL COMMUNITY IN KWA-ZULU NATAL**

By

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A thesis submitted in fulfilment of the requirements for the degree of Masters of Science in  
the Department of Physiotherapy, University of the Western Cape (UWC)

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## ABSTRACT

An estimated 387 million people worldwide already have diabetes mellitus (DM), with those numbers rising to an estimated 592 million people by the year 2035. The prevalence of diabetes mellitus continues to increase with the largest increase seen in low- and middle-income countries, such as South Africa (Shaw, Sicree, & Zimmet, 2010; Peer et al., 2012; International Diabetes Federation, 2014; Bertram et al., 2013; Mayosi et al., 2009). Lower-limb amputation is a common complication of uncontrolled diabetes mellitus (Moxey et al., 2011) and there is a marked increase in the incidence of diabetes mellitus in rural areas in South Africa. The impact that the amputation has on the individual's life can be devastating since the amputation of the limb is likely to be accompanied by a profound sense of loss. Rehabilitation can assist to retrain physical and functional abilities, psychological and emotional adjustment issues, as well as social and community reintegration (Manderson & Warren, 2010). Therefore, comprehensive rehabilitation is vital to mitigate the negative impact that a lower-limb amputation has on a person. Persons with disabilities who live in rural areas experience challenges accessing health services and rehabilitation (Harris et al., 2011). Even though challenges with accessing healthcare in rural settings are well documented, there is no literature specifically pertaining to persons with lower-limb amputations in a rural South African context.

The aim of this study was to determine the prevalence and common causes of lower-limb amputations, as well as to explore the barriers and facilitators to the utilisation of rehabilitation services in a rural setting.

The study was conducted in the iLembe district of Kwa-Zulu Natal. The quantitative study was conducted at the regional Stanger Hospital in Kwa-Dukuza and the qualitative study was conducted at the three sub-district hospitals, namely Umphumulo, Untunjambili and Montebello. Permission was requested by the Department of Health as well as the District Manager's office in order to conduct the study in this district. The quantitative study employs a retrospective archival study whereby 111 patient's medical folders were retrieved to extract the common causes of, and co-morbidities associated with, lower-limb amputations. The qualitative aspect utilised a descriptive study design to explore the barriers and facilitators perceived by persons with lower-limb amputations in a rural setting by means of a semi-

structured interview with 11 viable participants. Written consent was obtained from all participants prior to commencement of the semi-structured interview.

The results revealed gangrene as a result of diabetes mellitus to be the most common cause of lower-limb amputations, with the highest co-morbidities being diabetes mellitus and hypertension in a total number of 111 patients. Seven barriers and four facilitators were perceived by persons with lower-limb amputations with regard to the utilisation of rehabilitation services in rural settings. The barriers included financial constraints, lack of independence, accessibility, lack of transport, environmental barriers, lack of information and impairments. The facilitators included self-motivation, referral system, accessibility and family support.

Development and implementation of DM preventative measures should be carried out to reduce the incidence of lower-limb amputations. Education, health promotion and regular screenings should be done in rural regions where there is a scarcity of health information and awareness. Furthermore, persons with lower-limb amputations face numerous challenges with accessing rehabilitation services. These challenges need to be made aware to physiotherapists in rural areas, as well as the need for these challenges to be addressed by relevant stakeholders in the government and the department of health to actively reduce these barriers and allow for accessibility and utilisation of rehabilitation services. This may reduce the impact of the disability and improve functionality, quality of life and independence to persons living with a lower-limb amputation.

**Keywords:** amputation, lower-limb, barriers, facilitators, causes, co-morbidities, rural

## DECLARATION

I hereby declare that "Barriers and facilitators to utilisation of rehabilitation services amongst persons with lower-limb amputations in a rural community in Kwa-Zulu Natal" is my own work, and that I have not submitted it or any part of it for a degree at any university. All the sources that I have used or quoted have been indicated by means of complete references.

Signature: .....

Date: .....

Ugendrie Naidoo



## DEDICATION

I dedicate this work to my beloved parents, Babs and Vanilla Naidoo, whose love knows no bounds. Thank you for your endless support, encouragement and motivation in all my endeavours. No amount of words will ever be able to express my love, gratitude and appreciation.

To my better half, Kimolan Perumaul, thank you for your infinite love, support and patience. Your encouragement and motivation has always inspired me to reach greater heights.

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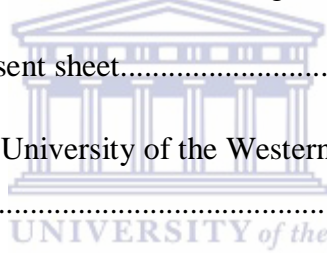




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## LIST OF ABBREVIATIONS

CBR ó Community based rehabilitation

CEO ó Chief executive officer

CDC ó Centres for Disease Control and Prevention

CHCC ó Community Healthcare Centre

COAD ó Chronic obstructive airways disease

COPD ó Chronic obstructive pulmonary disease

CRPD ó Convention on the Rights of Persons with Disabilities

DM ó Diabetes mellitus

DOH ó Department of Health

DWCPD - South African Department of women, children and people with disabilities

ICF -International classification of functioning, disability and health

IHD óIschemic heart disease

HPCSA ó Health Professions Council of South Africa

KZN ó Kwa-Zulu Natal

LEA ó Lower extremity amputation

LLA ó Lower-limb amputation

MI óMyocardial infarction

PVD -Peripheral vascular disease

SA ó South Africa

TB - Tuberculosis

UNCRPD ó United Nations Convention on the Rights of Persons with Disability

USA ó United States of America



WHO ó World Health Organization



## CHAPTER ONE: INTRODUCTION

### 1.1 Introduction and background

Lower-limb amputation (LLA) is a permanent surgical procedure that has important functional, psychological and social outcomes that can influence the quality of life of the person with an amputation (Zidarov, Swaine, & Gauthier-Gagnon, 2009). Amputations which involve the loss of a limb become necessary as a result of vascular disease, diabetes, trauma, tumours, infection and congenital deformities. Of all the foregoing conditions, vascular diseases and diabetes are generally the main reasons for amputations (Pedretti, 2006; Godlwana, Nadasan, & Puckree, 2008; Gutacker, Neumann, Santosa, Moysidis, & Kröger, 2010).

In 2010 an estimated 285 million adults had diabetes mellitus (International Diabetes Federation, 2014). This was projected to rise to 439 million adults by 2030; however, the most recent International Diabetes Federation estimates are that in 2014, 387 million people already had diabetes mellitus, and by 2035 this will rise to 592 million. The prevalence of diabetes mellitus continues to increase, with the largest increase seen in low- and middle-income countries; in South Africa (SA) the prevalence is also rising (Shaw, Sicree, & Zimmet, 2010; Peer et al., 2012; International Diabetes Federation, 2014; Bertram et al., 2013; Mayosi et al., 2009).

This increase is mainly due to the growth and ageing of the population, as well as rising rates of urbanisation with associated increased levels of obesity, physical inactivity and unhealthy diet (Bradshaw, Norman, Pieterse & Levitt, 2007; Mbanya, Motala, Sobngwi, Assah, & Enoru, 2010; Gill, Mbanya, Ramaiya, & Tesfaye, 2009).

This escalating number of people with diabetes mellitus will impact on disease management systems. Diabetes mellitus accounted for 4.3% of all deaths in SA in 2000, placing it as the seventh most common cause of death in this country (Bradshaw et al., 2007). The complications of diabetes are not only common but devastating, and include lower extremity amputations (LEAs), blindness and renal failure, with diabetes being the most common cause for non-trauma-related lower-limb amputations. There is a wide range in the proportion of lower-limb amputations due to diabetes mellitus, with studies showing that up to 90% of lower-limb amputations worldwide are associated with diabetes mellitus and up to 70% of patients who undergo a lower-limb amputation die within five years of the operation

(Bradshaw et al., 2007; Girach & Vignati, 2006). There is a marked increase in the incidence of diabetes mellitus in South Africa, particularly in rural areas (Gray, Vawda, & Jack, 2011).

There is also a strong co-existence of co-morbidities such as diabetes mellitus and hypertension related to lower-limb amputations. In a study conducted by Wegner and Rhoda (2016), 71% of people who lost their lower-limbs were diabetic and of that diabetic population, 81% were diagnosed with hypertension. Hypertension was found to be more common among diabetic patients with lower-limb amputations than non-diabetic patients with lower-limb amputations (Dunbar & Levitt, 2015). Diabetic-related risk factors for lower extremity amputation include longer duration of disease, poor glycaemic control, higher systolic blood pressure and treatment with insulin (Krittawong et al., 2006; Davis et al., 2006).

The impact that the amputation has on the individual's life can be devastating since the amputation of a limb is likely to be accompanied by a profound sense of loss. A person with an amputation has to come to terms with the loss of a limb and their resultant changed body image, discomfort, inconvenience, expenses, loss of function especially mobility, and restrictions in terms of leisure and productive activities. Socio-culturally, a person with an amputation may experience discrimination, stereotyping and adverse reactions to the amputation which can lead to self-hatred and self-deprecation (Pedretti, 2006; Unwin, Kacpersek & Clark, 2009; Manderson & Warren, 2010). It is not uncommon for an individual to feel self-pity, anxiety, shock, grief, depression, anger, frustration and a sense of futility in response to an amputation (Pedretti, 2006; Unwin, Kacpersek & Clark, 2009; Manderson & Warren, 2010). A person with an amputation, therefore, experiences disability and a poor quality of life (Spichler, Spichler, Lessa, Costa e Forti, Franco, & LaPorte, 2001). The impact of the amputation on the individual can be reduced through physical therapy and rehabilitation.

Rehabilitation can assist to retrain physical and functional abilities, psychological and emotional adjustment issues, as well as social and community integration (Manderson & Warren, 2010). Therefore, comprehensive rehabilitation is very important to mitigate the negative impact that a lower-limb amputation has on a person.

Rehabilitation of lower-limb amputees encompasses the pre-amputation, postoperative, pre-prosthetic and prosthetic rehabilitation stages, within which a person with an amputation is provided with a prosthetic aiding device. Throughout the course of this complex process, a



person with an amputation whose amputation arose as a consequence of an injury or a disease gets the chance to adapt to the prosthesis that supplements the lost limb part and to achieve the restitution of ambulation and other locomotive abilities with the aid of prosthesis. Medical rehabilitation should by all means be accompanied by an adequate psychological and social rehabilitation in line with the bio-psychosocial model, so as to attain the ultimate goal of each and every rehabilitation; that is to say, a successful reintegration of a person with an amputation into an everyday life that resembles the style and quality of the pre-amputation daily living as much as possible. Rehabilitation strives to achieve the maximal possible physical, emotional, social, vocational and financial independence of a person with an amputation and their maximal efficiency in all aspects of life (Kovac et al., 2015).

There is relatively sparse data on how persons with disabilities access healthcare including rehabilitation. Mostly it is accepted that persons with disabilities are faced with challenges when accessing healthcare services such as rehabilitation ó including physical access to buildings as well as access to information, services, care and support (WHO, 2011).

According to WHO (2011), barriers to the utilisation of healthcare services include: inadequate policies and standards, negative attitudes, lack of provision of services, problems with service delivery, inadequate funding, lack of accessibility, and lack of consultation and involvement, lack of data and evidence.

Persons with disabilities who live in rural areas experience even more challenges accessing health services and rehabilitation (Harris et al., 2011). Even though challenges with accessing healthcare in a rural setting, such as transport, travel distances, high travel costs, out of pocket expenditure and disempowered patients, are well documented, there is no literature specifically pertaining to persons with a lower-limb amputation, in a rural South African context.

In South Africa 38% of the population resides in rural areas. Kwa-Zulu Natal, one of South Africa's poorest provinces, has an estimated population of 10.5 million people, the second largest population in South Africa, with 53% residing in rural areas (Statistics South Africa, 2014). At the time of the national census in 2011, more than a quarter (26.3%) of all poor people in KwaZulu-Natal were mostly living below the per capita upper-bound poverty line of R620 per month (Statistics South Africa, 2014). According to the 2011 Census, 8.4% of Kwa-Zulu Natal's population is living with at least one disability.

High levels of poverty, together with the high incidence of disability and the large percentage of the population living in rural areas, present challenges to providing health for all in South Africa (Department of Health [DOH], 2010; Schaay & Sanders, 2008). Understanding the number of people with disabilities and their circumstances can improve efforts to remove these barriers and allow for the development of contextually appropriate rehabilitation interventions for persons with lower-limb amputations.

## **1.2 Problem statement**

The incidence of chronic diseases of lifestyle such as Type 2 Diabetes Mellitus (DM) is on the increase amongst the South African population (Gray et al., 2011). Lower-limb amputation is a common complication of poorly controlled or undetected DM (Moxey et al., 2011). Due to the numerous factors such as lack of education, inaccessibility of healthcare facilities and/or poor socio-economic background, DM often goes undetected in rural areas, resulting in an increase in lower-limb amputations in these areas (Nemet & Bailey, 2000).

People with disabilities in South Africa appear to have difficulty accessing rehabilitation and home care services, but not necessarily general healthcare services (Maart & Jelsma, 2014). According to O'Day, Dautel and Scheer (2002), little information exists from the perspective of people with disabilities about the healthcare barriers they face, while even less is known about what barriers people with specific impairments encounter.

There is currently not enough data on the situation of people with disabilities living in rural settings in South Africa (Loeb, Eide, Jelsma, Ka Toni, & Maart, 2008). In addition, persons with lower-limb amputations residing in rural areas experience difficulties accessing rehabilitation services, which negatively impacts on their functional status and quality of life. The barriers and facilitators experienced by persons with lower-limb amputations regarding access to rehabilitation services have not been studied in the rural regions of Kwa-Zulu Natal. Gaining insight into factors that impact the ability of a person with a lower-limb amputation to access rehabilitation services is crucial to developing strategies aimed at facilitating their access to such services.

## **1.3 Research questions**

1.3.1 What are the common causes and prevalence of lower-limb amputations in the iLembe district of Kwa-Zulu Natal (KZN)?

1.3.2 What are the perceived barriers and facilitators experienced by persons with lower-limb amputations in relation to the utilisation of rehabilitation services in a rural setting in KZN?

#### **1.4 Aims**

1.4.1 To determine the prevalence and common causes of lower-limb amputations performed at the regional hospital in the iLembe District of Kwa-Zulu Natal

1.4.2 To explore the facilitators and barriers to utilization of rehabilitation services in a rural setting

#### **1.5 Objectives**

1.5.1 To determine the demographic profile of persons with lower-limb amputations living in a rural setting

1.5.2 To determine the prevalence and common causes of lower-limb amputations in the iLembe District of Kwa-Zulu Natal

1.5.3 To identify any co-morbid diseases experienced by persons with lower-limb amputations

1.5.4 To explore the barriers and facilitators perceived by persons with lower-limb amputations to utilisation of rehabilitation services in a rural setting

#### **1.6 Significance**

The common causes of lower-limb amputations identified in this study are important in order to inform health promotion and preventative programmes. This may be accomplished through early detection of co-morbidities and screening for complications; as well as education on the causes, effects and prevention measures of lower-limb amputations. Highlighting the contextual challenges of persons with lower-limb amputations living in a rural region is vital to plan appropriate treatment, interventions and policies for persons with disabilities.

Understanding the barriers and facilitators to the utilisation of rehabilitation services directly from people with a lower-limb amputation, will assist therapists working in rural areas to reduce these barriers to access, and reduce participation restrictions experienced by persons with lower-limb amputations as a result of their impairment. The knowledge of these challenges enhances the importance of providing patients with the ability to use public transport in rural areas and to advocate for accessible and affordable public transport services

in the community. This study ought to encourage therapists to consider conducting home visits and community based rehabilitation (CBR) programmes and to educate community caregivers on assisting persons with lower-limb amputations with rehabilitation, in order to reduce the cost, time and distance of travelling to rehabilitation services at the local hospital. Services should be decentralised in order to provide services closer to patients' homes to improve accessibility.

### **1.7 Outline of the thesis**

This thesis explores the access to rehabilitation services for persons with lower-limb amputation in a rural area in South Africa. The primary research question addressed is: What are the barriers and facilitators to the utilisation of rehabilitation services amongst lower-limb amputees in a rural area of KZN?

The thesis includes both a quantitative and qualitative component. The quantitative component looks at the prevalence and common causes of lower-limb amputations, as well as the co-morbidities of patients who have undergone lower-limb amputations in a rural area of KZN. The qualitative component looks at the barriers and facilitators to utilisation of rehabilitation services in rural areas which are perceived by persons with lower-limb amputations.



### **Chapter one**

Chapter one includes an introduction to the thesis, explaining the definition of a lower-limb amputation and giving the reader a brief history of the common causes and co-morbidities which may influence an amputation. It outlines the significance and importance of undertaking this study, as well as the aims and objectives which are achieved.

### **Chapter two**

Chapter two contains the literature review. This chapter includes the existing information and literature that is available nationally and internationally regarding lower-limb amputation statistics, common causes, co-morbidities, barriers and facilitators to access of healthcare services, as well as the utilisation and access of rehabilitation services and the importance of rehabilitation. This provides an insight to the missing literature which this study will fulfil.

### **Chapter three**

Chapter three outlines the methodology used to execute this study. The quantitative and qualitative component each includes the study design, the setting in which the study is undertaken, the type of population that is included in the study, the instrument used to fulfil the objectives, the procedure of data collection and the way in which the data is analysed. The qualitative component also includes how trustworthiness, transferability and dependability are addressed. It also describes the way in which ethical considerations are adopted.

### **Chapter four**

Chapter four comprises of the results of the study in two components, quantitative and qualitative. The quantitative component illustrates the common causes of lower-limb amputations and the co-morbidities of patients who have undergone lower-limb amputations in a rural area of KZN. The qualitative results show the perceived barriers and facilitators faced by persons with lower-limb amputations with access to rehabilitation services in the rural areas of the iLembe district in KZN.

### **Chapter five**

Chapter five includes the discussion of the quantitative and qualitative findings of the study. Both the quantitative and qualitative components include the results found in the study, how they relate to the literature available and the clinical or practical implications they pose. The qualitative discussion component is divided into barriers and facilitators.

### **Chapter six**

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

## CHAPTER TWO: LITERATURE REVIEW

### 2.1 Introduction

The focus of the literature review is on the factors affecting utilisation of rehabilitation services by persons with lower-limb amputations. Prior to gaining insight on these factors, an overview on lower-limb amputations with regard to incidence, prevalence and causes are discussed to provide background information regarding an amputation. This overview is followed by the various factors affecting access to rehabilitation and healthcare services.

### 2.2 Definition of lower-limb amputation

Lower extremity amputation is a complete loss/ablation of any part of the lower-limb, for any reason, in the following anatomical planes: in the transverse plane proximal to, and including, the subtalar joint and in the frontal anatomical plane distal to the subtalar joint. An amputation can be -major or -minor. A major amputation is that through, or proximal to, the tarso-metatarsal joint, while minor amputation is one distal to this joint (The Global Lower Extremity Amputation (LEA) Study Group, 2000). An amputation is often performed to salvage the limb following a severe injury (e.g. a war injury or road traffic accident), when there is tissue loss due to vascular occlusive disease, or to control infection (Engstrom & Van de Ven, 1999).

### 2.3 Causes of lower-limb amputation

Diabetes mellitus is one of the major risk factors accounting for premature mortality and morbidity, due to its complications (American Diabetes Association, 2006; Narayan et al., 2006).

Diabetic complications such as neuropathic foot and ischaemic foot, peripheral vascular disease, trauma, infection, malignancy and congenital lower-limb defects result in lower-limb amputations, at varying rates (Wong, 2005; Spichler et al., 2001; The Global Lower Extremity Amputation (LEA) Study Group, 2000; Van Houtum, Lavery, & Harkless, 1996; Engstrom & Van de Ven, 1999). Burns, rhabdomyolysis, sepsis and cellulitis may result in lower-limb amputation (Eskelinen et al., 2004). Co-morbidities for lower-limb amputation include hypertension, coronary arterial disease, tobacco use and end stage renal failure (Abou-Zamzam, Teruya, Killen, & Ballard, 2003).

According to the literature, the primary cause of lower-limb amputation in industrialised countries is peripheral vascular disease which might or might not be complicated by diabetes mellitus (Ray et al., 2005; Clark, Kelman, & Colagiuri, 2006; Gutacker et al., 2010; Manderson & Warren, 2010). On analysis of clinical records of 1094 patients from Helsinki it was found that all 1094 patients underwent major lower-limb amputations due to vascular disease (Gutacker et al., 2010). According to Tate and Forchheimer (2002) in Australia, vascular disease accounts for one-third of all amputations, of which 40% is due to diabetes mellitus, which is often associated with vascular diseases. In developing countries such as Malaysia, a study that was carried out in Seremban Hospital reported that 34.3% of patients who had amputations were female and 65.7% were male. The average age of the patients was 39.7 years. The most common cause of amputations was not traumatic, but mainly due to diabetes or gangrene (Hazmy et al., 2001).

Sub-Saharan Africa has more than eight million people affected by diabetes currently, with a future estimation of around 19 million people by 2030 (Wild, Roglic, Green, Sicree, & King, 2004). In developing countries, diabetes mellitus was found to be one of the most significant complications of foot disease (International Diabetes Federation, 2005). Diabetes is the leading cause of lower-limb amputations and trauma accounts for the minority of cases (Godlwana et al., 2008). There is no recent information on the current causes and incidence of lower-limb amputation in South Africa. Henry (1993) found the mean age of amputation due to malignancy, trauma and Buerger's disease was relatively young, at 33, 37, 38 years respectively, compared to those who had been amputated due to diabetes and PVD.

Therefore, vascular causes were generally a later-age phenomenon (Henry, 1993). Traumatic lower-limb amputation occurs at a young age (mean age of 33 years old) (Kubheka, 1993). In the Western Cape, South Africa, the leading causes of lower-limb amputation are vascular (83%), trauma (12%), malignancy (3%), infection (2%), while congenital limb defects constituted 0.2% (Henry, 1993). Of those who were amputated due to infection and malignancy, the primary causes were meningococcal septicaemia and osteogenic sarcoma. Hypertension, chronic obstructive airway diseases (COAD), hemiplegia, ischaemic heart disease (IHD) and myocardial infarctions (MI) were the most prevalent co-morbidities in this study.

Independent of the cause of amputation, whether it is due to vascular, traumatic or orthopaedic causes, an amputation is considered a mutilating surgery which affects the lives of patients who undergo amputation (Braile, Buzatto, De Godoy, Fontes, & Longo, 2002).



Limb loss is one of the most physically and psychologically devastating events that can happen to a person. Not only does lower-limb amputation cause major disfigurement; it renders people less mobile and at risk for loss of independence (Gitter & Bosker, 2005).

Whatever the cause, individuals who have undergone lower-limb amputation need assistance from their social network and rehabilitation services, to overcome physical, emotional and social challenges, in order to take up their social roles once more (Unwin et al., 2009).

## **2.4 Incidence and prevalence of amputations**

The Global Lower Extremity Amputation Study Group (2000) that functions across national boundaries provides information on major lower-limb amputation rates from countries as diverse as Japan, Taiwan, Spain, Italy, North America and England. The Navajo population, in the United States of America, have at 43.9 per 100 000 people per year incidence, the highest amputation incidence rate in the world (Global Lower Extremity Amputation Study Group, 2000). The Navajo population lives on the largest land area assigned primarily to the Native American jurisdiction within the United States, occupying all of the north-eastern Arizona and extending into Utah and New Mexico. Diabetes in Navajo people has been reported since the 1960s, with recent reports in adults suggesting estimates of type 2 diabetes two to four times those of non-Hispanic white populations and rising over the past 20 to 30 years (Sugarman, Gilbert, & Weiss, 1992; Will et al., 1997). The population from Madrid, Spain has a 2.8 per 100 000 population per year - the lowest rate (Global Lower Extremity Amputation Study Group, 2000). The study done by the Global Lower Extremity Amputation Study Group (2000) included ten centres in Europe, North America and East Asia, with a population greater than 200 000 people. They found that the incidence of amputation rose steeply with age; most amputations occurred in patients over 60 years old and, in most centres, the incidence was higher in men than women, with the incidence of major amputations greater than that of minor amputations. Diabetes was associated with between 25% and 90% of amputations.

Not all countries have incidence or prevalence rates available. Data from other countries includes figures from Germany where a national survey found that a total of 62 880 amputations affecting the lower extremity were performed in 2006, with 63 005 in 2005 (Gutacker et al., 2010). According to Rommers (2000) an estimated 3300 lower extremity amputations are performed every year in the Netherlands.



Limited information and research on the incidence of lower extremity amputations could be found for Africa and South Africa. In South Africa, only studies by Henry (1993) and Kubheka (1993) were found. These are completed theses but unpublished work. However, these studies are relevant as they are South African and there are no other publications on this subject in South Africa. These findings should be treated with caution as they hail from before the 1994 democratic elections in South Africa. It is important to note that, since the elections, healthcare services in the country have been restructured with a focus on primary healthcare and the decentralisation of many services from tertiary to primary level (Kautzky & Tollman, 2008). However, an amputation represents a major surgery and is therefore not performed at primary level, with the result that the researcher considers the figures from a tertiary hospital, though dated, still provide useful information. According to this hospital-based survey, 597 major lower-limb amputations were performed over the three-year period from 1985-1987 (Henry, 1993). The data further indicated an upward trend in the number of amputations performed per year over the three years. In developed countries, peripheral arterial disease, as a result of atherosclerosis, is the most common reason for lower-limb amputation (Solagberu, 2003).

In some studies, the incidence of amputations increased with age and the average age of amputees was usually 60 years or older (Gutacker et al., 2010; Asano et al., 2008; Ayhan, Reyhan, Metin, Fusun, & Yetkin, 2004). However, in comparison to African studies, such as a study from Nigeria, Africa, mean age of 44.5 years was found (Kidmas et al., 2004), while Bakkes (1999) found a mean age of 48 years in a study on a selected population in the Western Cape Province of South Africa. Both these studies included a high number of traumatic amputations which might be the reason for the younger average age (Bakkes, 1999; Kidmas et al., 2004). In contrast to these two findings from Africa, Henry (1993), in a study done at Tygerberg Hospital in the Western Cape Province of South Africa, reported a mean age of 60.3 years at first amputation.

Men had a higher amputation incidence rate than women in both industrialised and developing nations (Bakkes, 1999; Kidmas et al., 2004; Asano et al., 2008; Gutacker et al., 2010). Regarding the level of amputations performed, the two African studies found that trans-femoral amputations were performed most often (more than 50%), followed by trans-tibial amputations (30-37%), with a very low level of hip disarticulations (2%) and through-knee amputations (1%) (Henry, 1993; Kidmas et al., 2004).

The impact of vascular diseases and diabetes mellitus on the body is high and a one-year mortality rate of 13.7% in clients who suffered an amputation due to vascular causes was reported by Basu et al. (2008). These diseases also led to a high incidence of further amputations as 9% to 20% of people suffered a second amputation within one year of the first, while 28% to 51% underwent a second amputation within five years of the first (Gayle & Reiber, 1995). The Global LEA study (2000) found that trauma in males accounts for less than 10% of major lower-limb amputation. People with high systolic blood pressure (135-221), high diastolic blood pressure (86-117), high pulse pressure (53-125), severe retinopathy, high number of packets smoked over the years (greater than or equal to 15) have a high incidence of lower-limb amputation (Moss, Klein, & Klein, 1999). Non-traumatic lower-limb amputation is associated with more than 80% of people over the age of 65 and retired, 5% unemployed and 2% working (Calle-Pascual et al., 1997). Low income and being single (whether divorced, widowed or never married) and having a history of foot ulcers are associated with a high incidence of lower-limb amputations in people with diabetes and those with cardiovascular diseases (Godlwana et al., 2008; Resnick et al., 2004; Hennis, Fraser, Jonnalagadda, Fuller, & Chaturvedi, 2004). The reported marital status was on studies done in the Caribbean on people of African descent.

There is an association between the incidence of lower-limb amputations and race (Feinglass, Rucker-Whitaker, Linqvist, McCarthy, & Pearce, 2005; Dillingham, Pezzin, & MacKenzie, 2002). These studies reported that black people are twice as likely to have a lower-limb amputation as a result of peripheral vascular disease (PVD) as other races. Racial differences in the incidence of lower-limb amputation are consistent regardless of the presence of diabetes (Dillingham et al., 2002).

## **2.5 Impact of lower-limb amputation**

An amputation can be seen as an archetypal impairment since it is visible, having a large impact on external appearance and the individual's self-image, emotional status and quality of life (Asano, Rushton, Miller, & Deathe, 2008; Manderson & Warren, 2010). The functional ability of the individual is often adversely affected, and it has a negative effect on productivity and social engagement (Manderson & Warren, 2010). Post-amputation outcomes are affected by variables such as age, level of amputation, cause of amputation, level of mobility and rehabilitation services (Kidmas, Nwadiaro, & Igun, 2004). Other studies (Asano et al., 2008; Basu, Fassidis, & McIrvine, 2008) indicate a direct relationship between a person's quality of life and their level of mobility following a lower-limb amputation. Other

aspects which impact negatively on personal quality of life after lower-limb amputation are depression, lack of social support, presence of co-morbidities, decreased social participation, problems with prosthesis and age (Asano et al., 2008). Some factors such as age and social support are not modifiable. However, all the modifiable factors such as mobility, depression, social participation and prosthetic problems should be addressed through rehabilitation (Manderson & Warren, 2010).

People who have amputations at an early age are more likely to walk, be independent in activities of daily living and end up using prostheses. Kubheka (1993) revealed that the sample used identified failure of rehabilitation personnel to identify limitations in home infrastructure. In this study, stump infection was reported to delay rehabilitation. Other physical problems associated with amputation are sores on the stump, joint stiffness, mobility problems and severe stump pain, including phantom pain. Although many people are accepted by their families, some are rejected mainly because they are in some way blamed for their condition

## **2.6 Rehabilitation**

Recent work by Jesus and Hoenig (2015) offers an innovative and thought-provoking view on rehabilitation quality of care. Their work integrates key attributes of rehabilitation, such as interdisciplinary team treatments and a biopsychosocial orientation, along with the Donabedian Structures Processes Outcomes framework, to offer a rehabilitation-specific conceptual model and framework for rehabilitation quality of care across the post acute rehabilitation continuum.

The purpose of rehabilitation is to assist the individual to reintegrate into the community and participate in life roles, that is, to carry on with life as it was before the amputation as far as is possible (Manderson & Warren, 2010). This includes the learning of new skills such as caring for the residuum (stump), using a prosthesis, wheelchair dexterity and the relearning of previous skills such as walking. Rehabilitation also includes the provision of assistive devices such as prostheses, wheelchairs and crutches, education on health management and the prevention of complications that arise from not maintaining a healthy diet or not taking care of the remaining leg. Finally, rehabilitation should assist the person to regain self-confidence and confidence in their abilities (McColl, Davies, Carlson, Johnston, & Minnes, 2001; Pedretti, 2006; Manderson & Warren, 2010; Western Cape Department of Health (WCDH), 2010).

Successful rehabilitation for persons with lower-limb amputations is dependent on many variables including: pre-operative interventions, comprehensive early post-operative interventions, teamwork, shared goal-setting as well as client confidence in the programme and trust in the capability of the rehabilitation professionals (Manderson & Warren, 2010; Western Cape Department of Health, 2010).

Rehabilitation goals focus typically on wellness, mobility and independence (Manderson & Warren, 2010). The core professional members of the team include the surgeon, nurse, physiotherapist, occupational therapist, social worker and prosthetist (Godlwana et al., 2008; Manderson & Warren, 2010; WCDoH, 2010). Of all these professionals the prosthetist is central in cases where the person will use a prosthetic leg for mobility. The prosthetist must develop a trusting relationship with the client in order for the client to trust the prosthesis. This relationship is on-going during the client's lifetime as prostheses require re-fitting, repair and replacement from time to time (Manderson & Warren, 2010).

Prosthetists are supported by the physiotherapist with regard to prosthetic preparation and mobility retraining. The physiotherapist also has a crucial role to play in terms of mobility in instances where the person will not get a prosthesis, but will walk with the aid of crutches or use a wheelchair (Manderson & Warren, 2010; WCDoH, 2010). The social worker and occupational therapists' roles focus on preparation for residential and community integration and include psycho-social counselling, support with financial matters, and physical access, by identifying and addressing environmental barriers during home and work visits (Manderson & Warren, 2010; WCDoH, 2010).

## **2.7 Rehabilitation services for persons with lower-limb amputation in South Africa**

Very little could be gathered on this topic from the literature; however, national studies from Zambia, Mozambique, Malawi, Namibia and Zimbabwe indicate huge gaps in, especially, the delivery of medical rehabilitation and provision of assistive devices (WHO, 2011). According to Kidmas et al. (2004), rehabilitation services for persons with an amputation are poorly managed and often not provided in Africa. They found that only 12 of the 87 people with lower-limb amputations in their study were referred for prostheses and that the majority of clients did not follow up after discharge. These numbers are especially low when one takes into consideration that the most common cause of amputation for this study population was trauma, and traumatic amputees have a better prognosis for prosthetic functioning than vascular amputees.

According to the philosophy of primary healthcare on which healthcare provision in South Africa is based, rehabilitation is one of the pillars of primary healthcare (Kautzky & Tollman, 2008). South Africa's policy framework for disability and rehabilitation, the White Paper on an Integrated National Disability Strategy (Office of the Deputy President, 1997) and the National Rehabilitation Policy (Department of Health, 2000), describe appropriate rehabilitation as a goal-oriented, time-limited process that assists people with disabilities to become fully participating members of society. They state that rehabilitation at primary healthcare level in South Africa should be delivered on community-based rehabilitation principles. Community-based rehabilitation has two main objectives, one focusing on the individual and one on the community. These objectives are:

a) Ensuring that people with disabilities can maximise their physical and mental abilities, can access services and opportunities and become active contributors to society (International Labour Organisation, United Nations Educational, Scientific and Cultural Organisation, & WHO, 2004);

b) Activating communities into promoting and protecting human rights of people with disabilities through changes in the community, for example, by removing environmental barriers (International Labour Organisation, United Nations Educational, Scientific and Cultural Organisation, & WHO, 2004).

Similarly, Article 26 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2007) calls for:

*“ . . .appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life”.*

The Article further calls on countries to organise, strengthen and extend comprehensive rehabilitation services and programmes, which should begin as early as possible, based on multidisciplinary assessment of individual needs and strengths, and including the provision of assistive devices and technologies (UNCRPD, 2007). The United Nations Convention on the rights of persons with disabilities (United Nations[UN], 2007) underlines the rights of individuals with disabilities to play an active role in society, emphasising that accessing rehabilitation services plays a key role in achieving this.

Literature on the provision of rehabilitation services in South Africa is scarce; the only national figures that could be found dated back to 1999 where the Community Agency for Social Enquiry survey found that 39% of persons in South Africa who needed rehabilitation received it (Community Agency for Social Enquiry (CASE), 1999). A more recent report on healthcare access in South Africa by the South African Human Rights Commission (2009) stated that access to rehabilitation is poor, but provided no further explanatory information or figures. Localised studies from various South African settings further point to limited rehabilitation services, especially at primary level (Saloojee, Phohole, Saloojee, & Ijsselmuiden, 2007; Rhoda, Mpofo, & De Weerd, 2009; Wasserman, DeVilliers, & Bryer 2009; Equitable, 2011).

Saloojee et al. (2007) studied children with disabilities in Orange Farm, a peri-urban settlement in Gauteng. They found that only 26% of children who needed rehabilitation services received it and that 233 children needed assistive devices, of which only 28% were either ordered or issued. Couper (2002) found similar results in Kwa-Zulu Natal where one third of children who needed rehabilitation received it. Wasserman et al. (2009) did a multi-centre longitudinal cohort study in rural Kwa-Zulu Natal, with the aim of assessing the discharge planning of stroke clients and evaluating integration and continuity of stroke care between hospital and the community. They found that there were no rehabilitation services available to clients after discharge.

Rehabilitation services at medical institutions such as community healthcare centres and hospitals are usually offered by therapists. It is true that the presence of a therapist does not automatically lead to the provision of comprehensive rehabilitation as findings by Henn (2009) and De Wit et al. (2005) indicate. Rhoda et al. (2009) found that only 20 of the 39 Community Healthcare Centres (CHCC) in the Western Cape Metro Health District offered therapy services. Of these, all 20 had physiotherapists, ten offered occupational therapy services and, at two of the centres, students were providing speech therapy. Thus, a large percentage of people living in this geographic area did not have access to therapy services and thus by extension, to rehabilitation services at the primary level of care.

One South African study which specifically evaluated a rehabilitation programme could be found in the literature (Henn, 2009). In this study, the rehabilitation programme for persons with complete paraplegia at Netcare Rehabilitation Hospital was evaluated. It was found that the rehabilitation programme was effective in terms of addressing the needs for physical



independence. Another positive finding of the study was that 80% of the population indicated that they had gained knowledge about their wheelchair, equipment and the maintenance thereof (Henn, 2009).

## **2.8 Rehabilitation of persons with a lower-limb amputation**

Disability is an interaction between impaired bodies and excluding environments. Yet, even to speak of 'disabled people' as a category is problematic, given the differences between types and causes of impairments, and the interrelation of impairment and disability with other social divisions and identities (Shakespeare, 2005, p. 147).

As can be deduced from the above paragraph, disability is complex and difficult to define (Altman, 2001; Goodley, 2011; Grech, 2009, 2012; Iezzoni, McCarthy, Davis, & Siebens, 2000; Iezzoni & Freedman, 2008; Parnes et al., 2009; Schneider & Nkoli, 2011; Shakespeare, 2014; WHO, 2011). It is impacted by a multitude of factors of which the impairment itself is only one. The impact of impairments differ due to the body function or structure involved, its severity, the way a particular impairment is interpreted in various cultures, and the financial and other means to mediate it (Grech, 2012; Shakespeare, 2005, 2014; WHO, 2011).

According to Broadhurst (1989), stump care must be carried out daily during a patient's hospitalisation, and the patient must be taught how to do this himself. Stump care encourages wound healing and it is important for preparing the stump for fitting of the prosthesis. This includes massage of the stump, positioning, bandaging and exercise. Exercises of the stump are also essential in order to prevent complications such as contractures. Included with the stump exercises are those exercises related to deep breathing and coughing to prevent pulmonary embolism, and exercises of the whole body, especially the upper limbs, which will be used when ambulating the patient on crutches (Footner, 1987). Ambulation or mobility must be achieved about four to six days post-operatively to prevent bedrest complications and the amputee is encouraged to learn free standing balance on one leg to prepare him for ambulation and walking independently (Farrell, 1982).

Individuals who have undergone a lower-limb amputation require comprehensive rehabilitation from the multidisciplinary team to ensure optimal treatment outcomes and social integration (Ennion & Rhoda, 2016). Physiotherapists play a pivotal role within the multidisciplinary team and offer patients physical and psychosocial rehabilitative care. A survey conducted by Chetty et al. (2015) found motivation was the driving force that

encouraged patients to adhere to therapy. A rehabilitation regimen, studied in patients with bilateral amputation of the lower extremities also outlined motivation as a key factor (Watkins & Liao, 1958). Chetty et al. (2015) found that personal barriers to adherence to rehabilitation included the aspects that affected the well-being of participants and included pain experienced, feelings of being emotionally burdened, stigmatisation and psychological issues. Pain often caused patients to be averse to exercises.

## **2.9 Access to healthcare in South Africa**

The right to access healthcare services in South Africa is guaranteed by Section 27 of the Constitution (Constitution of the Republic of South Africa, 1996). However, in South Africa little is known about barriers to healthcare for the population in general (Harris et al., 2011). Although healthcare is supported by the constitution, considerable inequities still remain, largely due to the discrepancies in resource allocation (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009; Gilson & McIntyre, 2007). Access barriers also include vast distances and high travel costs, especially in rural areas (Harris et al., 2011), high out-of-pocket payments for care (Goudge et al., 2009), long queues (Nteta, Mokgatle-Nthabu, & Oguntibeju, 2010), and disempowered patients (Schneider et al., 2010). According to Harris et al. (2011), these barriers are the result of uneven socio-power relationships. Their study on access to healthcare in South Africa concurs with previous South Africa studies, confirming that poor, uninsured, Black Africans and rural groups have poorer access to healthcare than do other members of South African society (Coovadia et al., 2009; Gilson & McIntyre, 2007; Goudge et al., 2009; Schneider et al., 2010).

WHO emphasises that people with disabilities require access to healthcare, as do the general population, and recommends their needs be met by primary healthcare, with specialist referral where necessary (WHO, 2011). They go on to state that often people with disability commonly need to be able to access appropriate mainstream healthcare and rehabilitation to a greater extent than people without disability because, in addition to having the same health needs as others, they may have higher levels of need related to their impairments, health conditions, or the lifestyle consequences of these. Yet, inequity in accessing healthcare for people with disability is a global issue ó in general, people with disabilities have poorer healthcare access (Ali et al., 2013), despite access to healthcare being of added importance to individuals with disabilities (Centres for Disease Control and Prevention, 2013).



Despite the fact of further access needs, and possibly increasing the gap between need and services offered, persons with disabilities constitute a marginalised group in health services research. Their experiences within the healthcare system are not well understood, and research-based health service improvement interventions commonly exclude people with disabilities (Scheer, Kroll, Neri, & Beatty, 2003). Persons with disabilities are also often marginalised socially and belong to the poorest sectors of society (United Nations, 2008). There is an association between poverty and increased need for healthcare. There seems to be some consensus in the conclusions drawn when it comes to work done regarding access to healthcare for persons with disabilities. According to Tomlinson et al. (2009), there is international evidence that people with disabilities face distinctive barriers when accessing healthcare services, while The World Report on Disability (WHO, 2011), published in 2011 by the World Health Organization and the World Bank, both presented a wide range of evidence confirming that, across the globe, disabled people have poorer access to healthcare and poorer health outcomes than nondisabled people. Gulley, Rasch, and Chan (2011) concluded that people with disabilities also experienced much greater healthcare access problems despite the greater need for healthcare services.

According to Shakespeare and Officer (2014), while disability cannot be seen solely or even mainly as a medical issue, people living with disability cannot perform at the optimal or full potential because of unequal access to health and rehabilitation services. This may also lead to them having a shorter lifespan as well as more difficulties in their lives.

Accessibility of healthcare services has been shown to be an important determinant of utilisation of health services in developing countries (Mekonnen & Mekonnen, 2002). An inadequate supply of healthcare workers in a rural healthcare facility might reduce the level of utilisation of such centres due to much time spent in accessing healthcare. The patient ratio per health personnel goes a long way to determine the workload of the personnel and their efficiencies on the job. The number of patients to attend to per healthcare personnel determines the waiting time of the patient, thereby measuring the accessibility of patients to the healthcare facility (Awoyemi, Obayelu, & Opaluwa, 2011).

## **2.10 Utilisation of rehabilitation services**

### **2.10.1 Barriers**

A number of barriers to access of healthcare services in rural areas, such as long distances to hospitals or clinics and poor public transport, have been identified in the literature (Maart, Eide, Jelsma, Loeb, & Ka Toni, 2007; Harris et al., 2011; Beatty et al., 2003).

People with disabilities face considerable and specific challenges in accessing health services, especially in rural areas. Physical barriers such as distance and terrain are obvious, but poor access to information (for example, through low literacy, lack of sign language interpreters (in the case of persons who are deaf)), and the prevailing stigma and discrimination in rural communities result in further significant barriers. The higher levels of poverty in rural areas pose financial barriers to facility access (transport costs) (Rural Rehab South Africa (RuReSA), 2011).

Transportation costs and travel distance emerged as key access barriers, especially for rural residents in South Africa (Harris et al., 2011). They found that access barriers relate to the geographic inaccessibility of health facilities, particularly in largely rural and poorly resourced provinces.

Babar and Hatcher (2004), in a study on health-seeking behaviour and health service utilisation in Pakistan, asserted that the factors determining the health behaviours may be seen in various contexts: physical, socio-economic, cultural and political. Therefore, they concluded that the utilisation of a healthcare system may depend on socio-demographic factors, social structures, the level of education, cultural beliefs and practices, gender discrimination, status of women, economic and political systems, environmental conditions, the disease pattern and the healthcare system itself.

#### **2.10.1.1 Assistive devices**

National studies on living conditions of people with disabilities conducted in Malawi, Mozambique, Namibia, Zambia and Zimbabwe revealed large gaps in the provision of assistive devices/services (Loeb & Eide, 2004; Eide & Kamalari, 2009; Eide, van Rooy & Loeb, 2003; Eide & Loeb, 2006; Eide et al., 2003). The studies found that only 17% to 37% of people received the assistive devices they needed. There is also a lack of appropriate

assistive devices to meet the demands of a rural environment (Ennion, Johannesson, & Rhoda, 2017).

It has been estimated that people needing orthoses or prostheses and related services represent 0.5% of the population in developing countries (WHO, 2005b) and that the number of people with disabilities in developing countries who require a wheelchair is approximately 1% of the population (ISPO/USAID/WHO, 2006). Assistive devices are key mechanisms by which disabled people can participate as equal citizens within society.

### **2.10.1.2 Financial constraints**

Affordability has been highlighted as one of the main reasons why people with disabilities do not receive needed healthcare in low-income countries ó with higher rates of unemployment and poverty than nondisabled people, many people with disabilities are unable to afford assistive technology and related services (WHO, 2011).

The total cost of seeking health services, the lack of public transport, the increased distance from home to health facilities, poor infrastructure and poor quality of access roads all have an inverse relationship with the utilisation of government healthcare facilities and services.

### **2.10.1.3 Distance**

Factors affecting experiences of health services are numerous and have generated an array of sub-fields. For instance, in addition to social and economical factors that affect access to healthcare services, a number of rural researchers have noted that physical issues play a big role. Numerous authors have noted the importance of distance to services as a significant challenge for rural populations (Edelman & Brian, 1996; Fryer et al., 1999; Joseph & Hallman, 1998; Nemet & Bailey, 2000). The distance that rural populations must travel generates multiple barriers in accessing health services when they are needed. These include the impact of distance on people's available time, their degree of flexibility to attend work and other responsibilities, and their capacity to meet the associated direct and indirect costs of travelling these distances. Secondly, the challenges of terrain and seasonal weather conditions can affect rural populations' to access healthcare services more significantly than urban ones. Distance is also likely to have a negative effect on utilisation of healthcare services due to long distances to travel to get to a healthcare facility, long transportation periods and the high cost of transportation to the facility. Thirdly, financial barriers have been noted in a variety of studies. These have included discussion of: service costs, individuals' and households'

incomes and access to financial support or insurance that can restrict rural populations to accessing healthcare services (Beck, Jijon, & Edwards, 1996; Comer & Mueller, 1995; Skaer, Robinson, Sclar, & Harding, 1996; Strickland & Strickland, 1996).

#### **2.10.1.4 Education**

Mekonnen and Mekonnen (2002) found that utilisation of healthcare facilities increases with educational attainment. This was consistent with the findings of Awoyemi et al. (2011) who found that a large percentage of households whose heads have tertiary education utilised modern healthcare facilities, while a higher percentage of households whose heads do not have access to formal education do not utilise modern healthcare facilities. Also, 60% of households whose heads have adult literacy education do not utilise modern healthcare facilities.

The greatest barrier to participation in physical exercise is a lack of knowledge of where to exercise (Amosun, Mutimura, & Frantz, 2005). The lack of knowledge as a barrier to participation in physical exercise in their study is consistent with the findings by Kim, Love, Quistberg, & Shea (2004), who report that people with adequate health literacy exercised more than those with lower literacy.

#### **2.10.1.5 Cultural beliefs**

Awoyemi et al. (2011), who conducted a study on the effect of distance on utilisation of health services in a rural area in Nigeria, found that the majority (62 %) of the rural households seek healthcare services from government hospitals, while a higher proportion (42.1 %) of rural households living within 15 to 19 kilometres away seek healthcare services from the traditional health centres. This indicates that utilisation of available public health facilities increases with proximity to the health centres. Thus, rural households utilise self-medication and traditional care closer to their residence. This is expected to reduce their cost of transportation and rigour of accessibility to distant government healthcare facilities (Awoyemi et al., 2011). Awoyemi et al. (2011) found that male-headed households utilise traditional healthcare while female-headed households use self-medication. However, a higher proportion of male-headed households seek modern healthcare services than female-headed households. This implies that the level of utilisation of modern health facilities is lower among female-headed households than among their male counterparts, which may be a result of a low level of access to productive assets among rural, female-headed households.

In a study in south- east Nigeria, Uzochukwu and Onwujekwe (2004) found that self-diagnosis was practised more by the poorer households while the least poor used the patent medicine dealers. Large family sizes and a low standard of living might limit the rural households from using modern healthcare facilities (Awoyemi et al., 2011).

Cultural beliefs and practices often lead to self-care, home remedies and consultation with traditional healers in rural communities (Wegner & Rhoda, 2014; Nyamongo, 2002). This is expected to reduce their cost of transportation and rigour of accessibility to distant modern healthcare services.

## **2.10.2 Facilitators**

### **2.10.2.1 Family support**

Adjusting to the change in body image and the limitation of mobility, with all the social, economic and psychological ramifications involved, is an enormous task for any person and requires a lot of support from all involved in their rehabilitation (Farrell, 1982). Thompson and Haran (1985) found that the key helpers of persons with lower-limb amputations were mostly women, with 82% being wives of the amputees, with the majority living in the same household as the patients they were helping. Lack of confiding relationships with a partner may be a contributing factor in the aetiology of depression (Park, 1991). Chilvers and Browse (1971) agreed with these findings and reported that amputees often did not have known sources of assistance for their practical problems, and that relatives were the most common helpers.

Persons with lower-limb amputations may need help from their partners or domestic helpers most of the time; they may end up having close relationships with their partners as a result of the lower-limb amputation and their children may be more caring towards them than before the amputation (Bosmans et al., 2007).

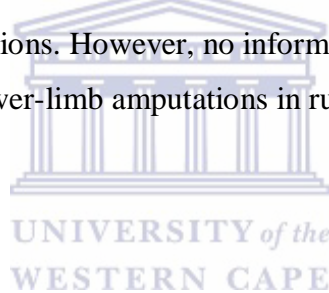
### **2.10.2.2 Accessibility**

A study conducted by Mangset, Dahl, Forde, & Wyller (2008) found that facilitators related to the rehabilitation process displayed the following traits: healthcare professionals treated their patients with humanity, they acknowledged them as individuals, and they respected their autonomy, while patients had confidence and trust in healthcare professionals and there was exchange of information. Crisp (2000) used interviews to examine the perception of people

with disabilities concerning their interaction with health and rehabilitation professionals. It was found that meaningful assistance from health and rehabilitation professionals, having therapeutic relationships with health and rehabilitation professionals, and being assertive and independent in rehabilitation, contributed on the part of facilitators to rehabilitation services. Zongjie, Hong, Zhongxin, & Hui (2007) also included provision of information, doctors having good skills, easy access to doctors, good understanding of rehabilitation services, confidence in the value of rehabilitation services, and easily accessible rehabilitation, which helped patients in accessing health and rehabilitation services.

## **2.11 Summary of the chapter**

The existing literature shows that lower-limb amputation has a multifaceted outcome. Notwithstanding the cause and level of amputation, persons with lower-limb amputations require early rehabilitation to improve quality of life and functional outcomes. The literature makes evident that there is a correlation between barriers and access to healthcare and rehabilitation services in rural regions. However, no information could be found on the barriers faced by persons with lower-limb amputations in rural areas of Kwa-Zulu Natal with access to rehabilitation services.



## CHAPTER THREE: METHODOLOGY

### 3.1 Introduction

Chapter three provides information of the two approaches used to meet the aims and objectives of this study, namely the quantitative and qualitative approach. The quantitative and qualitative sections are described separately. This chapter also explains the study design, study setting, the sampling of participants, data collection instruments and analysis procedures. Finally, the chapter describes the process of verification and trustworthiness of the data that was followed and the ethical considerations that were applied in the study.

### 3.2 Quantitative Study

This section outlines the methodology used to determine the prevalence and common causes of lower-limb amputation in a rural region of Kwa-Zulu Natal.

#### 3.2.1 Study design

A retrospective archival study design was applied to retrieve patient information from theatre records on those who have undergone lower-limb amputations over a five-year period (01 November 2010 to 30 November 2015). Retrospective research often requires the analysis of data that was originally collected for reasons other than research (Hess, 2004; Jansen et al., 2005). The scientific utilisation of existing health records is common in epidemiological investigations (Haley et al., 1980; Jansen et al., 2005) and in clinical research (Hellings, 2004; Rajeev, Srinath, Girimaji, Seshadri, & Singh, 2004; Staller, Kunwar, & Simionescu, 2005). The advantages of conducting chart reviews include: a relatively inexpensive ability to research the rich, readily accessible, existing data; easier access to conditions where there is a long latency between exposure and disease, allowing the study of rare occurrences; and, most importantly, the generation of hypotheses that then would be tested prospectively (Hess, 2004; VonKoss Krowchuk, Moore, & Richardson, 1995; Wu & Ashton, 1997; Worster & Haines, 2004). However, the limitations of incomplete documentation, including missing charts, information that is unrecoverable or unrecorded, difficulty interpreting information found in the documents (e.g. jargon, acronyms, photocopies and microfiches), problematic verification of information and difficulty establishing cause and effect and variance in the quality of information recorded by medical professionals (Dworkin, 1987; Hess, 2004; Pan, Fergusson, Schweitzer, & Hebert, 2005; VonKoss Krowchuk et al., 1995).



### 3.2.2 Study setting

The iLembe district has an estimated population of 606 809 people. It is situated about 75 kilometres from Durban and comprises of a small urban area and the remainder being largely deep rural. The iLembe district is divided into four smaller sub-districts namely, Maphumulo, Ndwedwe, KwaDukuza and eNondakusuka (Mandeni). The latter two areas are semi-urbanised, while Maphumulo and Ndwedwe remain primarily rural. The iLembe district comprises of one regional/district hospital (Stanger Hospital), three sub-district hospitals (Umphumulo, Untunjambili and Montebello) and two CHCC facilities (Sundumbili and Ndwedwe). Access to Stanger hospital is relatively better as it is a semi-urban area, as compared to the three sub-districts which are considered rural areas and therefore have more barriers in terms of transportation and infrastructure. Readily available transportation, tarred roads, sufficient infrastructure and adequate healthcare facilities make access to Stanger Hospital better than rural areas.

The quantitative study was conducted at Stanger Hospital, the regional district hospital of the iLembe district, situated in Kwa-Dukuza. Stanger Hospital is a 500 bedded Regional and District Hospital. The hospital serves an estimated population of 600 000 from the iLembe district and offers the following services:

Accident and emergency care, ante-natal clinic, antiretroviral (ARV) clinic, breast care clinic, CT scan, dermatology clinic, diabetic clinic, diagnostic imaging, dental clinic, electrocardiogram (ECG) services, echocardiography, endocrine clinic, Ear, nose and throat clinic, general medical and surgical outpatients, HIV (human immunodeficiency virus) counselling and testing (HCT), medical surgical and paediatric inpatient care, obstetrics and gynaecology, occupational therapy, operating theatre, ophthalmology clinic, orthopaedic outpatient clinic, paediatric asthma/cardiac and neurology clinic, psychiatric department, physiotherapy, Prevention of mother to child transmission (PMTCT), psychology, social worker, specialist medical clinic, speech, hearing and audiology services, crisis centre and urology.

All patients requiring surgeries are referred to Stanger Hospital as district hospitals do not perform any other surgery except a Caesarean section. All lower-limb amputations are performed at Stanger Hospital for the iLembe district.



### **3.2.3 Population and sampling**

The study population consisted of all patients that have had a lower extremity amputation done during the five year period of 01 November 2010 to 30 November 2015 at Stanger Hospital. In order to identify patients who have suffered a lower-limb amputation, theatre surgery records were examined. Patient details were retrieved from the theatre surgery records within the five-year period. A total number of 371 patients had undergone a lower-limb amputation during this five year period. Patients' medical folder numbers obtained from the theatre surgery records were used to retrieve the patients' medical folders retrospectively from the medical records room. Only 111 patients' medical folders were retrievable and used in this study. These folders were examined to determine the cause and co-morbidities of persons with lower-limb amputations. There were 260 patient medical folders missing.

### **3.2.4 Inclusion criteria**

All the medical folders that were available of patients who had undergone a lower extremity amputation during the period 01 November 2010 to 30 November 2015 were included in the study.

### **3.2.5 Exclusion criteria**

Patients identified from the theatre records, whose medical folders were not available, were excluded from the study.

### **3.2.6 Data collection instrument**

A retrospective archival medical data extraction sheet could not be found from the literature. Therefore, a basic self-developed, data extraction sheet (Appendix 1) was used to collect archival data which included the patient's demographics, folder number, type of amputation, date of amputation, cause of amputation and any co-morbidity which the patient might have had (Wegner & Rhoda, 2013).

### **3.2.7 Data collection procedure**

After receiving permission from the Department of Health iLembe district manager's office, the Medical Manager at Stanger Hospital was contacted to obtain permission to conduct the study at the facility. Once permission was obtained to carry out the study, the Chief executive officer (CEO) of Stanger Hospital escorted the researcher to the theatre department where the

study was explained to the head nurse of the department for her to assist with further information. It was found that Stanger Hospital has a designated theatre record book for all amputations completed. Information in this theatre record book included the date on which the amputation was performed, the names of patients, in patient folder numbers, the ward that the patients were admitted to, age of the patients, physical address and type of amputation performed. The information was extracted from this theatre record book during one session at the theatre department. Thereafter, the researcher captured all the data obtained from the theatre record book onto an Excel spreadsheet.

Permission was again obtained from the Medical Manager to obtain patient folders from the file room at Stanger Hospital. The researcher visited the filing room and explained the study to the filing clerk. Two filing clerks were assigned to assist in obtaining the patients' folders from the file storage room at the Stanger Hospital basement. All the patient medical folder numbers were given to the filing clerks to identify patients' folders in order for the researcher to extract the causes and co-morbidities from the files. This had to be done over three consecutive days as the filing clerks needed time to locate all the folder numbers on the list. Once the patients' folders were obtained, the records were examined by the researcher in order to complete the information on the archival survey data extraction sheet. Patient folders according to the in-patient folder numbers were then extracted from the records room with the help of the clerk staff. The clerk also checked for patients' folders in the out-patient admitting office file room, in the event that the file number written in the theatre records reflected the out-patient number instead of the in-patient number. The researcher was not allowed to remove patient folders from the filing room. Data was extracted from patients' folders inside the filing room and returned to the filing clerk once the necessary information had been extracted. Patients' folders were then scrutinised to determine the reason or cause of lower-limb amputation, as well as any co-morbidities which the patients had suffered. The process of extracting medical folders was challenging as many folders could not be found. Folders are usually kept for five years; however, due to the high volume of patient folders, many folders had to be transferred for storage in outdoor storage containers. Due to weather conditions, such as heavy rainfall, most of the 2010, 2011 and 2012 folders were damaged and had to be discarded. Other reasons for the limited number of files found were the possibility of incorrect recording of folder numbers in the theatre records and illegible handwriting. Two male patients' type/level of amputation was not recorded in the theatre records

and was therefore not included in the statistics. Their files were unable to be retrieved and the researcher was unsure if they had had the amputation performed or if it had been cancelled.

### **3.2.8 Data analysis**

Quantitative data was entered onto a prepared Excel spreadsheet by the researcher. The data was analysed using descriptive statistics to describe the basic features of the data extracted from the patients' folders. Data was checked and re-checked to ensure that it was captured correctly and accurately. The data was represented using Excel Coding. A coding key was established to make common causes easier to identify. Similar causes were coded and grouped together to identify common causes.

### **3.3 Qualitative study**

This section outlines the process that was undertaken in order to conduct semi-structured interviews and obtain information on the perceived barriers and facilitators experienced by persons with lower-limb amputation in the utilisation of rehabilitation services.

#### **3.3.1 Study design**

A descriptive qualitative study design was utilised. Qualitative research makes use of modifications or extensions of ordinary conversations (Rubin & Rubin, 1995). This method of data collection is used when the researcher is more interested in the understanding, knowledge, and insights of the interviewees rather than in categorising people or events. By asking open-ended questions, it allowed the participants to freely explore different avenues regarding the topic. This yielded more information and allowed for probing of the answers in order to explore the topic further. This allowed the researcher to further understand the participants' experiences from their point of view.

#### **3.3.2 Study setting**

The qualitative component of the study was conducted in three rural sub-districts in the Kwa-Zulu Natal (KZN) province of South Africa (SA). Sub-district hospitals which were included in this study were Umphumulo hospital, Untunjambili hospital and Montebello hospital. The population of these three sub-districts are predominantly of Zulu cultural origin with the first language being isiZulu.

An estimated 82% of the 606 809 people residing in the iLembe district speak isiZulu (Census, 2011). Statistics South Africa estimated that 43.7% of SA's population is rural (Kok & Collinson, 2006). Rurality is poorly defined in the South African context, but is generally defined on the basis of a number of indicators, including the lack of urban characteristics such as availability of amenities and infrastructure (Census, 2001). Duncan, Sherry and Watson (2011) define rurality as the combination of multiple factors affecting the quality of life of people living in sparsely habituated settlements with limited access to public services.

The majority of these three communities are extremely impoverished and disadvantaged. The iLembe district is rated among the poorer districts in Kwa-Zulu Natal according to the 2001 Census. Unemployment rates within these districts are stifling, with the greatest unemployment of 75.9% recorded in the Maphumulo sub-district. Tuberculosis (TB) and HIV remain the leading causes of death respectively. Diarrhoeal disease is highly prevalent in the district and can be attributed to the lack of safe water supply and poor sanitation practices. The communities in the three rural sub-districts, particularly, utilise water from the river for their daily needs. This water source is contaminated and harbours infectious organisms. Mountainous terrain, gravel roads and the presence of numerous wandering animals result in refuse removal vehicles being unable to access these areas, further compromising the health of this population. Some households still do not have electricity and the majority of the households make use of outside toilet facilities. In some areas, houses in a particular surrounding share a single toilet facility.

Umphumulo hospital is a district hospital with 158 beds. It is situated on the road between Stanger and Greytown. The hospital shares a sub-district with Untunjambili hospital. The catchment population of Maphumulo sub-district is 132 007, of which Umphumulo accounts for 60% of the catchment population. The hospital has seven fixed clinics and two mobile services which serves a total number of 40 mobile points. The hospital offers the following services: ARV Literacy classes and drugs, Child healthcare, Eye Clinic, Outpatient Department (24 hours), Medical (24 hours), Surgical (24 hours), Maternity (24 hours), Labour ward (24 hours), Male medical and TB ward, Female medical ward, TB ward (female), Obstetric (24 hours), Reproductive health (24 hours), Dental services, X-ray, Psychiatric Clinic, Social Work Services, Physiotherapy services, TB and TB Tracing team, sexually transmitted infections (STI) infections, HCT, PMTCT, Primary Healthcare, School Health, Pharmaceutical Services, Laboratory Services, Crisis Centre, Dietetics Department, Operating Theatres.

Untunjambili hospital is a sub-district hospital with 130 beds in the iLembe district. The hospital serves a total population of 160 342. Patients from Kranskop, Ngcolosi, Mabomvini, Makhabeleni, Cele and Mahlongwa frequent the hospital. This district hospital offers general medical and surgical, infectious cases, maternity, medical laboratory services, theatres, orthopaedics, psychiatric, tuberculosis, x-ray, social worker, physiotherapy, dental facilities, pharmacy, voluntary counselling and testing (VCT), primary healthcare, school health, outpatient department, PMTCT, eye care clinic.

Montebello hospital serves a population of an estimated 180 000 people. This hospital has similar services to Untunjambili and Umphumulo hospital.

### **3.3.3 Study population**

The total size of the population of persons with a lower-limb amputation in this area was unknown at the time of data collection.

### **3.3.4 Sampling procedure and size**

Non-probability convenient sampling was used to recruit persons with lower-limb amputations to participate in the study. Physiotherapists at each of the iLembe sub-district hospitals were asked to identify persons with lower-limb amputations in their area that they were familiar with and to provide their contact details. Saturation of data was reached after 11 interviews.

### **3.3.5 Inclusion criteria**

- Participants who have undergone a lower-limb amputation;
- Persons with a lower-limb amputation within the ages of 18-80 years. This study explored the barriers and facilitators experienced by adults on their perceived barriers and facilitators in accessing rehabilitation services, which makes up the largest population of people with lower-limb amputations;
- Participants who were able to understand the study and provide written consent.

### **3.3.6 Exclusion criteria**

- Those participants with co-morbidities that interfered with their function beyond that of the lower-limb amputation limiting their ability to access rehabilitation services

were excluded. An example would be if the patient had an amputation and a stroke (cerebral vascular disease).

### **3.3.7 Instrument of data collection**

A self-developed semi-structured interview guide (Appendix 2) was used to collect qualitative data. Probing questions were based on the barriers and facilitators found in the literature review. The semi-structured interview involved a set of predetermined questions which initiated the discussion, followed by further prompt questions that arose from the discussion. This style of interviewing allowed for more flexibility during data collection and created space for the interviewer to pursue lines of enquiry stimulated by the interview (Rule & John, 2011, p.65).

### **3.3.8 Data collection procedure**

The head of the therapy department at each of the three rural district rural hospitals was contacted telephonically. The nature of the study was discussed with the therapist. Therapists were asked to identify any persons with a lower-limb amputation in their surrounding area/community.

Montebello hospital physiotherapy department identified six people with lower-limb amputations; however, the therapist only provided contact information for three patients. Only three patients were identified from the Untunjambili physiotherapy department, also due to a lack of contact information. Umphumulo hospital provided 12 participants, along with contact numbers.

Participants were contacted telephonically to arrange a convenient time and place to conduct the semi-structured interview. A total number of 11 participants agreed to participate in the study. A translator was present for those interviews where the participant's first language was isiZulu. Data was collected by conducting face-to-face interviews which allowed for observation of facial expressions and body language changes. The interviews commenced with a full explanation of the study, obtaining written informed consent to participation and the use of an audio-recorder (Appendix 3). Each participant completed the demographic survey. Five of the interviews were conducted at therapy departments and six of the interviews were conducted at participants' homes. All interviews were tape-recorded and lasted approximately 45 minutes. Participants were given an opportunity at the end of all interviews to expand on any information provided. Semi-structured interviews aimed to

explore the participants' perceived barriers and facilitators in accessing rehabilitation services. This was initiated by two questions:

- Do you experience difficulties accessing rehabilitation services in your area?
- What helps you access rehabilitation services in your area?

Participants were prompted during the interviews to allow for further elaboration to be given on their responses.

### **3.3.9 Data analysis**

Analysis of the data was performed by using a thematic analysis approach. The qualitative data was analysed using Braun and Clarke's (2006) six-step process of analysis. This includes familiarisation with the data, coding, searching for themes, reviewing themes, defining and naming themes and writing up them up.

The interviews were transcribed verbatim by an independent translation and transcription company. All interviews were translated into the English language in order to be analysed. The transcriptions were read and re-read several times by the researcher in order to gain overall understanding of the data and to become more familiar with the information before commencing with the coding process. Transcripts were then coded to identify common themes within the participants' responses. Codes were grouped together into categories, and similar categories were analysed and emerging themes identified. The data was analysed deductively. An independent reviewer was asked to analyse the raw data and compare the various categories and themes identified.

### **3.3.10 Trustworthiness of qualitative data**

The study was piloted with two participants and changes were made to improve the clarity and credibility of the semi-structured interview guide. Two questions were chosen and repeated a week later to the pilot study participants. Participants answered the same questions similarly. This indicated that the answers that were given in the first interview were dependable. Data saturation was reached after 11 semi-structured interviews, as there was no longer any new data being produced by participants. An independent reviewer was asked to analyse the raw data and compare the various categories and themes identified.

During interviewing, credibility was enhanced by reframing questions, repetition of questions and probing questions on the matters raised by the participants (Krefting, 1991). At the end of



the interview, tapes were played back to the participants for their comments and additions to the original interview. This was done to allow the participants to comment to ensure that what they had said during the interview was interpreted in the way that they would like it to be understood.

Audio tapes were translated and transcribed by a professional translating company and were proofread. This was to prevent the researcher from being biased and dishonest.

A detailed description of the process of this study was outlined to provide the reader with sufficient information to judge the credibility of the study (Silverman, 2013; Tracy, 2010), or to determine to what extent conclusions can be transferred to other settings (Cohen & Crabtree, 2006; Hodgetts & Stolte, 2012; Silverman, 2013). The conclusion can be referred to the discussion and results sections and citing sources. The data collected can be linked to the study aims and objectives.

The nature of qualitative research can lead to variations in findings over time. However, a certain level of consistency is expected if the study is repeated with the same participants (McGloin, 2008).

### **3.4 Ethical considerations**

Ethical considerations for research in social sciences were adhered to. Permission to conduct the research study was obtained from the University of the Western Cape's Senate Higher Degrees Committee (Appendix 4). Permission was obtained from the Department of Health Research and Knowledge Management sub-component, to conduct the study in government hospitals in Kwa-Zulu Natal (Appendix 5). Permission was thereafter obtained from the Department of Health iLembe District Manager's Office to conduct the research at the iLembe district hospitals (Appendix 6), as well as verbal permission from the facility managers of the four hospitals included in this study. The nature of the study was explained in detail to all participants before the commencement of the semi-structured interview. All participants gave informed consent in writing and agreed that their voices could be recorded. Participants were guaranteed that their identity would be kept confidential, and pseudonyms (P1 to P11) were used in the transcription of the data instead of the participants' own names. Only the researcher and the person who did the transcriptions had access to the voice-recordings. Participants were ensured that they could withdraw from the study at any time during the interviews without any consequences, and that they could inform the researcher if,



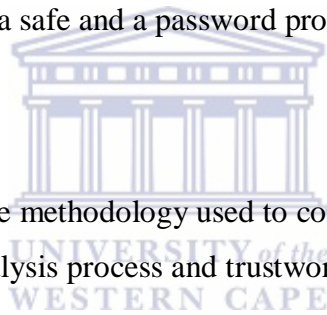
in hindsight, they decided that what they had said could not be used for research purposes. No participant made use of this opportunity or asked that anything that they shared should not be included in the study. A summary of the results of the research project will be disseminated to the various and relevant stakeholders involved.

For the quantitative component of the study, anonymity and confidentiality was guaranteed by:

- Only patient folder numbers were provided to the assisting file room clerks.
- Patient folders were not shown to anyone else but the researcher for data extraction.
- Patient folders were not removed from the file room, therefore not compromising the patients' information.
- Patients' information was only read by the researcher. Hard copies and electronic copies of the information were only in the possession of the researcher and were stored safely by means of a safe and a password protected computer.

### **3.5 Summary of the chapter**

This section presented in detail the methodology used to conduct the study by providing the study design, method, setting, analysis process and trustworthiness of both the quantitative and qualitative section.



## CHAPTER FOUR: RESULTS

### 4.1 Introduction

In chapter four the results of the study are presented. Findings are presented according to the objectives of the study. Quantitative data is presented first with the findings regarding the demographic details of persons with lower-limb amputations, prevalence of lower-limb amputations, the common causes of lower-limb amputations and the co-morbidities related to lower-limb amputations. Thereafter, qualitative data presents the demographic details of participants with lower-limb amputations and the perceived barriers and facilitators to the utilisation of rehabilitation services. The following types of amputations are discussed below: trans-femoral amputation (AKA- above knee amputation), trans-tibial amputation (BKA ó below knee amputation) and transmetatarsal amputation (TMA).

### 4.2 Quantitative Results

*Demographic details of all patients who had undergone a lower-limb amputation during the study period*

#### 4.2.1 Participant recruitment and prevalence of amputations

The iLembe district population consists of 606 809 people, living in Kwa-Zulu Natal, South Africa. The population of persons with a lower-limb amputation in this district over a period of five years was a total of number of 371. The prevalence rate was thus 12.1 lower-limb amputations per 100 000 people per year. On average, 74 lower-limb amputations were performed per year and six lower-limb amputations were performed per month.

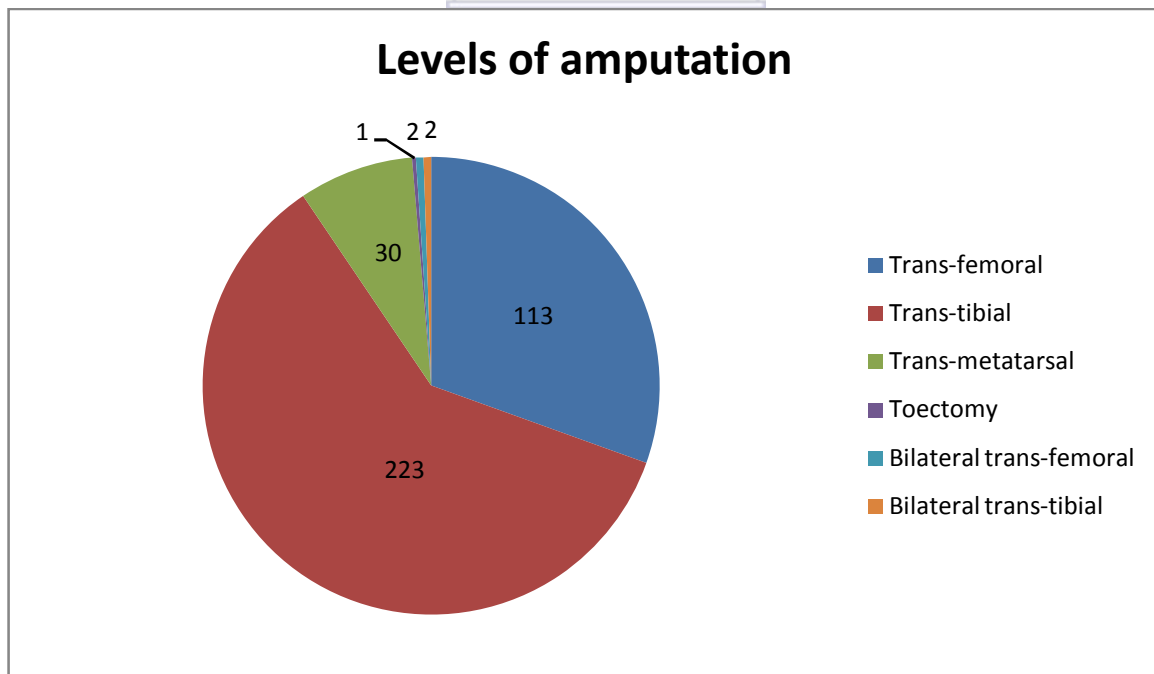
#### 4.2.2 Gender and age distribution

Males accounted for 210 of the lower-limb amputations; females accounted for 161 lower-limb amputations. The age range was 16- 98 years, mean 61 (SD+- 14) years. The majority of the amputations were performed on persons who were 61 and older [Table 1 and Figure 1].

**Table 1: Frequency distribution of the age and gender of participants**

Gender	Age (years) (N=371)						Total
	<30	30-40	41-50	51-60	61-70	>70	
Male	10 (5%)	8 (4%)	31 (15%)	52 (25%)	62 (29%)	47 (22%)	210
Female	4 (2%)	5 (3%)	17 (11%)	35 (22%)	40 (25%)	60 (37%)	161
Total	14 (4%)	13 (3%)	48 (13%)	87 (23%)	102 (28%)	107 (29%)	371

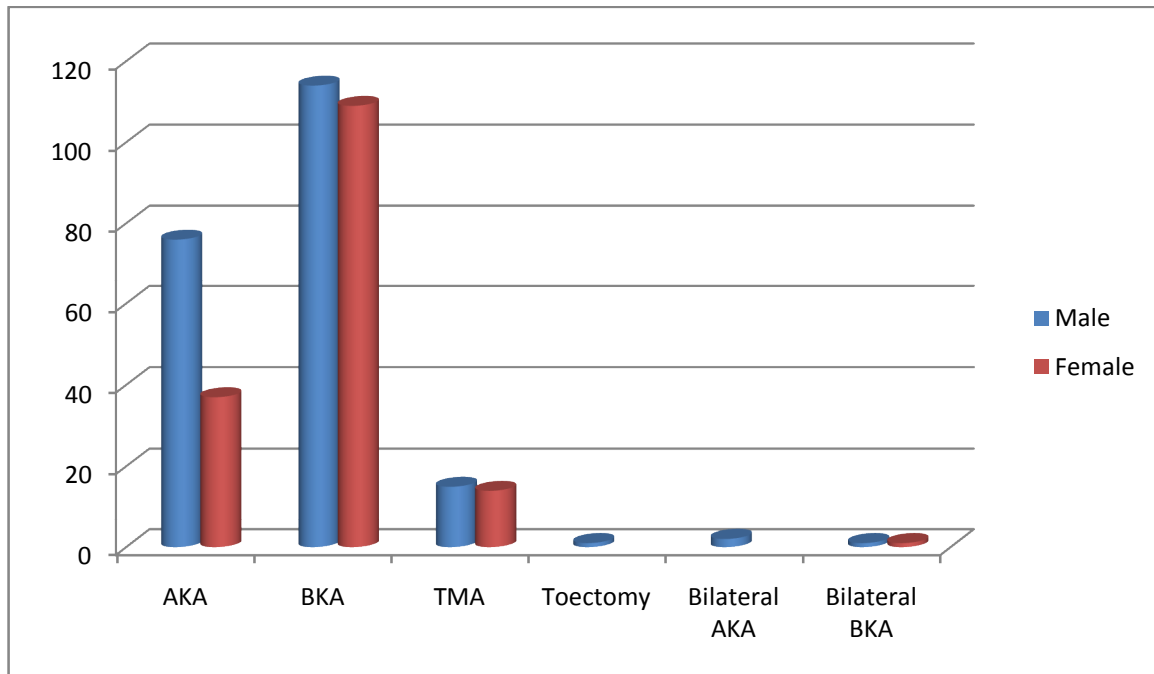
Of the 371 patients, 12% (n=45) of patients had undergone a revision of the lower-limb to a higher level amputation on the same leg and 4% (n=15) of patients had undergone a second amputation of the opposite lower-limb. The majority of patients had undergone trans-tibial amputations. Figure 1 illustrates the types of amputations that were performed on the study sample.



**Figure 1: Number of each level of amputation performed**

Males had a higher number of amputations compared to females in each of the amputation categories. Trans-tibial and trans-femoral amputations accounted for the majority of

amputations. Trans-metatarsal amputations accounted for the minority of amputations in the study sample and were a similar number in both males and females. Males had undergone trans-femoral amputations two times more than females. Trans-tibial amputations in both males and females were a similar number (Figure 2).



**Figure 2: Number of each level of amputation by gender**

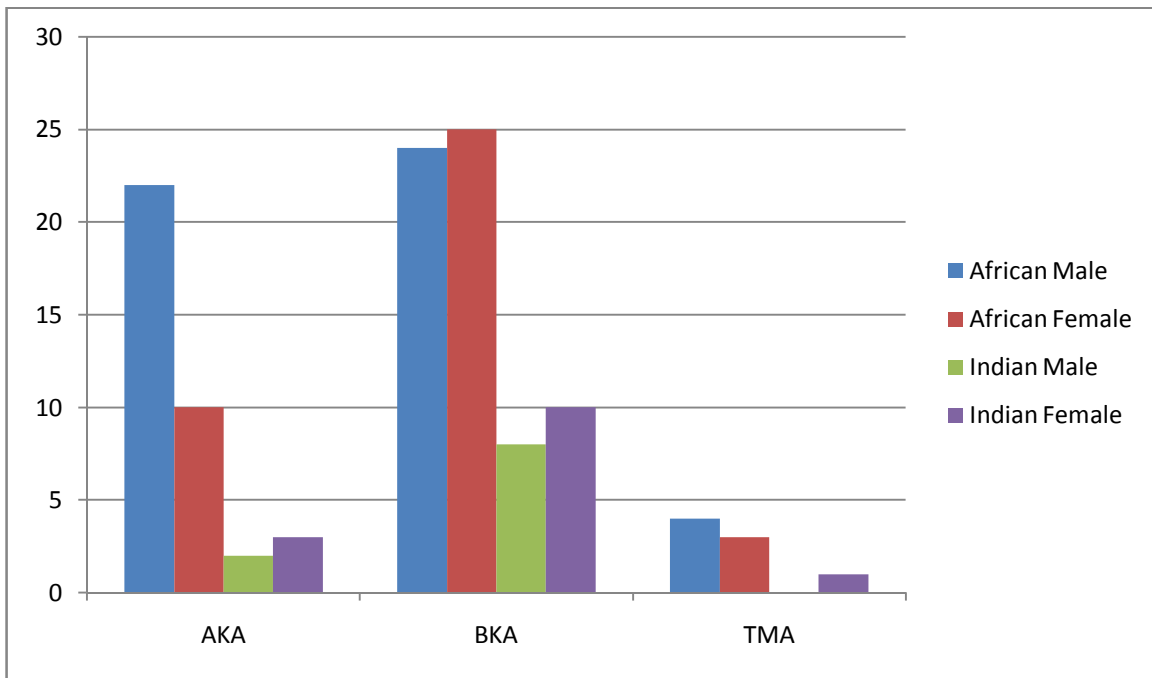
*Demographic details of folders that were available to retrieve in order to determine the cause of amputation*

Patient documents and file records were mainly stored in the basement room of Stanger Hospital. However, some medical folders were kept in the out-patient admitting office file room. Due to the large number of files and records, older records which were kept in the basement had to be moved to an outdoor container storage facility on the hospital premises. The researcher was told that many of the patient's files/records were not to be found due to rain damage in the container storage unit, as well as files which had been misplaced or not recorded correctly, due to the moving of records from one place to the other. Many records were stacked in huge bundles and had not yet been allocated to the correct filing system/method.

Medical folders/files were also unable to be retrieved due to illegible recording of patient folder numbers, as well as incorrect folder numbers being recorded in the theatre record book. In the theatre record book, abbreviations were used to describe the type of amputation

performed, e.g, AKA (trans-femoral amputation), BKA (trans-tibial amputation), TMA (transmetatarsal amputation). Some of these abbreviations were recorded incorrectly and were difficult to read to see if the alphabet was an ~~A~~ or ~~B~~ due to illegible writing. Two male patient's details were recorded; however, the type of amputation performed was not recorded in the theatre record book.

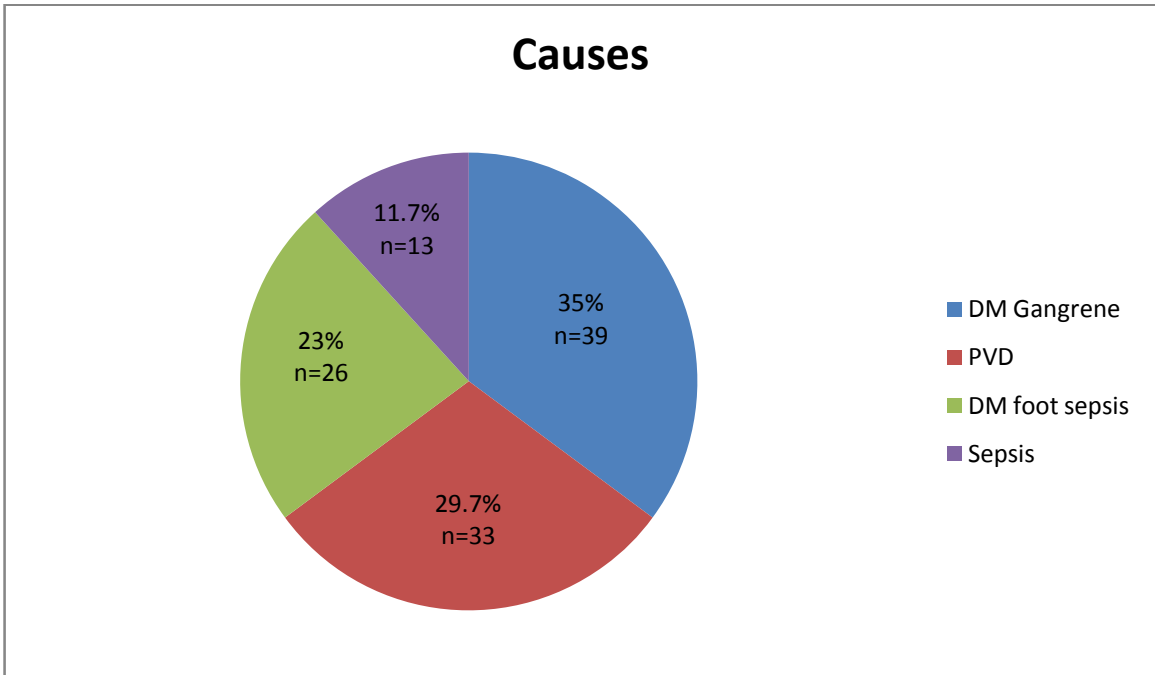
A total number of 111 patient medical folders out of 371 patients, who had undergone a lower-limb amputation, were available to be retrieved from the archives. A total number of 260 patient medical folders were missing. Patient's medical folders were mostly found between the years 2013 to 2015. The age range was 26-91 years, mean 61.75 (SD+- 14) years. Males accounted for 59 files and females accounted for 52 files. When considering the racial distribution, the majority of patients were African (n=87), and the rest were Indian (n=24). There were 65 patients with unilateral trans-tibial amputations and one with a bilateral trans-tibial amputation, 37 patients with unilateral trans-femoral amputations and eight patients with trans-metatarsal amputations. From the files retrieved, African males accounted for the highest number of amputations. African males accounted for 22 trans-femoral amputations, 24 trans-tibial amputations and four trans-metatarsal amputations. African females accounted for 10 trans-femoral amputations, 25 trans-tibial amputations and three trans-metatarsal amputations. Indian males accounted for two trans-femoral amputations and eight trans-tibial amputations. Indian females accounted for three trans-femoral amputations, 10 trans-tibial amputations and one trans-metatarsal amputation. Figure three below represents this data.



**Figure 3: Number of files retrieved according to type of amputation and gender**

#### **4.2.3 Common causes and co-morbidities associated with lower-limb amputations**

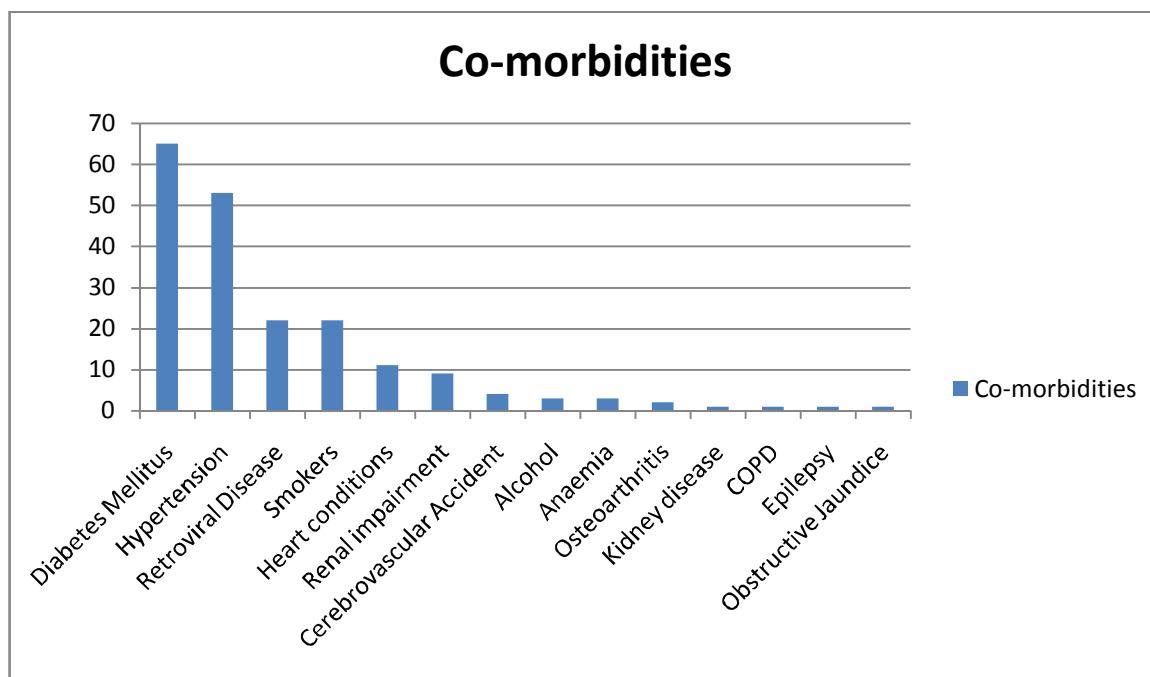
The major cause (35%) of lower-limb amputations were gangrene as a result of diabetes mellitus (DM gangrene). Other causes of lower-limb amputations as documented in the medical folders were peripheral vascular disease (PVD), diabetic foot ulcer/sepsis(DM sepsis) and sepsis (Figure 4).



**Figure 4: Causes of lower-limb amputations**

Most patients suffered from more than one co-morbidity. The most common co-morbidities noted were diabetes mellitus (n=65) and hypertension (n=53). Other co-morbidities identified included retroviral disease, cigarette smokers, alcoholics, renal impairment, cerebral vascular disease, heart conditions, anaemia, osteoarthritis, kidney disease, chronic obstructive pulmonary disease (COPD), epilepsy and obstructive jaundice (Figure 5).

Ten patients had no co-morbidities recorded in their patient record files.



**Figure 5: Number of patients with co-morbidities**

## 4.3 Qualitative Results

### 4.3.1 Introduction

This chapter serves to outline the outcomes of the in-depth interviews with the participants. Following the analysis of the interviews, findings were categorised into barriers and facilitators.

### 4.3.2 Demographic details of participants

Participants ranged from age 23 to 80 years old. The mean age of the participants was 55 years at the time of data collection. Seven participants were female and four participants were male. Nine participants accounted for single leg amputations (five having below knee amputations and four having trans-femoral amputations). Two participants had bilateral lower-limb amputations (one participant had bilateral trans-femoral amputations and one participant had a trans-tibial amputation and a trans-metatarsal amputation). The youngest participant was able to ambulate independently with a prosthesis. Four participants were wheelchair-bound and six participants were able to ambulate with crutches. In this isiZulu-dominated rural area of Kwa-Zulu Natal, barriers largely outweighed the facilitators in accessing rural rehabilitation services.



**Table 2: Demographic details of the participants**

<b>Participant number</b>	<b>Gender</b>	<b>Age</b>	<b>Level of amputation</b>	<b>Mobility</b>
1	Male	46	Bilateral trans-femoral amputation	Wheelchair
2	Male	67	Trans-tibial amputation	Elbow crutches
3	Female	60	Trans-tibial amputation and trans-metatarsal amputation	Wheelchair
4	Female	52	Trans-tibial amputation	Elbow crutches
5	Male	51	Trans-femoral amputation	Elbow crutches
6	Female	58	Trans-tibial amputation	Elbow crutches
7	Male	52	Trans-femoral amputation	Elbow crutches
8	Female	23	Trans-tibial amputation	Independently ambulant with a prosthesis
9	Female	60	Trans-tibial amputation	Wheelchair
10	Female	80	Trans-femoral amputation	Wheelchair
11	Female	59	Trans-femoral amputation	Auxiliary crutches

### 4.3.3 Themes of the qualitative findings

In this study there were more barriers than facilitators identified by participants during the interviews. Seven sub-themes were identified under the main theme of 'barriers' and four sub-themes were identified under the theme of 'facilitators'. These sub-themes are listed in Table 3 below.

**Table 3: Overview of the sub-themes that were identified under the themes of barriers and facilitators identified**

<u>Barriers</u>	<u>Facilitators</u>
1. Financial constraints	1. Self-motivation
2. Lack of independence	2. Referral system
3. Accessibility	3. Accessibility
4. Lack of transport	4. Family support
5. Environmental barriers	
6. Lack of information	
7. Impairments	

#### **4.3.4 Barriers and facilitators affecting utilisation of rehabilitation services**

##### **4.3.4.1 Barriers to the utilisation of rehabilitation services**

Seven sub-themes were identified under the main theme of barriers to accessing rehabilitation services. The barriers included financial constraints, lack of independence, accessibility, lack of transport, environmental barriers, lack of information and impairments. These will be discussed below.

##### **a) Financial constraints**

In this study, people with lower-limb amputations faced socio-economic challenges. Participants expressed their difficulty accessing rehabilitation services due to financial constraints. Participants relied solely on their disability grant as a source of income which, in some instances, was the only source of income for the household. The disability grant was used not only to support the family but also used to attend rehabilitation services.

*“...it is expensive to go there. There isn’t money... (P5) ó referring to the physiotherapy gymö.*

*“They said I must come back in September so they can check it . . . I didn’t go because I didn’t have money...” (P5)*

*“There are three of us. There isn’t anyone [working]. I get a pension. It is difficult because there are a lot of things that need money but at least it is something because I can’t make money myself. I used to be able to”. (P7)*

*“The transport is a problem. The transport is R300 from here [home] . . . I use private cars . . . I use a wheelchair. If there is no private transport to take me, I do not go to the hospital”. (P9)*

*“I do not go when the month is like this, I go there end of the month when I get paid”.(P10)*

*“I take whatever transport here at Mthombeni using the wheelchair . . . I would say it is R400”. (P10)*

#### **b) Lack of independence**

Some participants expressed their need for assistance due to their lack of independence following a lower-limb amputation. Their challenge with accessing rehabilitation services was the need of others to assist them with pushing them in a wheelchair. Participants also expressed other challenges such as activities of daily living which do not necessarily relate to access of rehabilitation, but further enforce their need of assistance due to the lack of independence. This also ties in with financial constraints. Although assistance was required, some participants could not afford to hire someone, which hindered their utilisation of rehabilitation services.

*“I can’t go alone...I need someone to push me...I pay for my brother...He push me in the wheelchair”.(P2)*

*“Money is not enough. I need it; it’s that I need someone to help me. A person to push me, maybe wash for me, if sometimes I need someone to do laundry for me and help me”. (P3)*

*“Sometimes I wish that they’d be someone I could ask to help me for a day...I don’t have money. The pension money I get is the money I use to feed myself... I can’t find someone*

*to help me. At times when I have found someone you find that it hurts me financially when the person wants their money”. (P6)*

*“I need a person to help me as I stay alone, but I do not have monetary means from the government grant to hire a person, but I do things myself, I can cook and wash clothes but the problem comes when I have to carry this washing, that is where I need a person to help me”. (P11)*

### **c) Accessibility to rehabilitation services**

Due to the nature of the surroundings and poverty constraints, most participants found distance to be a major barrier as it limited their accessibility to healthcare facilities. Some participants had to plan ahead and wake up early in order to reach the main road in time to seek transportation to the nearest rehabilitation facility. Others expressed their need for transportation to and from rehabilitation facilities, as there was no public transport available close to their home and private transportation was expensive.

*“...I woke up at 4(am) trying to find transport because there are no cars in our area. We come from all the way down there by foot...There are no cars here; you only get cars when you get up there to the main road...it’s far indeed”. (P7)*

*“It’s a 20-minute drive...I use public transport . . . I have to walk from home...it’s a 10-minute walk (to the main road to get the taxi)”. (P8)*

### **d) Lack of transport to rehabilitation services**

It was also noted that availability of transport played a key role in accessing rehabilitation services. Participants expressed their frequent visits to rehabilitation when transport was readily available; however, it was seen as a barrier when transport became inaccessible. Participants further expressed their need to use more than one mode of transportation in order to access rehabilitation services which was perceived as difficult. It was also noted that participants experienced difficulty when accessing transportation such as taxi services as they could only use the front seat. This was a challenge expressed by participants with regards to the suitability of the type of transport.

*“I went there (to physio) often then it became a problem when the car broke down”. (P3)*

*“To go from my house to the hospital...R50...first private van then two taxis. . . In the van I sit in the front when they fetch me from home, before there are other people. Even in the taxi I ride in the front because I can't ride at the back...it's difficult”. (P5)*

*“When I leave my house its R13...then R16...then R11 to come here (at the hospital)...I get a van from home to Mxhosa. It's a taxi from Mxhosa to Kranskop and a taxi when I go to the hospital from Kranskop. It's difficult to climb on but I manage to get on because when I get on the taxi, the guys, maybe the taxi drivers, can see that I am having a hard time walking I won't be able to get to the back. In the vans around our area, they let me sit in the front. The person who would be sitting in the front will move to the back and then I would get in front. It can be difficult because the taxi is so high up but I am able to get on. I can struggle with the crutch, step on and hold on to something inside and get in”. (P6)*

*“When I am about to leave home, if I am going to get on the cars that go to Kranskop, get off at Etiyeleni, leave Etiyeleni to get off at Maphumulo and only then turn to come to Umphumulo...I think to go and come back is R66. I'd find a van that was taking people to Kranskop then I'd also ask and then it gets me up there then I can get a taxi to take me to Maphumulo and then I'd find those that come here”. (P7)* ó This participant expressed the need to use one van and two taxis to attend rehabilitation services.

*“If I can get transport to fetch me and bring me back that wouldn't be a problem. It would be easy (to attend physiotherapy). Exercising is hard because there is nothing to pick me up and take me there...it is too far there. It's difficult”. (P7)*

#### **e) Environmental barriers**

All participants struggled in some way with their surroundings. Due to the poor socio-economic status of these participants living in rural areas, their conditions of living were deprived. It became more difficult to live under these conditions with an amputation. The structuring of their homes made it difficult to mobilise independently and leave the home if there was a step at the doorway. Those participants that used a wheelchair to mobilise found it more difficult to mobilise independently. Some participants' households were not adapted to suitably accommodate an assistive device, such as a wheelchair. Due to difficulties exiting and entering the home with the wheelchair, participants were more reluctant to attend rehabilitation at the local hospital. This in turn reduces their utilisation and accessibility to rehabilitation services.

One participant in particular who suffered a bilateral trans-femoral amputation, experienced difficulty exiting his home.

*“I can’t go outside...because of the condition”.* (P1)

*“I like going outside...the problem is that there isn’t room for me to do that otherwise I do”.* (P1) ó This participant was referring to not being able to propel his wheelchair out of the house doorway because of a step at the doorway and sand/stones outside the house.

#### **f) Lack of information**

Participants highlighted that they did not attend physiotherapy as a result of lack of information, no referral, no knowledge of the hospital or nearest clinic having a physiotherapist available and no signage at the hospital. Due to the lack of information, patients were left despondent and reluctant to attend physiotherapy.

*“I think that is something that I would get from them. I couldn’t take decisions for myself because they are the people who had my life in their hands, they’re the ones who were supposed to explain to me that ‘come to the physio, continue with the physio. . .”* (P7)

*“The leg for free... no-one told me anything... No-one showed me how the prosthetic leg is or educated me about the leg”.* (P9)

*“No, I did not see the physiotherapist, I just came back home from the hospital”.* (P10) ó

This particular participant was not informed that he needed to see a physiotherapist following rehabilitation services. It was explained that the participant returned home following the amputation. The only knowledge the participant had of a physiotherapist was that of receiving a wheelchair from the rehabilitation department.

*“...they did not tell me to see the physiotherapist ... No one has told me about what the physiotherapist does... To do the gym at the physiotherapy ... I have not done the gym ... I have not been told to go to see the physiotherapist...since I was discharged from the hospital, nobody told me anything”.* (P11)

#### **g) Impairments**

Under the sub-theme of *impairments* the two most commonly reported impairments were pain and psychological well-being.

Some participants experienced pain during their amputation recovery period. Rehabilitation amplified their pain experience which left the patients feeling pessimistic. Although the patients had tried to exercise and attend rehabilitation, experiencing pain during the rehabilitation session made them unwilling to attend rehabilitation.

*“It was still painful, I was still injured...They made me exercise inside (in the ward), I still had stitches, it was still very painful. Then that was the last time I exercised...” (P4)*

*“I’d be trying to exercise and feel pain and sit down. When I’d try to exercise I’d feel bad and sit down”. (P9)*

Dealing with the loss of a limb and the dramatic change in lifestyle affected all participants in some way. Some felt depressed, despondent, ridiculed and ineffectual. Most participants were not motivated to attend rehabilitation sessions which caused a barrier to their accessibility. Some participants were discouraged to attend due to mockery regarding their disability. Participants were not motivated to attend rehabilitations services.

*“...I get bored I sit on the wheelchair then sleep after that...I don’t do anything”. (P1)*

*“Even at the hospital they used to make fun of me when I’d take off my clothes and they’d see the strings that the healer put on me. They’d laugh at me...”(P1)*

*“I’d go if I was up to it”. (P5)*

*“When you’d know that there was a party somewhere and you’d go with the guys but now that doesn’t happen anymore. I just sit, you see”. (P7)*

*“...in the community, some friends, you’ll meet some people who are saying ‘ah that girl has an artificial leg’ so I can’t roll with them”. (P8)*

#### **4.3.4.2 Facilitators to the utilisation of rehabilitation services**

Four sub-themes were identified under the main theme of facilitators to accessing rehabilitation services. The facilitators included self-motivation, referral system, accessibility, and family support. These are discussed below.

##### **a) Self-motivation**

Self-motivation and motivation given by the physiotherapist or healthcare worker played a major role in motivating patients to not give up but continue with rehabilitation, as the



benefits of it were known to them. This encouraged participants to continue with rehabilitation in order to be better and do better in life. Participants had different insights to what motivated them to attend rehabilitation. Some believed exercising in order to get a prosthesis would allow them to walk independently again. Others were happy with the attitude of the physiotherapist and some wanted to regain independence by working again. One participant was encouraged by the counselling and information given by the physiotherapist who motivated her to attend rehabilitation.

*“I was working. I was living before the leg was cut. Maybe when I am better I can work for myself”*. (P4)

*“I saw the physio as someone who was going to help me ... The physio didn't tell me anything bad. He (or she) would just speak properly”*. (P4)

*“I could see that I was getting help because I could see that I was flexible. I was comfortable walking in crutches even when I hadn't put in the prosthesis”*. (P6)

*“. . . it was very good because we understood each other and I was able to listen to her although sometimes it got very hard. . . we had a good relationship”*. (P8)

*“I think because I went for counselling that really changed me like it made me realise that even though I have to like wear an artificial, it doesn't mean that my life was like changing completely. It made me realise that ya I can still live my life fully even though I have an artificial leg”*. (P8)

Some participants wanted to receive the prostheses in order to regain functionality and independence, therefore accessed rehabilitation services which would assist them.

*“...to stand up and walk is difficult. But I am able to get up into the wheelchair but the walking is hard...If I can just get the leg I know that I'll be able to stand and maybe be able to walk. I need to get the leg”*. (P3)

*“...I am looking forward to the shoe...”* (P9)

## **b) Referral system**

Due to most participants' lack of education, they are unaware of the services provided at the hospitals. Therefore, it is of utmost importance to bridge the gap between surgeries and post-operative care. Participants need to be informed and referred to physiotherapy. Those who



are informed correctly are more likely to attend and get further rehabilitation at a district level healthcare facility.

*“They cut the leg at Stanger and then said I should get further treatment at my local hospital”.* (P3)

*“...they put me in touch with a physio so that I could get a new leg after they had cut my leg”.* (P6)

### **c) Accessibility**

Participants were more likely to attend rehabilitation if there is a shorter waiting period to access a physiotherapist.

*“No, not wait long”.* (P2)

*“If there other wheelchairs in front of me, I join the queue, if not, they escort me in”.* (P3)

*“...it would take maybe 10 minutes”* ó to see the physiotherapist. (P4)

### **d) Family support**

All participants expressed their need for help and assistance in their daily lives. Most participants, who had family members present, explained how their families assist them in attending rehabilitation and also helps them at home.

*“...my wife she helps me...”* (P1)

*“...it’s good because I have my family to help me”.* (P2)

*“Sometimes I take my brother’s wife and other times my brother comes with me”.* (P5)

*“She (wife) is a great help to me. I wouldn’t be able to do it myself if she wasn’t there. She’s a great help...”* (P7)

## **4.4 Summary of the chapter**

Diabetes mellitus and hypertension are the most common associated co-morbidities related to lower-limb amputations in the iLembe district of Kwa-Zulu Natal, with diabetic-related

gangrene being the most common cause. Rehabilitation services are not successfully utilised in rural areas of the iLembe district due to the numerous barriers affecting accessibility. Although facilitators assist access to rehabilitation services, this is not expressed by all participants. This therefore decreases the number of participants accessing rehabilitation services in that region.



## CHAPTER FIVE: DISCUSSION

### 5.1 Introduction

This chapter will discuss the main findings of this study in relation to the relevant literature, and highlight potential clinical implications.

Living with a disability in a rural impoverished area such as the iLembe District, Kwa-Zulu Natal, South Africa, potentially has substantial implications for those living with a lower-limb amputation. These potential implications were investigated in this study with regard to those persons with lower-limb amputations accessing the necessary rehabilitation services in their area. Access to rehabilitation services was explored in terms of barriers and facilitators experienced by individuals with amputations. The need to understand rural poverty and disability is an important priority (as suggested by the Department of Social Development) (Graham et al., 2014). It is also important to first understand the causes resulting in an amputation and the co-morbidities influencing an amputation.

### 5.2 Summary of the findings

The quantitative results depict that the most prevalent cause of lower-limb amputations in the iLembe district is due to diabetic gangrene, followed closely by PVD, diabetic foot sepsis and sepsis caused by infection. The leading co-morbidities associated with these causes are diabetes mellitus, hypertension, retroviral disease, cigarette smoking, cardiac conditions and renal impairment. Overall, men underwent more lower-limb amputations than their female counterparts. Men accounted for 56.6% of lower-limb amputations, while females accounted for 43.39% of amputations. The African race group outweighed the Indian race group by more than double in numbers. The older the participants the higher the number of lower-limb amputations. The leading age group was 70 years and older, with the 61-70 years first and 51-60 years following. Unilateral trans-tibial amputations were the most frequent amputations performed on both males and females. Unilateral trans-tibial, trans-femoral and trans-metatarsal amputations were performed more on men than women.

The qualitative results have shown that persons with lower-limb amputations living in a rural community face numerous barriers with regard to accessing rehabilitation services. Barriers include financial constraints, lack of independence, accessibility, lack of transport, environmental barriers, lack of information and impairments. The facilitators include self-motivation, referral system, accessibility and family support.

## 5.3 Discussion of quantitative findings

### 5.3.1 Inadequate medical records

The theatre department at Stanger Hospital records the patient's particulars prior to the amputation surgery in a theatre record book specifically kept for amputation surgeries only. This includes information such as the date, name and surname of the patient, in-patient folder number, age, gender/ward, address and the limb being amputated. It was found that limitations to extracting the data accurately included: 1) illegible writing, 2) abbreviations used to describe the amputation which were sometimes incorrectly recorded and 3) incorrect folder numbers being recorded. There were also missing data which included an incomplete entry for two male patients as the type of amputation was not recorded in the theatre book. These two male patients were therefore excluded from the quantitative findings as the type of amputation performed was unknown and the patient's medical folders were not retrievable due to missing folders. These findings were echoed by researchers Wegner and Rhoda (2013) who conducted a study in a similar rural setting, and reported on a large number of missing medical records. They found that inadequate record keeping was a major obstacle to conducting archival research in rural settings. Inadequate medical records can also result in patient mismanagement or iatrogenic injuries (Wegner & Rhoda, 2013).

Only 29.9% (n=111) of the total number of folders (N=371) could be retrieved for medical data extraction. This, according to the administration file room clerk, was due to the lack of storage room. Older files had to be removed from the basement filing room to be stored in the container outside. However, due to weather conditions, many of the files were discarded and irretrievable. Many of the recent files were also unavailable due to the poor storage system. Some patients only had their outpatient folder numbers written on the medical folder thereby making it difficult to locate the patient file, as only the in-patient folder number is recorded in the theatre book. Other folders were rendered useless as the patient's name on the file did not correlate with the patient's name on the folder; however the in-patient folder number was accurate. This could be due to misfiling and misplacement of the patient's records.

It is required by law that adequate medical records are kept by all health professionals to ensure continuity of care and to share relevant information with other members of the multi-disciplinary team (Health Professionals Council of South Africa [HPCSA], 2008; Claeys, 1996). These records contain valuable information regarding the patient's condition and management at the healthcare institution and are frequently used as a source of quantitative

information for research purposes (HPCSA, 2008; Zegers et al., 2009; Raff & James, 2003). In South Africa, all private and public healthcare facilities should retain patient records for at least six years (HPCSA, 2008). Good records management is essential for the continuity of care of your patients, and can reduce the risk of adverse incidents through misplaced or untraceable records. Problems with medical records - lack of accessibility, poor quality information, misinformation, poorly organised notes, misfiling and many others - are known to lie at the root of a high proportion of adverse incidents (Medical Protection Society, 2013).

According to Pourasghar et al. (2008), it is necessary to find ways to ensure that the documentation of information will be in a readable and retrievable format. Due to illegible records, missing folders and damaged files, difficulties presented with locating folders and retrieving patient medical information in order to extract data. This limits the data needed to gain insight on the topic and conduct further research. Due to patients' folders being lost or damaged, the hospital is forced to open new patient folders which lose those patients' past medical history. This prevents continuity of care for the patient as well as time wasted restarting the medical process.

### **5.3.2 Prevalence of lower-limb amputations**

The iLembe population in Kwa-Zulu Natal, has a prevalence rate of 12.1 lower-limb amputation per 100 000 people per year. This is relatively low as compared to the Navajo population in the United States of America which has a 43.9 per 100 000 people per year incidence rate. However, it is considerably higher as compared to Madrid, Spain (Global Lower Extremity Amputation Study Group, 2000). No other South African studies were found on the prevalence of lower-limb amputations, which made it difficult to compare these results with other South African statistics. In this study, the incidence of lower-limb amputations increased with age, with the average age of persons with lower-limb amputations being 61 years. This also correlates with international studies which found that the incidence of amputation rose steeply with age; most amputations occurred in patients over 60 years (The Global LEA Study Group, 2000). This agrees with other authors who documented peak age incidences of peripheral vascular disease and diabetes in the sixth and seventh decades of life (Nwankwo & Katchy, 2004; Onyemaechi et al., 2012; Obalum & Okeke, 2009). This may be because the risk factors are more common in the ageing populace.

Trans-tibial amputations accounted for the majority of all lower-limb amputations performed. In this study it was found that over the five year period trans-tibial amputations accounted for

60.1% of the amputations performed while trans-femoral accounted for 30.4%. This is a similar finding to a study conducted in the Western Cape who found the most common level of amputation was trans-tibial amputations (Frederiks & Vasagie, 2013). In contrast to these studies, older African studies found that trans-femoral amputations were greater in number than trans-tibial amputations (Kidmas et al., 2004; Henry, 1993). These are older studies which mainly reported on traumatic lower-limb amputations. However, similar to South Africa, other developing countries such as India also found that more than 50% of the subjects who underwent major lower-limb amputations accounted for trans-tibial amputations and 11.9% accounted for trans-femoral amputations (Viswanathan & Kumpatla, 2011).

The male preponderance found in this study agrees with the findings in other studies (Nwankwo & Katchy, 2004; Yinusa & Ugbeye, 2003; Ogbera, Fasanmade, & Ohwovoriole, 2006, Gutacker et al., 2010; Manderson & Warren, 2010). This may be explained by the fact that males are more active and thus more likely to sustain foot injuries. In addition to general awareness programmes and prevention of lower extremity amputation programmes, gender-specific programmes should be carried out to target the increase in the number of male lower-limb amputations.

### **5.3.3 Co-morbidities and common causes of lower-limb amputations**

The most common cause of lower-limb amputations were gangrene as a result of diabetes mellitus. Similarly, diabetic related gangrene was found to be the most common indication for amputation accounting for 71.4% of a total of 91 amputations performed in a Teaching Hospital in Nigeria (Ndukwu & Muoneme, 2015). This differs from studies in developed countries where vascular insufficiency is reported to be the most common indication for amputations but is similar to evidence from recent studies in Africa and Nigeria showing that diabetic gangrene is becoming a leading cause of amputation (Onuminya, Obekpa, Ihezue, Ukegbu, & Onabowale, 2000; Ogunlade, Alonge, Omololu, Gana, & Salawu, 2002; Akiode, Shonubi, Musa, & Sule, 2005; Ahmad, Thomas, Chan, & Gill, 2014; Dada & Awoyomi, 2010; Ogbera et al., 2006). The high evolving incidence of diabetic complications may be complicated by a low awareness of the disease and its complications with inappropriate patient education on foot care, and poor health-seeking attitude (Ogbera et al., 2006).

Other common causes of lower-limb amputations included peripheral vascular disease, diabetic foot ulcer/sepsis and sepsis. Interventions, such as diabetes self-management education and targeted foot screening programmes, have been shown to be effective in

reducing the risk of foot ulcers and subsequent amputation (Mayfield, Reiber, Nelson, & Greene, 2000; Larrson, Apelqvist, Agardh, & Stenstrom, 1995; Rith-Najarian & Reiber, 2000; Strine, Okoro, Chapman, Beckles, Balluz, & Mokdad, 2005). Given that nearly 85% of lower extremity amputations are preceded by a foot ulcer (Reiber, Boyko, & Smith, 1995; Armstrong, Lavery, Harkless, & van Houtum, 1997; Larrson, Agardh, Apelqvist, & Stenstrom, 1998; Pecoraro, Reiber, & Burgess, 1990), these interventions may significantly reduce the impact on the prevalence of lower-limb loss.

The leading co-morbidities identified in this study were diabetes mellitus followed by hypertension, retroviral disease and cigarette smoking, alcohol and renal impairment. This finding was strengthened by the literature by both national and international studies as the same results were found (Dunbar & Levitt, 2015; Frederiks & Vasagie, 2013; Viswanathan & Kumpatla, 2011). Dunbar & Levitt (2015), found the most commonly associated co-morbidities to be hypertension, ischaemic heart disease and renal impairment which were more common in diabetic patients, whereas smoking, asthma/COPD was more prevalent in the non-DM group. This is also similar to other studies and is thought to be due in part to the increasing westernisation of lifestyles (International Diabetes Federation, 2005; Gamba, Gotlieb, Bergmaschi, & Vianna, 2004; Levitt, 2008). Dunbar & Levitt (2015) also associated renal impairment in DM patients with poor glycaemic control. Adequate training and education programmes should be conducted at all healthcare facilities, with nurses and healthcare workers, as well as community health workers, to enable patients to actively participate in their own care, to screen for at-risk feet and to be appropriately referred for further management. In addition, regular hypertension and diabetes mellitus screening should be performed to lower the risk of lower-limb amputations.

## **5.4 Discussion of qualitative findings**

### **5.4.1 Barriers to accessing rehabilitation services**

The summary of the findings of this study show that persons with lower-limb amputations, living in the rural regions of the iLembe district, experience numerous barriers to access to rehabilitation services. Persons with lower-limb amputations expressed problems with mobility, financial constraints, transportation, lack of information, lack of independence, intermittent illnesses, pain and psychological well-being.



Physical barriers included mode of transport, transport costs, the actual journey to the nearest rehabilitation facility, not knowing where to go, not knowing about rehabilitation/physiotherapy, decreased mobility (type of assistive device used), having other illnesses such as asthma limiting mobility/endurance, pain and decreased independent activities of daily living. Communication barriers included lack of information by doctors with no referral to physiotherapy following surgery, no follow-up dates given by the physiotherapist, lack of education and information regarding the condition, no down-referral to the nearest healthcare facility with rehabilitation services and lack of long term goal setting during treatment. Psychological barriers included unemployment, mockery and criticism from other individuals, lack of motivation to further their rehabilitation treatment, feeling discouraged by their lack of independence, thus evoking feelings of being a burden to others.

The conceptual framework of the International Classification of Functioning (ICF) recognises that the environment has an impact on the ability of persons with disabilities to participate and contribute meaningfully to life of the community and to benefit from all services provided (WHO, 2001). This was relevant to persons with lower-limb amputations living in the rural areas of the iLembe district as there were many environmental challenges, such as the topography of the area, reliability of untimely public transport, as well as availability, poor basic household facilities such as water, electricity, sewerage and lavatory systems. Although these do not directly influence access to the utilisation of rehabilitation services, they pose as challenges experienced by persons with lower-limb amputations.

#### **5.4.1.1 Public transport**

In this study, participants expressed their need to walk from their home to the main road; this posed many difficulties in accessing transport to health services.

Some of the physical barriers that were highlighted in this study were mainly to do with transport issues. The issue with transportation with regard to healthcare services has received increased attention (Paez, Mercado, Farber, Morency, & Roorda, 2010). Travelling in rural areas in global south countries is challenged by problems such as difficult terrain; flooding; poor quality of roads; expensive; inadequate or non-existent public transport (Kiwanuka et al., 2008; Obrist et al., 2007; Schoeman et al., 2010) and unavailable or expensive private transport (Obrist et al., 2007). South Africa has 221 000 kilometres of rural roads, some of which are difficult to negotiate by motorised vehicle. This creates barriers to the provision of transport (DWCPD, 2013). In addition, in emergencies, ambulances are not always available



or, when they are available it takes a long time for the ambulance to arrive (Couper, Hugo, Tumbo, Harevey, & Malete, 2007; Gaede & Versteeg, 2011; Harris, Eyles, Penn-Kekana, Thomas, & Goudge, 2014). Walking, often over difficult terrain, is the most common way of reaching healthcare services in rural Africa (Hjortsberg & Mwikisa, 2002; Khan, Hotchkiss, Berruti, & Hutchinson, 2006; Kiwanuka et al., 2008). In a nationwide South African study, Harris et al. (2011) found that 45.2% of participants used public transport to access healthcare while 37% walked.

Syed, Gerber, and Sharp (2013) stated that transportation barriers are often cited as barriers to healthcare access. According to them, studies have found that rural patients face greater transportation barriers to healthcare access than urban patients. Similar results were found in this study as persons with lower-limb amputations reported transport and distance as the primary problem, with the cost of transport to rehabilitation services highlighted as an issue. They expressed their difficulty with entering the transport, such as climbing into a taxi or van due to the increased height of the entrance, due to their disability and mobility with assistive devices. In South Africa, public transport is notoriously inaccessible (Emmet, 2006). Accessibility and lack of transport are major barriers to the utilisation of medical services in rural communities (Gallagher, Hart, O'Brien, Stevenson, & Jackson, 2011; Goins, Williams, Carter, Spencer, & Solovieva, 2005; Gordon, 2009; Maart et al., 2007). In some of the communities, persons with disabilities would be allowed onto the taxi, but would have to pay double if they had a wheelchair or even an assistive device. Although none of the participants in this study had to pay extra to take their assistive devices into the public or private transport, it is important to note that those who mobilised with wheelchairs were unable to make use of public taxis; they used private vehicles or vans to attend rehabilitation at the nearest facility. It was found that those who made use of private vehicles paid much more for transport as compared to those who used taxis. However, transportation was also problematic for those who made use of taxis, as they had to utilise more than one taxi, or sometimes more than one mode of transport, in order to get to the rehabilitation facility. Participants in this study expressed their need to wake up earlier than usual in order to walk to the main road to use public transport to get to the hospital. The reasons for waking up earlier than usual were: slow gait using assistive devices; rugged terrain in the area and vast distances to get to the main road from their homes. Many participants had to wait along the roadside in the early hours of the morning for transport, as they needed to use more than one mode of transportation. The earlier they reached the hospital, the earlier they would be seen by

healthcare providers and the earlier they would be able to travel back home. Access may be especially challenged when services must cover large geographical areas (Goodridge et al., 2015). Many people who have undergone lower-limb amputations never learn to walk again, or manage to walk only short distances, because of physical or prosthetic problems. This leaves them dependent on a wheelchair for mobility, with the environmental barriers inherent to wheelchair use such as stairs, narrow doors, turnstiles and rough terrain limiting their mobility (Rommers, Vos, Groothoff, & Eisma, 2001; Manderson & Warren, 2010). Similarly, in this study, it was found that persons with lower-limb amputations found it problematic to exit the house with a wheelchair due to stairs and narrow doors, as well as accommodating inclined surfaces and gravel terrain.

Implementation and regulation of the transport industry in South Africa has not adequately addressed barriers of access for rural poor persons with disabilities, despite the policies attempting to be inclusive (South African Human Rights Commission, 2009). According to Gaede and Versteeg (2011), persons with disabilities have only a few public transport systems available to them- and even fewer in rural areas.

Unavailability of transport for persons with disabilities to access healthcare services has been widely reported on (Ahmad, 2013; Drainoni et al., 2006; Iezzoni, Killeen, & O'Day, 2006; Kahonde, Mlenzana, & Rhoda, 2010; Maart & Jelsma, 2014; Scheer et al., 2003; Smith, 2008; Van Rooy et al., 2012). Challenges occur with private transport, public transport and specialised transport programmes for persons with disabilities (Scheer et al., 2003). Public transport is often not an option due to unavailability (Heap, Lorenzo, & Thomas, 2009), inaccessibility (Ahmad, 2013; Gaede & Versteeg, 2011; Heap et al., 2009), and distance between route stops and the person's home or provider's office (Scheer et al., 2003). In South Africa, taxis sometimes do not stop for persons in wheelchairs or charge extra for the wheelchair (Kahonde et al., 2010; Ntamo, Buso, & Longo-Mbenza, 2013). Van Rooy et al. (2012) report from Namibia that transport is provided by private car, donkey car or homemade sledge, but that the majority of people with disabilities walk to access healthcare. Hiring transport increases the cost of healthcare and may deter people from accessing services. In instances where the person is very sick, an ambulance can be arranged, but it can take a long time for the ambulance to arrive (Van Rooy et al., 2012).

De Koker, De Waal, and Vorster (2006) found in a nationwide South African study that 59% of disability grant recipients walk to access healthcare facilities. However, in this study,

participants ambulated with an assistive device with made it difficult to walk to healthcare facilities. They relied on public or private transport to access rehabilitation services but due to the lack of funds and living solely on a disability grant, to save money participants chose not to attend physiotherapy rehabilitation at all.

#### **5.4.1.2 Financial barriers**

In this study, persons with lower-limb amputations experience greater financial burdens due to their condition. Living in an impoverished region proves difficult already, without the added implications of living with a physical disability. Social grants are not enough to sustain adequate daily living and provide for the family, especially when the disabled person is the head of the household and was previously the breadwinner. Rehabilitation and medical healthcare become an afterthought and is only thought to be necessary if there is money left over at the end of the month. Due to their disability, unemployment becomes financially burdening to the family and household.

A lack of health insurance, financial problems and/poverty decreased access to healthcare and in instances led to poorer health outcomes for persons with disabilities in the United States of America (USA) (Chevarley et al., 2006; Drainoni et al., 2006; Gulley & Altman, 2008; Iezzoni et al., 2006, 2011; Mitra, Findley, & Sambamoorthi, 2009; Winitzer, Bisgaier, Grogan, & Rhodes, 2012). Van Rooy et al. (2012) found that in Namibia the cost of healthcare prohibited persons with disabilities from accessing healthcare in some instances, but that payment was waived in other instances. Ahmad (2013) found that in Pakistan out-of-pocket payment for things like transport, medication and tests increase costs of service and in some instances rendered services unaffordable for persons with disabilities. In a South African study, Maart and Jelsma (2014) reported that 71% of study participants did not access rehabilitation services, because they could not pay for it, and Ntamo et al. (2013) found that 29% of stroke survivors did not access rehabilitation due to a lack of money. Ntamo et al. (2013) linked the findings to transport costs incurred by rural dwellers, of which 32% lived more than 100km from the service they had to access. Maart and Jelsma (2014) did not discuss the findings further and it is possible that in this instance participants also referred to indirect costs such as transport, since healthcare to persons with disabilities should, according to South African national policy, be free of charge.

Most participants survived on the disability grant which they received monthly. This was mostly the reason for those participants not to utilise rehabilitation services in rural areas.

Therefore, every session available with each client should be focused on the participants' specific needs and provide the best possible value for money. Treatment sessions should always cover a home-based exercise programme for continuity of rehabilitation.

#### **5.4.1.3 Lack of referral**

Some participants experienced barriers to rehabilitation services due to the lack of referral and information. This was expressed by poor referral from the doctor to the physiotherapist and also from the physiotherapist themselves regarding the lack of follow-up appointments and continuity of care. Therefore participants did not have knowledge regarding the role of a physiotherapist and the importance of rehabilitation for an amputation.

Service providers may have limited knowledge of referral pathways for persons with disabilities, assistive devices, alternative ways of performing activities, and the impact of environmental barriers, and how to deal with these. Thus they may not be able to advise the person on functioning and fulfilling their life roles, or they might give unfeasible recommendations and management strategies (such as advising a wheelchair user to rest the shoulder muscles), both of which will impact quality of life negatively (Iezzoni, 2006b; Scheer et al., 2003). The lack of education was also supported by other researchers (Harris, Hayter, & Allender, 2008) who suggested that communication and lack of information were barriers related to healthcare professionals when managing patients with chronic illnesses.

Drainoni et al. (2006) found poor continuity of care due to high staff turnover and a lack of effective communication between service providers. Participants also expressed the lack of information given by physiotherapists as no follow-up dates were given to them, therefore participants did not return for rehabilitation.

Open communication and consultation is often lacking between healthcare service providers and users with disabilities (Iezzoni & Long-Bellil, 2012; Shakespeare, Iezzoni, & Groce, 2009; WHO, 2011). Ineffective communication can create long-lasting barriers, fear and anxiety, erode trust and lead to poor compliance and suboptimal health and functional outcomes for users with disabilities (Drainoni et al., 2006; Iezzoni, 2006b, 2009; Shakespeare et al., 2009). The reasons for ineffective communication are multifaceted and might be related to the service provider or the impairment (Drainoni et al., 2006; Iezzoni, 2006c). Mlenzana and Mwansa (2012) found in their Zambian study that persons with disabilities

were dissatisfied with the manner in which doctors listened to them (17%) and provided explanations to them (25%).

A study by Chetty and Maharaj (2013) identified the importance of teamwork, but also added that impediments to collaboration were communication barriers and lack of understanding of roles within the team. Stiller and Drury (2009) recommended that patient and practitioner should work together in setting achievable goals for rehabilitation and should be guided by patients' expectations of therapy.

#### **5.4.1.4 Pain**

In this study it was found that, although participants would like to attend rehabilitation, pain limited their access and willingness to exercise. Most participants experienced a great deal of pain and discomfort following lower-limb amputations. This may include phantom pain in the stump, pain during rehabilitation exercises or even pain from ischaemic changes of the contralateral leg. In a study by Kamel (2000), participants' pain was the main focus of their despair and walking was the main focus of their hope. However, pain might actually be alleviated by ongoing rehabilitation and exercise.

Pain often caused patients to be averse to exercises and attending rehabilitation. Although pain is a barrier to rehabilitation and limits function (Schoppen et al., 2003), it is a factor that can be managed by physiotherapists. A study of in-patient physiotherapy rehabilitation of amputee patients proved to reduce bodily pain and aided in patients' functional ability (Pezzin, Dillingham, & MacKenzie, 2000).

#### **5.4.1.5 Psychological factors**

Some participants in this study were reluctant to reintegrate back into society and continue with their daily community participation. They felt that they had no choice but to be at home. This reduced their chances of attending rehabilitation regularly or at all. Participants with lower-limb amputation were conscious about their image. A lower-limb amputation changes one's physical appearance so much that they feel that the general public will perceive them differently. Lower-limb amputation has notably resulted in changes in perception of body image, and social function (Engstrom & Van de Ven, 1999; Resnick et al., 2004; Zidarov et al., 2009).

Those who were criticised and mocked by others felt despondent to continue with rehabilitation and preferred staying at home. Stigmatisation of persons with physical disabilities is well documented (Bagenstos, 2000; McMaugh, 2011; Tyrrell, Hetz, Barg, & Latimer, 2010; Wang & Dovidio, 2011). According to Bagenstos (2000), society has historically discriminated against persons with disabilities based on their 'abnormal' appearance.

On the other hand, participants look forward to getting their prosthesis. They hope that they will walk again and return to their normal state. This motivated them to come for rehabilitation in order to receive a prosthesis.

Another aspect that came across affecting participants' psychological status regarding access to rehabilitation is the lack of consideration from the community. This may be in the form of jokes, mockery and exclusion from the group due to them using a prosthesis 'fake leg'. Some participants were affected by these inappropriate comments which made them exclude themselves from society. This was evident in the older participants; however, the younger participants showed motivation and determination to prove others wrong and worked harder at rehabilitating themselves to function independently. It was expressed by a younger participant that a lot of their willingness to attend rehabilitation was due to the good relationship and motivation given by the physiotherapist.

Some participants dealt with a lot of psychological issues, while others seemed to have found the best solution for their condition was by having an amputation. Those who were counselled prior to the amputation and understood why they needed an amputation seemed more likely to access rehabilitation as a means of regaining functionality. The study by Kamel (2000) revealed that a number of participants felt like they were forced to accept the operation as they had no other choice. This was also the case in some instances in this study where a participant felt that he just had to live with it and it had to be done. The problem with comparing the study by MacNeill et al. (2008) is that it was done on participants with bilateral trans-tibial amputations, while this study involved participants with unilateral and bilateral amputations on varying levels. The advantage of the MacNeill et al.'s (2008) study was that it was done on people who had had amputations as a result of diabetes and peripheral vascular disease, which is similar to this study.



One participant (P1) only attended rehabilitation to collect a wheelchair, but did not find it necessary to attend regularly in order to regain function. This participant had considerably more barriers than other patients, due to him having bilateral trans-femoral amputation.

Effective counselling and effective use of the referral system to the multi-disciplinary team should be utilised to reduce these psychological barriers.

## **5.4.2 Facilitators to accessing rehabilitation services**

### **5.4.2.1 Satisfaction with services**

Some participants expressed their willingness to attend rehabilitation services due to the physiotherapist. Participants perceived the physiotherapist as someone who was helping them and became motivated to attend rehabilitation due to the good relationship between the therapist and participants. Chetty et al. (2015), who conducted a study on the satisfaction and adherence of patients with amputations to physiotherapy service at public hospitals in Kwa-Zulu Natal, South Africa, found that patients were generally satisfied with the physiotherapy service. Patients who are satisfied with the service delivery adhere to therapy regimes and will in turn perpetuate positive reference and referrals to the rehabilitation practice (Keith, 1998).

Communication between patient and practitioner influenced patient satisfaction and adherence to physiotherapy treatment (Chetty et al., 2015). Similarly, Beattie et al. (2002), found a positive correlation with patient-practitioner interaction and satisfaction with therapy. The shared information, education and time spent with the patient reflected greater patient fulfilment. Congruently, Brokalaki, Sotiropoulos, Tsaras, & Brokalaki (2005) emphasised patients distaste for technical language, poor feedback and depersonalized care when communicating with their practitioner. In this study, participants expressed their satisfaction with attending rehabilitation due to having a good relationship with the physiotherapist. Another motivating factor was the notion of receiving a prosthesis and being able to ambulate independently once more.

### **5.4.2.2 Intrinsic motivation**

Motivation was a driving force that encouraged patients to adhere to therapy. Patients showed appreciation toward their physiotherapists when the therapist encouraged their active involvement in their personal health and care. As a result, motivation and feedback offered to

patients on their progress, positively affected compliance to the exercise programme. Functional outcomes can be affected by patients' levels of motivation and in turn can result in positive rehabilitation outcomes of treatment (Greive & Lankhorst, 1996). A rehabilitation regimen was studied in patients with bilateral amputation of lower extremities and once again motivation reappeared as a contributing factor (Watkins & Liao, 1958).

Other patients were motivated as they were the breadwinners of their household hence they were obligated to speedily recover so they could return to work and once more provide for their families. Some patients adhered to therapy regimens as they were driven to achieve their pre-morbid state of functioning as self-sufficient individuals (Olugbemi, Olukolade, Alao, & Adebisi, 2013).

#### **5.4.2.3 Social support**

Participants in this study expressed their need for family support, individual assistance and help from caregivers for activities of daily living. People with a lower-limb amputation may end up having closer relationships with their partners as a result of the lower-limb amputation and their children may be more caring than before the amputation (Bosmans et al., 2007). It has been reported that children visit more frequently after the operation and during the rehabilitation phase, while the visits cease later on. Partners of persons with an amputation are reported to be more caring with the person after the amputation (Bosmans et al., 2007).

People with amputation may need help from their partners or domestic helpers most of the time. The impact of amputation on the balance of interpersonal relationships and loss of status within the family may surface. People with a lower-limb amputation handle social relationships in different ways, e.g. phantom pain does not always influence social relationships; however, dependency hampers people from carrying out their daily activities of shopping, working, pursuing hobbies, participation in sport and visiting family and friends, thus hampering them in achieving status and affection (Bosmans et al., 2007).

#### **5.5 Summary of the chapter**

Persons with disabilities often have greater healthcare needs than their peers, while experiencing greater barriers to healthcare access. Accessibility of healthcare services, especially rehabilitation for persons with lower-limb amputations, is negatively impacted by financial constraints, lack of independence, distance of travelling, lack of transport, environmental barriers, lack of information, intermittent illness, pain and psychological well-



being. However minute the facilitators may be in comparison to the barriers, they still fulfil the necessary role of assisting persons with lower-limb amputations in accessing rehabilitation services.

While there is evidence in South Africa that suggests that policies are good, implementation may be failing people with disabilities on these issues (Graham et al., 2014; Maart et al., 2007). Maart et al. (2007) goes on to say that disability in South Africa is framed within a medical and welfare framework, which results in the exclusion of people with disabilities and their exposure to barriers. According to these authors, government strategies should be focused on universal access for people with disabilities and placing disability within a human rights framework.



**CHAPTER SIX: SUMMARY OF THE STUDY,  
CONCLUSION, LIMITATIONS AND RECOMMENDATIONS**

**6.1 Introduction**

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

**6.2 Summary of the study**

The purpose of this study was to explore the barriers and facilitators to utilisation of rehabilitation services in a rural setting in the iLembe district in Kwa-Zulu Natal, and also to determine the number and common causes of lower-limb amputations performed at the tertiary hospital in the iLembe district of Kwa-Zulu Natal. In fulfilling the aim of this study, the demographic profile of persons with lower-limb amputations had to be determined, the common causes and co-morbidities associated with lower-limb amputations were identified and the perceived barriers and facilitators to utilisation of lower-limb amputations were concluded.

The iLembe population has a prevalence rate of 12.1 lower-limb amputation per 100 000 people per year. The mean age of lower-limb amputations was 61 years. Trans-tibial amputations were predominantly performed. The African race group was more likely to have lower-limb amputations in all amputation categories as compared to the Indian race group. Other race groups such as Whites and Coloureds could not be commented on as there were no findings of lower-limb amputations performed within the five year period for these race groups. Although the iLembe population does consist of other race groups such as Whites and Coloureds, it could be that they did not undergo a lower-limb amputation within the five year period or that they have had the surgery performed at another institution other than Stanger Hospital.

It was found that the most common co-morbidities associated with lower-limb amputations in the iLembe district during the study period were diabetes mellitus and hypertension. The most common cause of lower-limb amputations was gangrene as a result of diabetes.

Seven sub-theme barriers and four sub-theme facilitators were perceived by persons with lower-limb amputations in rural areas of the iLembe district. Barriers included financial

constraints, lack of independence, accessibility, lack of transportation, environmental barriers, lack of information and impairments. The facilitators included self-motivation, the referral system, accessibility and family support.

### **6.3 Study limitations**

A number of challenges were experienced during the data collection for this study. Firstly, the quantitative retrospective archival survey was limited by the number of folders which were retrievable, thereby reducing the data size due to missing medical folders. It was found that limitations to extracting the data accurately included: 1) illegible writing, 2) abbreviations used to describe the amputation which were sometimes incorrectly recorded and 3) incorrect folder numbers being recorded. There were also missing data in the theatre surgery records book which made retrieving accurate patient details impossible.

Secondly, persons with lower-limb amputations identified for the qualitative study did not consent to participating in the interviews, thereby limiting the available sample size for the qualitative study. Many participants explained that they could not travel to the nearest healthcare facility which posed as a limitation to participating in the study. The driver available to the researcher did not know the route to the homes of the participants, making it impossible for the researcher to conduct a home visit, which also limited the study population. Purposive sampling could not be used for the qualitative component. This type of sampling would have provided richer information regarding the barriers and facilitators to accessing rehabilitation.

This study focused on one rural area in South Africa. Understanding the context in which people with specific disabilities face barriers to access rehabilitation is fundamental, in that societies create their own healthcare systems and how they are shaped, in their structure, process and expected outcomes, entirely depend on what each society defines as relevant, meaningful, approachable and sustainable (Cabieses & Bird, 2014, p. 856). Relevant and contextually appropriate interventions can only be developed if local conditions and optimal use of local resources are taken into consideration (Braathen, Vergunst, Mji, Mannan, & Swartz, 2013). As Neille and Penn (2015) concur, understanding both the context and culture is fundamental to the development of appropriate interventions that address the needs of people living with disabilities in rural communities.

## **6.4 Recommendations**

Target specific interventions and programmes need to be created and implemented with reference to rural contexts. To reduce the impact of lower-limb amputations, the co-morbidities related to the cause of amputations need to be reduced. This may be successfully done by educating patients on self-screening for lower-limb foot complications and early signs of infection, preventative measures of foot injuries, as well as regular hypertension and diabetes mellitus screening at local facilities. Due to the findings of this study, gender-specific education is required to prevent the increase in lower-limb amputations in men. Due to poverty and the lack of transportation, services should be decentralised to allow for better accessibility of rehabilitation services for persons with lower-limb amputations. Community-based rehabilitation programmes and home visits should be initiated by rural healthcare providers. Barriers may be reduced by the involvement of relevant stakeholders such as the DOH, local municipalities, the government, etc. Healthcare workers and physiotherapists should also reduce some of the barriers identified by providing better-informed and holistic management of the patient, providing patient education, being more aware of the patient's financial status and transportation problems ó thereby either referring the patient to the nearby clinic or providing the patient with a suitable return date at their convenience. Physiotherapists can also assist in motivation and education of the patient on factors such as pain and lack of functionality due to an amputation, as well as the importance and relevance of rehabilitation to mitigate these factors. This will encourage patients to access rehabilitation facilities to improve quality of life. Facilitators can be enhanced by family-assisted group therapy sessions, whereby therapists involve the family members in the rehabilitation process to advise them on how to assist the patient. Health professionals must be educated on the facilitators of persons with lower-limb amputation access to rehabilitation, in order to enhance the outcomes. Therapists can then make departmental environment and staff changes to improve accessibility.

## **6.5 Conclusion**

This study provides preliminary evidence on rehabilitation accessibility by people with lower-limb amputations residing in the rural iLembe district of Kwa-Zulu Natal. It was undertaken to contribute to the evidence base on disability in the country, and to help inform discussions on the policies and practices of those working in rural areas.

The high prevalence of lower-limb amputations in the iLembe district is cause for concern. This is due to the vast majority of persons with lower-limb amputations having diabetes and hypertension which influenced the amputation. Diabetic-related gangrene was the most common cause of lower-limb amputations in this region, with men having a higher number of lower-limb amputations as compared to women. This highlights the need for ongoing education and disability prevention programmes to be enhanced in rural regions.

The barriers affecting utilisation of rehabilitation services in rural regions of Kwa-Zulu Natal included: financial constraints, lack of independence, accessibility, lack of transport, environmental barriers, lack of information and impairments. These identified barriers need to be reduced significantly in order to improve functionality and, essentially, quality of life of persons with lower-limb amputations. To increase access for persons with lower-limb amputations in the iLembe district to rehabilitation services, these services need to increase proportionally, and a policy should be implemented for financial compensation to enable those persons to afford transportation to the rehabilitation centre. Facilitators that were identified in assisting persons with lower-limb amputations in accessing rehabilitation in rural regions were self-motivation, referral systems, accessibility and family support. The policies developed in accordance with the Convention on the Rights of Persons with Disabilities need to be further implemented, to decrease existing barriers to access to general healthcare and rehabilitation and prosthetic services for persons with disabilities in the iLembe district.

Several recommendations on how to enhance access to rehabilitation for people with lower-limb amputations have emerged from this study. It is crucial for health and disability administrators to work collaboratively, particularly appropriate government sectors, the Department of Health and local municipalities, in order to strengthen each other's services and systems and ensure that affordable and appropriate services are available to people with lower-limb amputations. In addition, disability-related data must be systematically and routinely collected as part of the health information system in order to better understand the needs and health-seeking behaviours of people with disability, particularly people living in rural regions with lower-limb amputations. This is to ensure that disability programmes and services are meeting their goals and to provide an evidence base for advocacy. Also, the capacity of healthcare services providers needs to be enhanced to engage better with people with lower-limb amputations with training needs assessments. Finally, people with lower-limb amputations need to be made aware of and meaningfully engaged in issues and processes that affect them.

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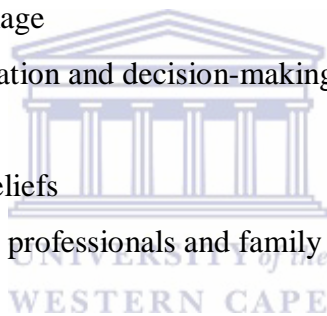
## APPENDIX 2: SELF-DEVELOPED SEMI-STRUCTURED INTERVIEW GUIDE

- 1) Do you experience difficulties accessing rehabilitation services in your area?
  - What are those difficulties?
- 2) What helps you access rehabilitation services in your area?

### Probing Questions:

- Finance
  - Do you receive a disability grant
  - How much is the grant
  - Who do you need to support
  - How much does it cost to attend a healthcare facility
  - Do you need to pay for an extra person
- Distance
  - How far is the nearest healthcare facility
  - How do you get to the nearest healthcare facility
  - How do you get to the nearest transport available
  - How far do you stay from the main road
  - Type of terrain to get to the healthcare facility
- Family
  - How many family members do you live with
  - Do you have someone to assist you daily
  - Does someone attend rehabilitation services with you
  - Do you need assistance? With what
  - Who is the bread winner
  - Do they support and motivate you to attend rehabilitation
  - Assistance with ADLs
  - Home terrain/building ó exiting the house
- Education
  - Highest level of education
  - Information given by healthcare professionals
  - Do you know where is the rehabilitation department
  - Employment: current and previous
  - Do you know what rehabilitation entails

- Assistive devices
  - Did you receive an assistive device
  - Where did you receive an assistive device
  - Type of assistive device
  - Is it adequate for the terrain in the area
  - Ability to walk with assistive device to attend rehabilitation
- Rehabilitation
  - Where you referred
  - Who referred you
  - In-patient and out-patient rehabilitation
  - Continuation of rehabilitation ó contributing factors
  - Assistance attending rehabilitation
  - Healthcare professional attitude and approach
  - Proper signage
  - Communication and decision-making
- Motivation
  - Cultural beliefs
  - Healthcare professionals and family motivation
  - Stigma
- Transport:
  - Cost to travel to a healthcare facility
  - Additional payment for an assistive device
  - How many modes of transport taken
  - Public or private transport? Reasons?
  - Accessibility of the transport
  - Assistance needed to use transport
  - Availability of transport



## APPENDIX 3: INFORMATION AND INFORMED CONSENT



### UNIVERSITY OF THE WESTERN CAPE

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#### INFORMATION SHEET

**Project Title:** Barriers and facilitators to utilization of rehabilitation services amongst persons with lower limb amputations in a rural community in Kwa-Zulu Natal.

**What is this study about?**

This is a research project being conducted by Miss Ugendrie Naidoo, from the University of the Western Cape. We are inviting you to participate in this research project because you are a suitable candidate for this research project. The purpose of this research project is to explore the perceived barriers and facilitators to utilization of rehabilitation services amongst persons with lower limb amputations residing in a rural community in Kwa-Zulu Natal.

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

You will be asked to participate in a semi-structured interview and discuss your perceived experiences in utilizing rehabilitation services at your nearest healthcare facility. These semi-structured interviews will take place at the local hospital or at your most convenient location and the duration of the discussion would be no longer than 90 minutes. The researcher will explain the research topic to you and you would be asked to thereafter discuss how you feel and what you experience in relation to the topic. Further prompting will be given as the discussion continues to allow you to examine related avenues and explore the topic more in-depth.

**Would my participation in this study be kept confidential?**

We will do our best to keep your personal information confidential. To help protect your confidentiality, identification codes will be used on data forms, only the researcher and supervisor will have access to raw data collected, all data will be kept on a password protected computer and audiotapes will be locked in the researcher's safe. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

**Audio taping**

This research project involves making audiotapes of the entire focus group discussion as the research would need to transcribe the data collected from the discussion word for word (transcribe verbatim). Only the researcher and the supervisor will have access to this raw data. All audiotapes will be stored in a locked safe.

- I agree to be [videotaped/audiotaped/photographed] during my participation in this study..
- I do not agree to be [videotaped/audiotaped/photographed] during my participation in this study..

What are the risks of this research? ..

There are no known risks associated with participating in this research project. ..

What are the benefits of this research? ..

This research is not designed to help you personally, but the results may help the investigator learn more about the barriers and facilitators which persons with lower limb amputations experience in rural communities with utilization and accessibility of rehabilitation services. We hope that, in the future, other people might benefit from this study through improved understanding of these barriers which can be reduced, thereby reducing disability and improving quality of life for persons with a lower limb amputation. ..

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. ..

Is any assistance available if I am negatively affected by participating in this study? ..

If any participants become emotional or psychologically affected by speaking about the topic at hand, they will be referred for counselling or referral of care. ..

What if I have questions? ..

This research is being conducted by Ugendrie Naidoo, Physiotherapy Department at the University of the Western Cape. If you have any questions about the research study itself, please contact the researcher Ugendrie Naidoo at 084 474 5002 or [ugendrie\\_aidoo@yahoo.com](mailto:ugendrie_aidoo@yahoo.com). ..

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

Head of Department: ..  
021 959 2542 ..

Dean of the Faculty of Community and Health Sciences: ..  
University of the Western Cape ..  
Private Bag X17 ..  
Bellville 7535 ..

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



## UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa.  
Tel: +27 21-959, Fax: 27 21-959  
E-mail:

### CONSENT FORM.

**Title of Research Project: Barriers and facilitators to utilization of rehabilitation services amongst persons with lower limb amputation in a rural community in Kwa-Zulu Natal.**

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

Participant's name.....

Participant's signature.....

Witness.....

Date.....

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

**Study Coordinator's Name: Ugendrie Naidoo.**

**Cell: 084 474 5002.**

**Email: ugendrie\_naidoo@yahoo.com.**

**APPENDIX 4: PERMISSION FROM THE UNIVERSITY OF THE WESTERN CAPE  
SENATE HIGHER DEGREE COMMITTEE**



**UNIVERSITY of the  
WESTERN CAPE**

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

09 September 2014

**To Whom It May Concern**

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:  
Ms U Naidoo (Physiotherapy)

**Research Project:** Barriers and facilitators to utilization of rehabilitation services amongst lower limb amputees in a rural community in Kwazulu-Natal.

**Registration no:** 14/7/14

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

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 'Josias'.

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

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





## APPENDIX 5: PERMISSION FROM THE DEPARTMENT OF HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT SUB-COMPONENT



health

Department:  
Health  
PROVINCE OF KWAZULU-NATAL

Health Research & Knowledge Management sub-component  
10 – 103 Natalia Building, 330 Langalibalele Street  
Private Bag x9051  
Pietermaritzburg  
3200  
Tel.: 033 – 3953189  
Fax.: 033 – 394 3782  
Email.: [hrkm@kznhealth.gov.za](mailto:hrkm@kznhealth.gov.za)  
[www.kznhealth.gov.za](http://www.kznhealth.gov.za)

Reference : HRKM 030/15  
NHRD: KZ\_2015RP53\_440  
Enquiries : Mr X Xaba  
Tel : 033 – 395 2805

Dear Ms U Naidoo

**Subject: Approval of a Research Proposal**

1. The research proposal titled 'Barriers and facilitators to utilization of rehabilitation services amongst lower limb amputees in a rural community in kwa Zulu Natal' was reviewed by the KwaZulu-Natal Department of Health.

The proposal is hereby **approved** for research to be undertaken at Montebello, Stanger, Untunjambili and Umphumulo.

2. You are requested to take note of the following:
  - a. Make the necessary arrangement with the identified facility before commencing with your research project.
  - b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200 and e-mail an electronic copy to [hrkm@kznhealth.gov.za](mailto:hrkm@kznhealth.gov.za)

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

**Dr E Lutge**

Chairperson, Health Research Committee

Date: 23/02/15

uMnyango Wezempilo . Departement van Gesondheid

*Fighting Disease, Fighting Poverty, Giving Hope*

**APPENDIX 6: PERMISSION FROM THE DEPARTMENT OF HEALTH ILEMBE  
DISTRICT MANAGERS OFFICE**



health

Department:  
Health  
PROVINCE OF KWAZULU-NATAL

**ILEMBE HEALTH DISTRICT/DISTRICT MANAGERS  
OFFICE**

Private Bag x 10620  
KwaDukuza 4450  
King Shaka Centre, 1 on King Shaka building  
2nd Floor, Room 66 KwaDukuza 4450  
Email: melusi.ndaba@kznhealth.gov.za

Enquiries: Miss T O Thwaia  
Date: 28 January 2015

Miss U Naidoo  
Private Bag X 17  
Bellville  
7535

Dear Miss Naidoo


**RE: PERMISSION TO CONDUCT A RESEARCH: BARRIERS AND FACILITATORS  
TO UTILIZATION OF REHABILITATION SERVICES AMONGST LOWER LIMB  
AMPUTEES IN A RURAL COMMUNITY IN KWAZULU NATAL**

I have pleasure in informing you that permission has been granted to you by the District Office to conduct your research: Barriers and facilitators to utilization of rehabilitation services amongst lower limb amputees in a rural community in KwaZulu Natal.

Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This study will commence once this Office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Please ensure this Office is informed before you commence your research.
4. The District Office / Facilities will not provide any resources for this research.
5. You will be expected to provide feedback on your findings to the District Office and the hospitals selected for the research.

Thank you

  
Mr. C.M Ndaba  
Acting District Manager  
Ilembe Health District

## APPENDIX 7: LETTER FROM THE EDITOR

*This is to confirm that the proofreading and editing of the Master of Science in the Department of Physiotherapy thesis:*

**BARRIERS AND FACILITATORS TO UTILISATION OF REHABILITATION SERVICES AMONGST PERSONS WITH LOWER-LIMB AMPUTATIONS IN A RURAL COMMUNITY IN KWA-ZULU NATAL**

By Ugendrie Naidoo

A thesis submitted in partial fulfilment of the requirements for the degree of Masters of Science in the Department of Physiotherapy, University of the Western Cape (UWC) was completed by Jenny Mostert in April 2017.

*I have a Masters Degree in Education; in 2004 I completed John Linnegar's Training Course in Copy Editing and Proofreading; and in 2012 I completed John Linnegar's Advanced Training Course in Copy Editing and Proofreading. I have since worked in the field of school textbooks, journals, magazine and book articles, university theses and doctorates. I am a full member of PEG (Professional Editors' Guild).*

Part-time proofreader and editor



Jenny Mostert

Address: 28 The Crescent

Dreyersdal Farm Road

Bergvliet 7945

Cape Town

Email: [jennymostertza@gmail.com](mailto:jennymostertza@gmail.com)

Tel: 021-7122784 or 0837843311