

**UNIVERSITY OF THE WESTERN CAPE**

**Faculty of Community and Health Sciences**

**MASTER THESIS**

**Participation restrictions and vocational needs amongst persons with a lower limb  
amputation in Cape Town, South Africa**

**Student Name:**

**Yu Tak Wing**

**Student Number:**

**304 5 231**

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**Department:**

**Department of Physiotherapy**

**Supervisor:**

**Dr. Liezel Ennion**

**Co-supervisor:**

**Prof. Julie Phillips**

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**Keywords: Participation restriction, vocational rehabilitation, lower limb amputation.**

## DECLARATION

I hereby declare that “**Participation restrictions and vocational needs amongst persons with a lower limb amputation in Cape Town, South Africa**” is my own work, that is has not been submitted, or part of it, for any degree of examination at any other university, and that all sources I have used or quoted have been indicated and acknowledged by means of complete references.

Tak Wing Yu

Signature: 廣德宇

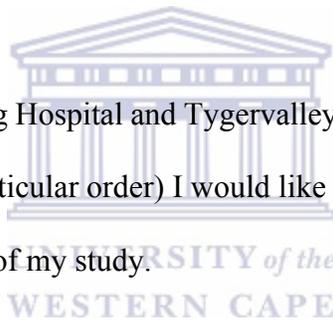


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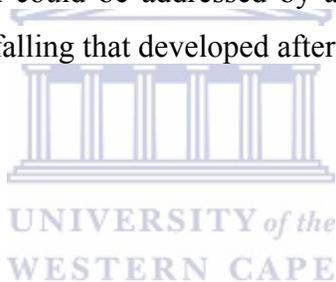
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Thank you!

## ABSTRACT

Vocational rehabilitation relates to rehabilitating a person with an amputation back into actively participating in society. Although vocational rehabilitation is important, before it can be implemented, the participation restrictions should be identified. Even though lower limb amputation surgery is commonly performed in South Africa, and given the high unemployment rate in the country, no research has been done into the participation restrictions and vocational needs of a person with a unilateral lower limb amputation in the Western Cape. The aim of this study was to determine and explore the participation restrictions and vocational rehabilitation needs in terms of hobbies, sport activities, employment and employment needs of persons with a unilateral lower limb amputation (LLA) in the Western Cape. The objectives were to: 1) Determine the participation restrictions of persons with a unilateral LLA in the Western Cape. 2) To explore the vocational rehabilitation needs of persons with a lower limb amputation. A mixed methods approach, and an explanatory sequential design was used in this study. The study was conducted in two phases. The first phase utilised a quantitative approach and the WHODAS 2.0 was used as the instrument to collect data. The second phase aimed to explain the data collected in the first phase in more depth, and semi-structured telephonic interviews were utilized to collect the qualitative data. The study was set in the Cape Metropole region of the Western Cape. Participants were recruited from Tygerberg Tertiary Hospital and a private sub-acute rehabilitation centre. In the quantitative (first) phase of the study, 50 participants were conveniently recruited to participate. In the second phase eight participants were purposefully selected from the pool of 50 participants from the first phase of the study who consented to participate in the second phase. Quantitative data was analysed using SPSS vs. 22 and analysed for descriptive and inferential statistics. Qualitative data has been analysed using Creswell's seven step process of thematic analysis. Ethical clearance has been obtained from the University of the Western Cape, permission to access patients' details has been obtained from Tygerberg Tertiary Hospital and private sub-acute rehabilitation centre. Written informed consent as well as permission for audio recording during the telephonic interview was obtained. An information sheet with explicit information regarding the aims and objectives for the study, their right to withdraw at any time without negatively affecting them, as well as any possible risks were provided. Candidates' identities were kept confidential, but they were not anonymous, as the participants were contacted for the selection of the interviews. In the demographic section of

the study, 52% (n = 26) suffered a trans-tibial amputation, 14% (n =7) had a prosthesis and only 8% (n = 4) of the participants were employed. In this study, 75% (n = 35) of the total participants had moderate to extreme difficulty with standing for a long period of time. In addition, 92% (n=46) of the participants struggled with long distance walking. Approximately half of the participants (52%) struggled with doing their household tasks. The majority of participants in this study 92% (n=46) were either retired, went to school or did not complete this section, which limited the potential to explore vocational needs relating to employment. Participants reported a lack of vocational rehabilitation, and felt that the rehabilitation that they received in hospital was not sufficient for them to function independently and participate fully in society. In conclusion, participants' difficulty in mobilising independently negatively affected their participation in society and vocational activities such as work, hobbies, employment and sport. The main restrictions reported were difficulty with standing and walking long distances. The underlying reasons reported which could be addressed by adequate rehabilitation was poor balance, endurance and the fear of falling that developed after the amputation.



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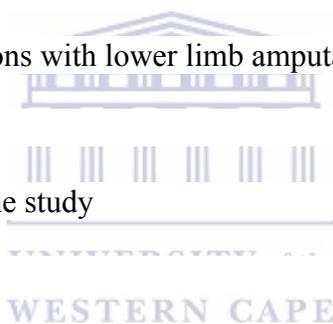
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## ABBREVIATIONS

ICF:	International Classification of Function, Disability and Health
PSF:	Paul Steyl Foundation
TBH:	Tygerberg Hospital
DM:	Diabetes mellitus
WHO:	World Health Organization
WHODAS:	World Health Organization Disability Assessment Schedule
LLA:	Lower Limb Amputation
ULA:	Upper Limb Amputation
QOL:	Qualitative of Life
ADL:	Activity of Daily Living
PR:	Participation Restriction
AL:	Activity Limitation
HD:	High Difficulty
LD:	Low Difficulty
MD:	Missing Data
IDF:	International Diabetes Federation
MDT:	Multi-Disciplinary Team
ICC:	Intra-class correlation coefficients

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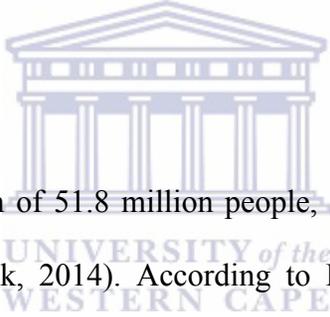
# CHAPTER ONE

## INTRODUCTION

### 1.1 INTRODUCTION

This chapter describes the problem of disability and the impact of lower limb amputations on an individual's ability to return to work and participation in vocational activities. It further outlines the overall aim and specific objectives of the study. The chapter ends with an outline of the thesis.

### 1.2 BACKGROUND

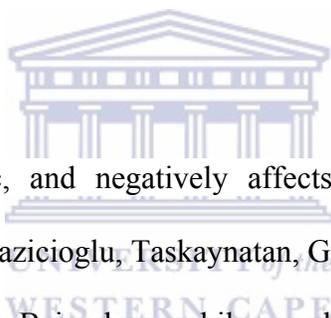


South Africa has a total population of 51.8 million people, of which 25% of the economically active is unemployed (World Bank, 2014). According to Lehohla (2014), 7.5% of the total population in South Africa suffers from some kind of disability. Considering that poverty predisposes disability and disability places increased financial demands on the person with a disability, vocational rehabilitation should be a priority in South Africa.

The loss of a lower limb has a significant impact on the ability of an individual to return to work or participate in previous leisure activities (Burger and Marincek, 2009). Only 66% of individuals with a unilateral amputation return to work after their amputation surgery. Of the few that do return to work, only approximately 22% remain in the same occupation (Burger and Marincek (2009).

There are numerous factors that affect the person with an amputation's ability to return to work. According to the WHO (2001), these factors can be classified into demographics (gender, age and educational factors), impairment and disability factors (level of amputation, morbidity and prosthesis) and work-related factors (which includes salary, support from the implementing body and employment).

Diabetes mellitus is one of the most common diseases in South Africa. According to the International Diabetes Federation (IDF) (2014) 8.4% of South Africans has diabetes mellitus. DM is also one of the major causes of a lower limb amputation (Ziegler-Graham, MacKenzie, Ephraim, Trivison and Brookmeyer, 2008).



The loss of a limb is traumatic, and negatively affects the patient both physically and psychologically (Lehohla, 2011; Yazicioglu, Taskaynatan, Guzelkucuk and Tugcu, 2007). Limb loss also affects a person's mobility. Being less mobile can change the ability of the individual to cope with the demands of their previous employment and their ability to reintegrate back into the community (Manini, 2011).

Psychologically, the loss of a limb can cause depression, stress and anxiety (Lehohla, 2011; Yazicioglu et al., 2007). Lehohla (2011) and Yazicioglu et al., (2007) noted that amputation not only causes a change of body image, but also a burden of extra expenses due to medical complications. Shamir (1986) stated that not being able to work or participate in society's leisure activities has a major impact on a person's self-esteem. Working and being a part of a community gives a sense of meaning to one's life (Shamir, 1986). Shamir (1986) continues to state that people

who are unemployed generally have a lower-self-esteem, damaged ego, loss of self-worth, loss of self-respect and a lack of confidence. Unemployment can result in a loss of social status and feelings of inferiority (Lehohla, 2011).

Apart from unemployment, barriers in participating in previous activities, such as sports and hobbies, are other commonly known challenges following the loss of a limb. The inability to participate in sport and active exercise magnifies the feelings of loss and depression (Lehohla, 2011).

Rehabilitation is a long process, and according to Esquenazi and DiGiacomo (2001), there are nine steps to rehabilitating a patient before, during and after amputation surgery. Vocational rehabilitation is one of these nine steps. Vocational rehabilitation is essential for reintegration of persons with lower limb amputations into society, and becoming economically productive again. Even though some international studies have highlighted the importance of vocational rehabilitation for the successful reintegration of persons with lower limb amputation in society, there is limited research on this topic internationally and in South Africa. Considering that vocational rehabilitation is also aimed at assisting people to become economically productive, the importance of such studies should be viewed in relation to the already dire socio-economic conditions and high unemployment rate in South Africa.

### **1.3 RATIONALE FOR THE STUDY**

According to the knowledge of the researchers, there are currently no studies focusing on the participation restrictions and vocational needs of persons with a lower limb amputation in the

Western Cape or South Africa. It is therefore crucial to understand and explore the participation restrictions and vocational rehabilitation needs of a person with a lower limb amputation in order to holistically manage the patient. This information could be gathered and used to create a more holistic approach to rehabilitation programmes. Even though most persons receive some acute rehabilitation following lower limb amputation, there are currently no standardized guidelines informing therapists on vocational rehabilitation for this population.

#### **1.4 PROBLEM STATEMENT**

International studies have highlighted the importance of vocational rehabilitation for the successful reintegration of persons with a unilateral lower limb amputation into society. Vocational rehabilitation is also vital in order to return to work and becoming economically productive again. In order to inform an appropriate vocational rehabilitation strategy or programme, the participation restrictions and vocational needs of persons with a unilateral lower limb amputation in their specific context has to be established. Currently there is limited research on the topic internationally and no research providing insight into the participation restrictions experienced and vocational needs of persons with a lower limb amputation in South Africa.

#### **1.5 RESEARCH QUESTIONS**

1. What are the participation restrictions that a person with a unilateral lower limb amputation experience?
2. Are there any differences between the participation restrictions experienced by persons with trans-tibial and trans-femoral amputations?

3. Are there any differences between the participation restrictions experienced by prosthetic and non-prosthetic users?
4. What does the person with a unilateral lower limb amputation require for them to reintegrate back into society?

## **1.6 STUDY AIM AND OBJECTIVES**

The aim of the study is to determine and explain the participation restrictions and vocational rehabilitation needs amongst persons with a unilateral lower limb amputation (LLA) in Cape Town, South Africa.

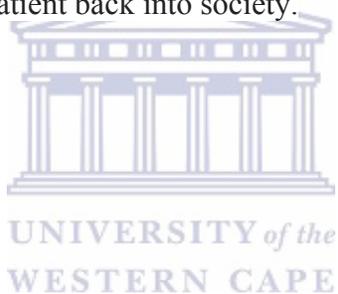


The objectives of the study are:

1. To determine the participation restrictions of persons with unilateral lower limb amputation in Cape Town, South Africa.
2. To determine and describe:
  - 2.1 Any relationships between level of amputation and severity of participations restrictions.
  - 2.2 Any differences between participations restrictions of prosthetic and non-prosthetic users.
  - 2.3 To determine and describe the factors associated with severity of participation restriction?
3. To explore the vocational rehabilitation needs of person with unilateral lower limb amputation in terms of hobbies, sport activities and employment.

## **1.7 SIGNIFICANCE OF THE STUDY**

Considering that poverty pre-disposes disability, and disability places increased financial demands on the person with a disability, vocational rehabilitation should be a priority in South Africa. Identifying the participation restrictions that a person with a unilateral lower limb amputation would suffer from, and their vocational needs, would assist therapists in planning and providing appropriate vocational rehabilitation. Internationally, amputation rehabilitation has been well studied, but in South Africa, not much research has been done in this field. This study explores and assesses the different participation restrictions. This study will highlight some of the barriers that our participants faced in participation in community and vocational activities. The results of this study will assist to inform health professionals on what rehabilitation is needed from the patient's perspectives before discharging a patient back into society.



## 1.8 DEFINITION OF TERMS

**Amputation:** is defined as a complete loss or removal of any part of limb for any reason (Malawer & Sugarbaker, 2001).

**Disability:** is a complex term, could be defined as the interaction between the individual with an impairment or health condition and their personal and environmental factors (WHO, 2001).

**Impairment:** Dysfunction with physiological or psychological function (WHO, 2001).

**Activity limitation:** The difficulty of the individual in executing life activity, such as activity of daily living (WHO, 2001).

**Participation restriction:** Defined as the problem of an individual in an involvement in an in-life situation, such as at school or in the community (WHO, 2007).

**Sport participation:** is defined as a physical exertion whether with or without competition or game elements, with a duration of no less than half an hour, where physical endurance and skills or techniques are either to be improved or is required (Bragaru et al., 2013 and Kars et al., 2009).

**International Classification of Function, Disability and Health:** It is also a common language for functioning, A framework in assessing health and function (WHO, 2007).

**Vocational Rehabilitation:** It is activities and curriculums that focuses on preparation for employment, hobbies and sport (WHO, 2007).

## **1.9 OUTLINE OF THE THESIS**

Chapter One – Introduction: In this chapter the background to the study, and the challenges that persons with disabilities experience in daily life were described. It was followed by an overview of the research questions, study aim and objectives that guided the data collection for this study. Lastly the significance of the study and need for more research in this field were highlighted.

Chapter Two – Literature Review: The epidemiology of lower limb amputations and disability internationally and nationally, causes of lower limb amputation, disability and poverty, barriers experienced by persons with disabilities, quality of life, social participation, rehabilitation process and sport participation are explored in this chapter. This chapter also describes the conceptual framework that was used in this study, and justifies the applicability of the International Classification of Function, Disability and Health (ICF) to the study's aims.

Chapter Three – Methodology: In this chapter the study setting was discussed. The institute involved in the study was mentioned. Research design, reason for selecting the design and why it was appropriate for the study was listed. The population sampling strategy and sample size was stated and determined using Yamane's formula as a guideline. Furthermore, instruments used for data collection and methods of data collection and data analysis is outlined.

Chapter Four – Results and Data Analysis: This chapter presents the findings of the data collected from the WHODAS 2.0 survey and the telephonic interviews. It outlines the major findings of the study and highlights the important sections related to the objectives.

Chapter Five – Discussion: In Chapter five, the results of the two phases of the study is integrated and contextualised within the global literature. Possible explanations for findings, and their clinical implications are discussed, and explored in more depth.

Chapter Six – Conclusion, Challenges and Recommendations: The thesis is concluded by summarising the most important findings of the study and recommendations are made based on these results. The limitations of the study findings and challenges faced during the study are also discussed in this chapter.

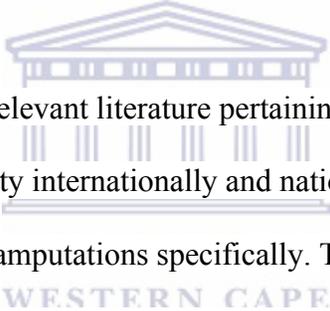


# CHAPTER TWO

## LITERATURE REVIEW

In this section, the epidemiology of persons with unilateral lower limb amputation will be discussed and explored. The topic related to disability (internationally and nationally) will be covered. This will be followed by barriers, quality of life, social participation, rehabilitation process and sport participation.

### 2.1 INTRODUCTION



In this chapter, an overview of the relevant literature pertaining to the topic will be provided. Firstly, the epidemiology of disability internationally and nationally will be presented, followed by the epidemiology of lower limb amputations specifically. The common causes of lower limb loss will be discussed. The influence of poverty on disability will be highlighted and the challenges experienced by persons with disabilities will follow. Lastly, the potential positive influence of rehabilitation on these challenges will be reviewed. The chapter also outlines the conceptual framework used for the study.

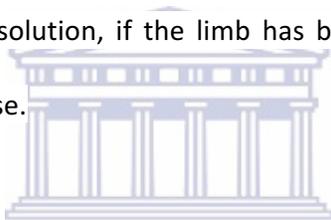
### 2.2 EPIDEMIOLOGY OF DISABILITY INTERNATIONALLY AND NATIONALLY

The World Health Organization, Disability and Health (2015) stated that about 15% of the world's population suffer from some kind of disability, with the numbers varying between 110 million (2.2%) and 190 million (3.8%). The WHO (2015) further states that there is a gradual rate of increase in disabilities globally due to population aging and increases in the amount of chronic

health issues. With a total of 51.8 million people in South Africa, 7.5% of the total population suffers from some form of disability (World Bank, 2014). Of the total population of persons with disabilities, 12.9% reside in the Western Cape.

### **2.3 EPIDEMIOLOGY OF LOWER LIMB AMPUTATION**

The majority (86.4%) of amputations are performed on the lower limb in the northwest of Tanzania (Phillipo, et al., 2012). The increase in the number of lower limb amputations performed in South Africa can largely be attributed to the increase in the incidence of Diabetes Mellitus (DM) and its resultant complications (Moses, Julius, and Sarah, 2010). According to Fredericks and Visagie (2013) amputation is sometimes the only solution, if the limb has been damaged through DM, trauma, tumors, infection and vascular disease.



The Global Lower Extremity Amputation Study Group (2000) did a study on the epidemiology of lower limb amputation in East Asia, Europe and North America, and determined that the global incidence rates varied between 2.8 to 43.9 per 100 000. In a more recent review of the global incidence of lower limb amputations, Moxey et al. (2011) reported a variance of 5.8 – 31 per 100 000 of the total population. Dillon, Kohler and Peeva (2014) mentioned that Australia's amputation incidence has not experienced a major change over the past ten years (2000 – 2010). Similarly, in the Netherlands, the rates of amputations did not experience major changes over the past ten years (Fortington et al., 2013). Fortington, Rommers, Postema, van Netten, Geertzen and Dijkstra (2013) continued that (of all ages) 8.8 per 100 000 people and for patients 45 years old and older it was reported that 23.6 per 100 000 people were affected in 2013. According to Ziegler-Graham, et al.

(2008), nearly two million people in America are living with an amputation, and approximately 185 000 new amputations are performed every year.

## **2.4 COMMON CAUSES OF LOWER LIMB AMPUTATION**

Diabetes mellitus (DM) is the most common cause of lower limb amputation globally (Fredericks and Visagie, 2013). Other common causes include: trauma, vascular diseases, tumors, congenital disorders, infection and other minor causes (Feinglass, Shiverly, Martin, Huang, Soriano, Rodriguez and Gordon., 2012) There is a marked difference in the causes of lower limb amputations between developed and developing countries (Phillipo et al., 2012). Traditionally, the most common causes of lower limb amputation in developed countries were dysvascular causes such as peripheral vascular disease and DM (Feinglass et al., 2012; Johannesson, et al., 2009), while in developing countries it was trauma, cancer and congenital deformities (Abbas & Musa, 2007; Awori & Ating'a, 2007; Thanni & Tade, 2007). This is, however, changing fast with the increasing incidence of DM in developing countries (Abbas and Musa, 2007). Currently there is no information relating to the causes of lower limb amputation in South Africa.

Results from Ziegler-Graham, et al. (2008), show that in America, 25 per 100 000 people suffer from diabetes. According to Moses et al. (2010), in Sub-Saharan Africa, a large number of amputations due to diabetes can be expected. Furthermore, Moses, et al. (2010) explained that there is no data listing the number of diabetic amputations performed in rural populations. In other parts of Africa, North-Western Tanzania, it was noted that the most common causes of lower limb amputation were: diabetic foot (41.9%), trauma (38.4%) and peripheral vascular diseases (8.6%) (Moses et al., 2010).

The International Diabetes Federation (IDF) (2014) stated that 8.4% of the total population in South Africa suffer from DM. Diabetes is not only a major cause of lower limb amputations, but according to Ziegler-Graham et al. (2008), it is a significant pre-disposing risk factor for re-amputation within two to three years of initial amputation.

Once a patient is diagnosed with DM, regardless if the patient is diagnosed with Type One or Type Two, they are prone to certain complications. These complications could include ulcer formation, which, if not taken care of, can eventually result in an amputation. According to IDF (2014), nearly two million people in South Africa suffer from DM. The two million people exclude those that are undiagnosed with DM, therefore the number of DM in South Africa could be even higher, as according to IDF (2014), about 50% of Africans has DM, but are undiagnosed.

According to Moses et al. (2010), in developed countries, most vascular amputations occur in individuals older than 65 years old. They also found that males were more prone to vascular amputation when compared to females (aged below 60), but for patients above the age of 60, the ratio was 1:1. In Africa, cardiovascular disease and diabetes are the major causes of the morbidity in elderly people. Diabetic vasculopathy coupled with infection caused the most amputations in elderly males. The number of vascular amputations will thus increase as the population ages.

In other countries such as Trinidad and the Caribbean Islands, diabetic foot complications were the main cause of lower limb amputations (Moses et al., 2010).

## 2.5 DISABILITY AND POVERTY

Emmett, Watermeyer, Swatz, Lorenzo & Priestley (2006) speak about the disability-poverty cycle; this explains the struggle of many developing countries, where these two elements feed on each other. Globally, people with disabilities are economically and socially excluded (Hanga, DiNitto and Leppik, 2015). Over the past decade there has been an increase in disabilities, and this is directly affecting public expenditure for medical services, and putting more financial pressure on people in poorer countries (Hanga, DiNitto and Leppik, 2015).

In 2007, 47% of South Africans lived below the poverty line (Arntz, 2011). A person would be classified as living below the poverty line if the total household income was below R322.00 per month (Arntz, 2011). Arntz (2011) also stated that 25.7% of South Africans who should be employed are unemployed, indicating a very high unemployment rate amongst the productive workforce of the country. Within the age category of 18 – 25 years old, 2.4 million people are unemployed. The total amount of people living in poverty has decreased by 20.2%, and in the category of moderate poverty, there has been a 45.5% decrease.

The table below will show how poverty has decreased over the course of five years in extreme and moderate poverty.

Table 2.1: Illustrates the number of people living in poverty in 2011 compared to 2006.

**Table 2.1: Population Sample**

	<b>2011</b>	<b>2006</b>
Moderate poverty	23 million	27.1 million
Extreme poverty	10.2 million	12.6 million

The government also has interventions in place such as the Social Wages (National Treasury, Republic of South Africa, 2017). This social wage includes:



- Free basic primary health care
- Free basic education
- State subsidized housing
- Provision of basic services

The SAinfo report (2014) continues that approximately 60% of government spending went towards social wages in order to help those who are suffering from poverty. Emmett et al. (2006) spoke of disability, poverty, gender and race. There is a strong relationship between disability and poverty (Emmett et al., 2006), as disability is both the cause and the consequence of poverty. Poverty and disability affect each other in both ways, as both could be the cause of the other. That is because, as disability can make the patient more prone to poverty, while environment or situation that poverty creates could increase the rate of them sustaining some kind of disability. In addition to that, disability could mean unemployment, which leads to financial difficulties and eventually

leading to poverty as appropriate health care is costly. This is referred to as the poverty and disability cycle (Emmett et al., 2006).

Disability is normally associated with mental or physical impairments; these impairments hinder the capability of a person to do or complete their tasks. In Indonesia, people with a disability are seen as dependent, a burden and unproductive (Kamil and Shantini, 2015). In addition, people with disabilities are more likely to have a lower education and literacy level than the rest of the population (Kamil and Shantini, 2015). They are also less likely to have savings and/or other assets than people who do not have a disability. People with disabilities are also less likely to be homeowners compared to able-bodied people. These findings are true for both developed and developing countries.



Many factors contribute to disability, poverty is not the only impact on disability, age also plays a role (Jetha, Besen and Smith, 2016). According to Jetha et al. (2016), younger disabled persons will have a better outcome when compared to those who are older. When looking at the age groups that are mostly affected in South Africa, the demographic statistics indicate that on average, disability is most prevalent between 50-64 years old (Lehohla, 2011). According to Hoffstaedter, Grefkes, Roski, Caspers, Zilles & Eickhoff (2015), aging includes a decrease in motor and cognitive abilities. There is also a definite decline in motor performance, coordination as well as mobility. The decline in mobility is possibly related to changes in the skeleto-muscular system (Hoffstaedter et al., 2015). It is important for researchers to consider age when developing rehabilitation programmes.

The World Health Organization, Disability and Health (WHO) (2015) concludes that there are two main reasons why patients with a disability do not receive the effective treatment they need due to affordability of health care and services, and transportation. With that stated, the WHO (2015) continues further to say that in low-income countries, 32-33% of non-disabled cannot afford health care services, where 51-53% disabled persons cannot afford health care services.

## **2.6 BARRIERS EXPERIENCED BY PERSONS WITH DISABILITIES**

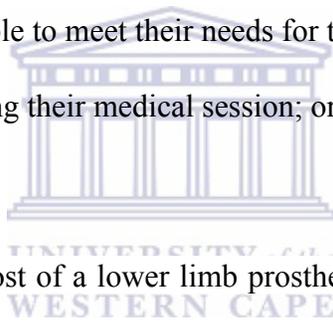
Patients with a disability face some challenges interacting with their environments. The World Health Organisation, Disability and Health (WHO) (2015) explains the different types of barriers that people with disabilities could face. One of these barriers is the increase in expenses, which they are unable to afford. In South Africa, the government does provide social wages (or disability grants) but a social wage is not nearly close to a normal income salary. Besides the financial barriers, there is also a physical barrier. Here the WHO (2015) looked at disability-friendly facilities. This includes inaccessible medical equipment, not only the ramps to different levels in a building.

The WHO (2015) speaks about another significant barrier to what is preventing access to health care services, which is the lack of appropriate services for patients with disabilities. According to the statistical report of 2015, the mid-year estimates of South Africa's population is 54 million. In comparison, the number of public health facilities in South Africa is only 4200 health care centers. At these public health care centers, patients are often discharged before any rehabilitation programs has been implemented.

Persons with mobility limitations (such as lower limb amputations and wheelchair users) suffer from numerous barriers in order for them to maintain and/or obtain employment (Martins, 2014). Many patients suffer additional limitations outdoors, and cannot fulfill their role at home for their family. This includes activities such as: doing heavy tasks at home, doing minor repairs and going on holiday with the family (Van Twillert, Stuive, Geertzen, Postema & Lettinga. 2014).

According to Van Twillert et al. (2014), when patients with a disability seek medical treatment, there is often a gap in the skills and the knowledge of the health workers. Patients with a disability reported that:

- Medical staff are often unable to meet their needs for their medical condition;
- They are treated badly during their medical session; or
- Treatment is rejected.



According to Turner (2009), the cost of a lower limb prosthetic would range from: \$5000-00 to \$50 000-00. In South Africa, on a waiting list for a prosthetic limb at a public hospital, a patient would wait at least six (6) months, on average, for a prosthetic limb, and the waiting list at public hospitals can easily exceed thousands of patients (Sayagues, 2009).

## **2.7 QUALITY OF LIFE**

Quality of life (QOL) is an important aspect to consider, as it determines the health and comfort of a person. In an older study done by Burgess et al. (1983), often the QOL of the patient can be affected by the ability to exercise naturally. It may be agreed that prosthetic usage will and does improve the patient's quality of life, as well as the ability to be rehabilitated back into society. It is important to assess and follow up on the QOL of the patient, as the QOL shows and gives an

indication of the degree of their impairment. According to the WHO (2001), there are many ways of assessing QOL in a person. The ICF and WHODAS 2.0 both assess the QOL. According to Godlwana, Stewart and Musenga (2012) persons with a lower limb amputation is commonly noticed to have a lower score in quality of life when comparing to the population norms. It was also stated by Godlwana (2012) that the mortality rate across countries are generally high. The mortality rate is 10.4% within a 30-day period. It is even higher (14.7%) with patients that is diagnosed with DM.

A person with a lower limb amputation is normally associated with isolation, anxiety and depression (Deans, McFadyen & Rowe, 2008). Amputation will not only affect the persons with a lower limb amputation physically, but is also a long-lasting social and psycho-social stress (Fredericks, 2013). Having negative long-lasting social and psycho-social stress impacts the individual's interest in hobbies and social activities (Yazicioglu et al., 2007). Amputation also changes the person's ability to be active and mobile. Van der Schans, Geertzen, Schoppen, Dijkstra (2002) said that the QOL in persons with a unilateral lower limb amputation are poor, because of physical function limitations and pain. These physical limitations will be the barriers for the person with lower limb amputation to participate in ADL and other physical exercises. In the study conducted by Van der Schans et al. (2002), their results show that patients with phantom pain have a poorer QOL, compared to those that are phantom pain-free. Persons with a lower limb amputation that experience phantom pain will thus potentially have a lower quality of life.

Besides a poor QOL, amputation also could cause a temporary or permanent decrease in mobility (Bragaru et al., 2011). Individuals with an amputation often look at themselves differently, as if

they are part of a special group (Fredericks, et al. 2013). This special group, according to the able-bodied people, requires additional attention and has special needs. These discernments add on to the high anxiety and depression rates amongst amputations, especially for the first two years' post-operation. The persons with a lower limb amputation would feel isolated and different from the rest, and this factor would hinder their willingness to participate in society. Ultimately, this results in them having difficulties to return to their everyday life and participation in society, and ultimately a worse quality of life.

It is important for rehabilitation to continue with the patient up until community participation is reached. Persons with lower limb amputation not only suffer from physical immobility, but also psychological factors that hinders their disposition to participate in society and community activities. Van Twillert et al. (2014) stated that once a patient has been discharged from their rehabilitation, that is when the patient starts to face the struggle, as the patient will go back to their previous living conditions but this time with a disability and without the help of the medical multiple-disciplinary team (MDT). Elderly patients are more affected than younger patients. Van Twillert et al. (2014) continued that possible missing information on the factors that may be affecting the outcome of the patient, and without this required information, the current rehabilitation programme will not be able to change. Once more information is available or studies are done, it can help improve rehabilitation programmes and then persons with lower limb amputation can then prepare themselves for this post-rehabilitation phase.

It is important to cover the causes of poor QOL, but the factors that contribute to a good QOL also needs to be explored. Studies have been conducted by Van Twillert et al. (2014) to identify what

factors contribute to a good QOL. In addition to what other studies have found, a recent study done by Martins (2014) stated that there are multiple components that constitute QOL. These factors include: the age of the patient, the ability of the patient to balance on the unaffected leg, cognitive impairments and co-morbidities.

The basic requirements for activities of daily living (ADL) would not be the only concern to persons with lower limb amputation, but also the quality of life that is shown in participating in recreational and sporting activities should also be focused on (Bragaru, Dekker, Geertzen and Dijkstra, 1983). In addition, Action (2013) mentions that patients with prosthetics are shown to be more positive and tend to have a better quality of life when compared to non-prosthetic users. Yazicioglu et al. (2007) also added that, with the help of a prosthesis, those candidates who are functionally capable, could nearly regain their pre-morbid functional independence. In support of this statement, Millstein, Heger and Hunter (1986) also states that training and fitting of the prosthesis is essential to having an effective rehabilitation and reintegration back into society for persons with unilateral lower limb amputation.

## **2.8 SOCIAL PARTICIPATION**

Studies have shown that if a patient/person has self-efficacy, that is a good predictor of social participation (Martins, 2014). In addition, social participation is positively related with self-efficacy and personal attitudes (Martins, 2014). In recent studies of Martins (2014), it showed that the higher the person's self-efficacy and self-confidence, the easier it is to achieve a desired goal. Having a positive attitude and self-efficacy towards disability could well improve participation, as well as the outcome of physiotherapy and occupational therapy rehabilitation. Martins (2014)

noted that it is important to have good vocational rehabilitation and education in order to have the specific skills for employment opportunities in the market, therefore increasing opportunities to gain employment, as well as the ability to maintain current employment.

In a holistic approach, there are three processes that need to be covered before good quality of rehabilitation can be implemented. Firstly, a comprehensive initial needs assessment must be done; this ensures that basic patient information is gathered and obtained. Secondly, rehabilitation services follow, which includes hospital professionals ensuring that the patient receives appropriate treatment for their condition. Lastly, referral to social rehabilitation, which includes community integration professionals, where they will assess and identify the possibility of reintegrating the patient back into their society (Hanga, DiNitto & Leppik. 2015).

Social rehabilitation is the most challenging part of the rehabilitation process, as within the first two processes, the patient would still have guidance by health professionals. The final process of Hanga et al.'s (2015) programme is to reintegrate, which means that the patients would be on their own when living in the community space. Furthermore, most patients who came for social rehabilitation assessment, have unmet health care needs rather than social rehabilitation needs. Persons with a lower limb amputation are seen as persons with a disability, and according to Kamil and Shantini (2015), they face problems of discrimination and limited access, which means there will be unmet medical needs. These needs are contributing factors to limiting the persons with lower limb amputation's ability to do housework, tasks, community and social activities and school.

In addition, Hanga et al. (2015) mentions that social rehabilitation is needed for patients with disabilities, but as indicated above, many people who seek social rehabilitation have unmet medical needs. Hanga et al. (2015) suggests that health problems are not the only issue that persons with lower limb amputations face, once the patient returns to the community there are bigger issues.

## **2.9 SPORTS PARTICIPATION OF PERSONS WITH LOWER LIMB AMPUTATION**

Participating in sports has a positive effect on a person's physiological, physical and social well-being, regardless if that person is disabled or not (Kars, Hofman, Geertzen, Pepping & Dekker 2009). Therefore, it was recommended by different health organisations that one would need to do more than 30 minutes or more of exercise per day. Individuals with a unilateral lower limb amputation tend to be less active than those without (Bragaru et al., 2011). Decreased mobility is a health risk factor that predisposes a person to cardiovascular disease (Bragaru et al., 2011). After the loss of a limb, a person with an amputation is more likely to suffer from depression and have decreased mobility. Bragaru et al. (2011) proved that regular physical activity and sport participation has a positive effect on the persons with a lower limb amputation. Similarly, according to Kars et al., (2009) participation in physical activity or sport has a positive influence on muscle force, body mass and cardio-pulmonary system of a person with lower limb amputation. In Kars et al. (2009), it stated that the time of rehabilitation was decreased when physical training was part of the rehabilitation programme. It is important for exercise, especially in persons with unilateral amputation, as the amputation and the underlying disease still persists after the amputation.

Physical activity is an important factor for a good QOL and having a healthy lifestyle. In both Bragaru et al. (2011) and Bragaru et al. (2013), one of the major health risk factors is little or no physical activity as this contributes to early death. It is therefore vital that exercise and physical activity are promoted with persons with lower limb amputations. By executing physical activity or sport participation, it plays a role of decreasing life-threatening diseases.

Health is an important aspect for QOL, in order to achieve good health, one has to exercise and participate in sports. Internationally, more than half (64%) of America's population partake in some kind of physical activity. In the population where one has some kind of disability, 56% of this population in America does not participate in any physical activity (Kars et al., 2009). Looking into other countries, percentages of persons with lower limb amputations fluctuate between 11% to 60%. This depends on which country they reside. According to Bragaru et al. (2013), the Netherlands is between 32-39%, where 56% of the Dutch individuals participate in some kind of sporting activity.

Physical exercise is important for health, yet more than half of the population who have some kind of disability does not exercise. In addition, persons with some kind of disability tend to be more inactive when compared to the general population (Bragaru et al., 2013).

Sport participation is defined as a physical exertion whether with or without competition or game elements, with a duration of no less than half an hour, where physical endurance and skills or techniques are either to be improved or is required (Bragaru et al., 2013 and Kars et al., 2009).

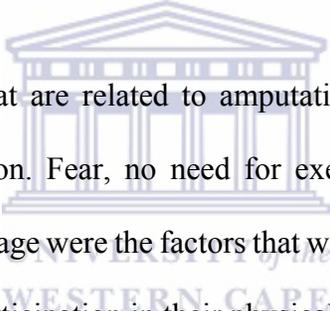
Martins (2014) stated that there are components that we could use to give ourselves a good indication of the patient's post-amputation outcome. One: those patients that can adjust and move on when unexpected events occur, generally would have a healthier, happy and active life. Two: compared to those who are negative in accepting their disabilities, they have a more difficult time accepting their appearance and changes and will lead to an unhealthy life (Martins, 2014).

Physical activity is a need, but furthermore, maintenance of the physical activity is equally important. Bragaru et al., (2011) stated that deteriorating physical state is a consequence to little or no physical exercise. Therefore, it is important to maintain physical fitness, and to do this, persons with a lower limb amputation can participate in physical activities or sport. In addition, when looking at individuals with an amputation, they in general have poor physical condition, not only because of the amputation itself, but it is also due to the illness that the person with lower limb amputation had which preceded and led to amputation (Bragaru et al., 2011).

The four most common sporting activities in person with lower limb amputation were noted by Kars et al., (2009) as: fitness, swimming, walking and cycling. Kars et al. (2009) also suggest that if an person with lower limb amputation is, or were participating in a sport before their amputation, then it's more than likely that the person with lower limb amputation would participate in a sport post-amputation.

There are sporting activities available for persons with lower limb amputations, but they are required to fulfill certain requirements before they can participate. The sporting activities include swimming, fitness, walking and cycling. To ensure the safety of the individual, it is important that

the person with a lower limb amputation is able to balance, possibly be a prosthetic user and physically fit. When exploring further, the difficulties experienced by persons with a lower limb amputation, the aspect of coordination, balance and ambulation surfaced. It is normal that balance is affected, as persons with lower limb amputation no longer have two lower limbs to balance on. According to Yazicioglu et al. (2007), they found that many person with lower limb amputation have difficulty in coordination, balance and ambulation that may result to quality of life limitations. Again, Yazicioglu et al. (2007) suggested that the main focus of rehabilitation for person with lower limb amputation should always include proprioception, coordination, increasing balance, strengthening and endurance. These components are vital in physical and sporting activities.



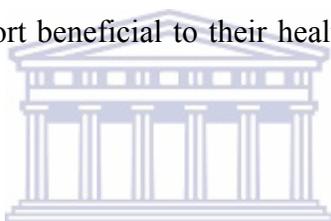
Unfortunately, there are factors that are related to amputation that affects the participation of persons with lower limb amputation. Fear, no need for exercise, no facilities, problems with prosthesis, disease, skin lesions and age were the factors that were mentioned by Kars et al., (2009). These complaints hindered their participation in their physical activity or sport. Kars et al. (2009) continued to mention that the main reasons given for participating in sports were: need to participate, good for health, social contacts, good feeling and doctors' orders.

In the recent decade, the importance of physical exercise and sport participation has been well documented. Despite the promotion of physical exercise, there is still a large section in the population that does not exercise regularly.

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Kars et al. (2009) stated those with limb amputations who participated in physical activity or sports had a higher self-esteem and quality of life when compared to those who did not participate in either. Self-esteem and quality of life plays an important role in the outcome of the person with a unilateral lower limb amputation when rehabilitating them. Sport participation represents a part of human behavior related to beliefs, attitude, personal goals and social norms (Bragaru et al., 2013). Not only is physical activity or sport beneficial to their health, but it also increased their social interaction.



In conclusion, all of the above emphasises that physical activity or sport participation is absolutely beneficial for persons with lower limb amputation in terms of their rehabilitation back in society.

## **2.10 REHABILITATION PROCESS**

Persons with a unilateral lower limb amputation will suffer from common physical impairments that include balance problems, proprioception, mobility and ambulation (Yazicioglu et al., 2007). When exploring the common psychological impairments that persons with unilateral amputation could experience, they could suffer from fear of falling, resulting in fear to move, and change in body image leading to depression.

It is expected that a person with a unilateral lower limb amputation will have decreased balance and proprioception which will negatively affect function. Proprioception plays an important role for both dynamic and static balance, as impaired proprioception affects the ability to maintain balance and to coordinate movements (Yazicioglu et al., 2007). Impaired balance in turn largely impacts the mobility of persons with a lower limb amputation. Furthermore, Yazicioglu et al., (2007) noted that fear of falling, and falling is also a problem with the person with lower limb amputation is due to poor balance. In addition, there are psychological impairments that also contribute to deterioration in muscle endurance, flexibility, strength, coordination and balance.

Recent studies have shown that 52% of persons with a unilateral lower limb amputation have fallen in the past twelve (12) months, whereas 49% of them had fears of falling within the same period (Yazicioglu et al., 2007). It is thus understandable that persons with a unilateral lower limb amputation would be fearful to move, hence psychological counselling should be included in treatment to ensure that they are psychologically adapted to their condition.

Rehabilitation is essential when referring to disability, as rehabilitation is aimed at improving function, QOL, ambulation and independency (WHO, 2001). If rehabilitation is not executed or is done poorly, it directly affects the functional outcome of people with disabilities. Rehabilitation entails not only physical rehabilitation, but also social and psychological rehabilitation (Esquenazi and DiGiacomo, 2001). Rehabilitation is an important process for persons with a unilateral lower limb amputation as they have impairments that need to be overcome before they are able to fully reintegrate back into society. It is therefore important for rehabilitation professionals to be aware and target the common impairments faced by persons with unilateral lower limb amputations. On

the contrary, if assessment of the impairments is not done, or is done poorly, the rehabilitation of the impairments will not be effective. According to Yazicioglu et al. (2007), to control and maintain balance requires a complicated chain of motor tasks, which can be addressed by rehabilitation.

Although rehabilitation can address the impairment during a therapy session, according to Soöderlund and Nordgren (2015), when a patient encounters a healthcare professional, their response is more positive. Besides the positive encounters with the health professionals, the results from these encounters were also beneficial for the patients themselves. Nearly half of participants in the Soöderlund and Nordgren (2015) study agreed that the encounters with their health professional facilitated their ability to return to work. Treatment of a patient does not always result in medical treatment. The results in the Soöderlund and Nordgren (2015) study showed that a health professional could support and aid the patient's ability to return to work by simply just believing that they can and have the ability to which shows the impact that a health professional has on a patient. On the contrary, those that have had negative encounters with their health professionals, also resulted in a negative impact on their ability to return to their daily lives and work (Soöderlund and Nordgren, 2015).

Therefore, before the rehabilitation even begins, the health professional should firstly believe and bring a positive attitude into the therapy session, as that will be able to help and boost the patient's confidence and ability to return to work (Soöderlund and Nordgren, 2015).

The health professional should secondly assess the patient's psychological and physical state so that an effective and appropriate treatment process can be put in place for the best outcome of the

rehabilitation (Martins, 2014). These process components should include the treatment of balance and proprioception issues and following up with psychological support. According to Yazicioglu et al. (2007), when patients undergo an amputation, it could cause low self-esteem, social isolation and introversion. Therefore, it is vital that psychological support must be included to prevent the patient from depression and feeling useless.

Once the assessment is thoroughly studied, the rehabilitation programme can then commence. The programme will be developed based on the findings in the assessment. According to Esquenazi and DiGiacomo (2001), there are nine steps in the rehabilitation programme for a person with a lower limb amputation. These nine phases focus on different assessments of function, planning of treatment goals and objectives.



## **2.11 CONCEPTUAL FRAMEWORK OF THE STUDY**

This study used the International Classification of Function, Disability and Health (ICF) as a conceptual framework. This framework is used to “provide standard and unified framework that describes health and health related conditions” (WHO, 2001). It is also a common language for functioning, disability and health. In this framework, not only is health defined, but also health-related issues such as education and labour. According to WHO (2001), “the ICF captures human functioning as the results of the interaction between body/person and environment, measured through activity and participation.”

The ICF emphasises the importance of a systematic and comprehensive perspective on human functioning and stresses that a holistic approach is needed. The ICF consists of two factors:

environmental factors and personal factors. Both of these factors are included in the ICF, and with the assistance of these two factors, it shows the impact not only on functional outcome but also the various interventions (WHO, 2001). Within this holistic approach, different factors should be addressed, namely: psychological, biological and socio-cultural factors (Hanga et al. 2015). In addition, the ICF framework enables the health professionals to set goals, assess their functions, plan treatment and measure different outcomes (WHO, 2015). This study used the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) as an instrument for data collection.

This study will not be focusing on all the components of the ICF, but only on participation restrictions. The WHO (2001) defines participation restriction as “a problem experienced by an individual in involvement in life situations.” The study aimed to determine and explore the barriers that the person with a lower limb amputation faces post lower limb amputation. Participation restrictions will then be further explored within the context of Esquenazi et al.’s (2004) nine phases of amputation rehabilitation, with emphasis on the vocational rehabilitation phase. Health impairment mostly affects or restricts employment and participation in hobbies and sports.

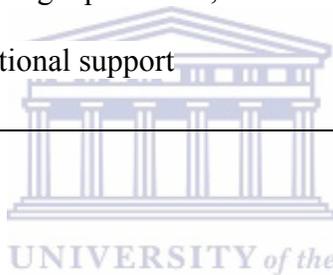
According to Escorpizo et al. (2011), vocational rehabilitation should be patient-centred and evidence-based. A further exploration of the interaction between the ICF and vocational rehabilitation is also advised, especially involving the persons with health impairments (Escorpizo et al., 2011).

According to Esquenazi and DiGiacomo (2001), there are nine steps in the rehabilitation programme for a person with a lower limb amputation. These nine phases focus on different assessments of function, planning of treatment goals and objectives.

Table 2.2: Illustrates Esquenazi and DiGiacomo’s (2001) nine steps of rehabilitation

<b>Description:</b>	<b>Nine steps in the rehabilitation programme</b>
Pre-operative rehabilitation	Medical and body condition assessment, patient education, surgical-level discussion, functional expectations, phantom limb discussion
Amputation surgery and dressing	Residual-limb length determination, myoplastic closure, soft-tissue coverage, nerve handling, rigid dressing application, limb reconstruction
Acute postsurgical rehabilitation	Wound healing, pain control, proximal body motion, emotional support, phantom limb discussion
Pre-prosthetic rehabilitation	Residual-limb shaping, shrinking, increasing muscle strength, restoring patient’s sense of control
Prosthetic prescription/fabrication	Team consensus on prosthetic prescription

Prosthetic training	Prosthetic management and training to increase wearing time and functional use
Community integration	Resumption of family and community roles; regaining emotional equilibrium; developing healthy coping strategies, recreational activities
<b>Vocational rehabilitation</b>	<b>Assessment and training for vocational activities, assessment of further education needs or job modification</b>
Follow-up	Lifelong prosthetic, functional, and medical assessment; emotional support



Vocational rehabilitation is directly related to minimising the participation restrictions endured by persons with lower limb amputations in relation to employment, hobbies and sport. In order to provide appropriate and relevant vocational rehabilitation, the therapist needs to know what the needs of the population are, and what challenges person with lower limb amputation face, in these specific areas. This study will focus on the participation restriction and vocational rehabilitation in order to develop an in-depth understanding of what needs are for persons with a lower limb amputation.

In the phase of vocational rehabilitation of persons with a unilateral lower limb amputation will be assessed in terms of difficulty experienced with certain activities such as hobbies, sport and employment, which can be contextualised within the ICF domain of participation restrictions.

## 2.12 SUMMARY OF CHAPTER

This chapter provided an overview of the relevant literature, which included the framework that has been used in this study. Related research topics covered internationally and nationally are described and explored. The methods used to collect data for the study is outlined in the next chapter.



## CHAPTER THREE

### METHODOLOGY

#### 3.1 INTRODUCTION

In this chapter, the methods used to answer the research questions are described. The study sample and sampling strategy for each phase is outlined. In addition, the data collection methods and analysis of each phase is presented. The ethics guiding the study is also described.

#### 3.2 STUDY SETTING

The study was conducted in the Cape Metropole region of the Western Cape. In this region, there are two tertiary hospital, one was Tygerberg Tertiary Hospital and another is Groote Schuur Tertiary Hospital. Permission was granted at Tygerberg Tertiary Hospital to gain access to persons with lower limb amputations. The second facility was a private sub-acute hospital that also resided in the Western Cape region. From these two facility, the snowball sampling was used to accumulate more participants.

#### 3.3 RESEARCH DESIGN

This study applied a mixed methods approach and an explanatory sequential design (Creswell, 2003). The mixed methods approach lends itself to using both quantitative and qualitative instruments in one study to have a deeper understanding of the research problem (Creswell, 2003). In mixed method studies, it also builds a bridge between the two types of research: quantitative

and qualitative, allowing for more depth of exploration than just quantitative research (Leech and Onwuegbuzie, 2006).

Creswell (2003) described the explanatory sequential design as a study method where the researcher seeks to explain, expand and elaborate on the results from one method using another method. The sequential explanatory design starts with a quantitative method where concepts and theories are tested, then followed by a qualitative method to explain and to elaborate on the few and/or individual cases. Creswell (2012) further states that the study could provide a better understanding of the research question and problems when applying both qualitative and quantitative methods, than only using one and the other methods.

Migiro and Magangi (2011) mentioned that the strengths of a mixed methods research approach are :

- The researcher is not limited to using one or the either method, the study could answer a more complete and comprehensive range of research questions.
- The weakness of either study could be overcome by the strength of another study method.
- Strong evidence is produced when using a mixed methods research.
- Better understanding is provided when using both methods of research which, if only using one or the either, could be missed.
- Mix method research results have an increased generalisability.

The mixed methods approach is the most appropriate for this study, as the participation restrictions will first be determined quantitatively, and then the underlying reasons for it and vocational rehabilitation needs will be explained qualitatively.

### 3.4 METHODS OF DATA COLLECTION

Data for the study was collected in two phases as described above. The steps followed for each phase will be described separately below:

#### 3.4.1 Quantitative phase:

##### Population and sample

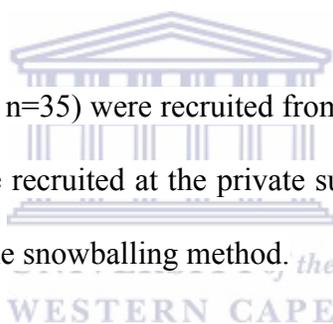
The total population of persons with lower limb amputations in the Cape Metropole is currently unknown. The Paul Steyn Foundation (PSF) is a public benefit non-profit organisation that advocates for persons with lower limb amputations which resides in the Cape Metropole region. In 2016, approximately 500 individuals were registered with the foundation. This number was used as an approximate total population size in order to determine the ideal sample size, even though it cannot be considered a true reflection of the total population of persons with a lower limb amputation in Cape Town. The Yamane formula was used as a guideline to determine the sample size needed for the study (Yamane, 1967).

- $n = N / (1 + Ne^2)$
- $n = 500 / (1 + 500 \times (0.05)^2)$
- $n = 222$

The ideal sample size was determined at 222 participants. In this study convenience sampling was used to recruit participants into the study. Convenience sampling is a non-probability

sampling strategy where participants who are accessible to the researcher is sampled (Creswell, 2012). Paul Steyn Foundation contacted the possible participants and the researcher was notified when the participants agreed. When contacting the registered patients from the Paul Steyn Foundation, none of the registered individuals responded to the request. Therefore, other facilities were approached and permission was granted. These facilities included Tygerberg Hospital and private sub-acute hospital. Due to major delays in obtaining access and permission to more health facilities, only 50 participants could be recruited into the first phase of the study. There were only 50 participants available for the study. Therefore, only 50 participants could be recruited to participate in the first phase of the study.

The majority of participants, (70%, n=35) were recruited from Tygerberg Hospital. An additional three participants (6%, n = 3) were recruited at the private sub-acute hospital and the remaining 24% (n=12) were recruited using the snowballing method.



### **3.4.1 INCLUSION CRITERIA**

- Males and females
- All levels of unilateral lower limb amputation
- Prosthetic or non-prosthetic users

### **3.4.2 EXCLUSION CRITERIA**

Persons with unilateral or bilateral upper limb amputations and neurological impairments, such as cerebrovascular accidents, as well as person with bilateral lower limb amputation have been

excluded. Therefore, this study has only included persons with a unilateral lower limb and does not suffer from any other functional impairments.

### **3.4.3 DATA COLLECTION**

#### **3.4.3.1 INSTRUMENTS FOR DATA COLLECTION**

A basic demographic survey [Appendix C] was developed by the researcher to capture information such as age, gender, race, cause of amputation, level of amputation and use of prosthesis, as well as level of education and household income. The World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) [Appendix B] was used to collect data regarding participation restrictions (WHO, 2001). WHODAS 2.0 is a Likert scale survey consisting the following options: None, mild, moderate, severe and extreme difficulty (WHO, 2001). For the purpose of this study, the Likert scale classification has been grouped to: low difficulty (none and mild) high difficulty (moderate, severe and extreme difficulty) and missing data (did not or cannot answer). Permission [Appendix A] was obtained online from the World Health Organization (WHO) in order to use the WHODAS 2.0 for research purposes. WHODAS 2.0 is a questionnaire of thirty-six (36) questions developed by the World Health Organization to assess the level of difficulty due to health-related conditions. There are eight parts in this questionnaire focusing on different areas namely: understanding and communicating, ambulation, self-care, socialising, life activities, health related difficulties and participation in society. The English and isiXhosa versions already existed, and the survey has been translated into Afrikaans. For the study, only the English version of the WHODAS 2.0 was used, as no participant required the isiXhosa or Afrikaans versions.

### 3.4.3.2 PROCEDURE FOR DATA COLLECTION

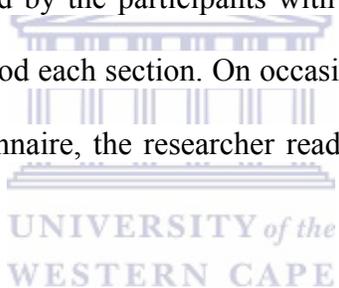
Ethical clearance was obtained from the University of the Western Cape's Ethics Committee (15/4/33) [Appendix D]. Permission was obtained from the Provincial Department of Health [Appendix E] to gain access to Tygerberg Tertiary Hospital's patient database and medical records. In addition, permission was granted by the Head of the Physiotherapy Department for the researcher to come back and investigate their departmental statistics in order to contact patients on their database. Potential participants' medical folders were retrieved and reviewed against the inclusion criteria in order to establish their suitability for the study. The same process was followed to review statistics and identify potential participants from the weekly wound clinic where persons who had a lower limb amputation would return for follow up. Once the participant was deemed suitable based on the available information in the medical folder, the participant was contacted telephonically, and a convenient time to complete the WHODAS 2.0 at the hospital was arranged. The purpose of the study was explained to each participant, and written informed consent was obtained prior to participation. The participant then completed the demographic survey followed by the WHODAS 2.0.

Additional patients were recruited from a private sub-acute hospital. Permission to conduct research was granted from the relevant departments of the private sub-acute hospital. In the private sub-acute hospital's facility, the patients were identified by the physiotherapist in charge of the ward, and written informed consent to participate was obtained. Only persons who had a re-amputation or who had an amputation but was admitted for another condition, were included in the study, in order to ensure that they would have experienced life without a limb prior to inclusion.

Once the physiotherapist at the private sub-acute hospital obtained consent, the researcher was notified and met with the patient in the ward in order to collect data.

The final section of the patients was recruited from the community via snowball sampling. The researcher identified a patient in the community and personally requested their consent to participate in the research study. After informed consent was obtained the participant completed the demographic survey as well as the WHODAS 2.0. This participant then identified other persons in the community who also had an amputation.

The WHODAS 2.0, was completed by the participants with the assistance of the researcher to ensure that the participant understood each section. On occasions where the participant could not answer the WHODAS 2.0 questionnaire, the researcher read the questions and the participants answered the question.



#### **3.4 4 ANALYSIS OF QUANTITATIVE DATA**

The data was coded, captured in Microsoft Excel and imported to a Statistical Package for the Social Sciences (SPSS vs. 22) for analysis. Descriptive analysis of the demographic data and components of the WHODAS 2.0 were performed to identify central tendencies such as the mean, median and the standard deviation. The grouping of the responses was due to the fact that many participants could not and did not fill in the employment / school section in the WHODAS 2.0. Thus, hindering the usage of the scoring system that the WHODAS 2.0 recommended. According to the WHODAS 2.0 manual, if one or more points in a section of the WHODAS 2.0 is missing, the recommended scoring system for the WHODAS 2.0 could not be used. Chi-squared test is used

to show whether there were relationships between two variables. In this study three chi-square test were executed. First test was: Relationship for level of amputation and mobility difficulty. Second test was done for mobility difficulty and prosthesis users and non-prosthesis users. Third test was done for participation and level of amputation. After the analysis, results have been presented using graphs and tables. These results include frequencies, standard deviations and means of the different demographic details of the participant.

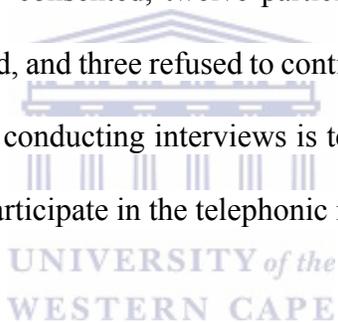
### **3.4.5 SCIENTIFIC RIGOR: VALIDITY, RELIABILITY AND GENERALISABILITY OF QUANTITATIVE DATA**

The WHODAS 2.0 is a valid and reliable instrument for assessing disability and participation restrictions, as it has been piloted and reviewed by the WHO (2001). The WHODAS 2.0 has a good internal consistency with a Cronbach's Alpha of 0.86, high sensitivity to change and a high intra-class correlation coefficients (ICC) of 0.98 (Üstün, et al., 2010). A value of 0.98 is a very high value for an overall domain according to the WHO, and thus the WHODAS 2.0 has a good test-retest reliability (Üstün, et al., 2010). The results of this study would not be generalisable to a specific geographical location or to the greater population being studied due to the small sample size. In addition, this study was done using convenient sampling, therefore it will not be generalisable for an area, but the result would still have some clinical significance.

### **3.5 POPULATION AND SAMPLING STRATEGY FOR PHASE TWO: QUALITATIVE DATA**

The population size for phase two of the study was 50 and included all the participants who completed the WHODAS 2.0 in the first phase. In Phase One, participants were asked if they would be interested in participating in the second phase of the study which included a telephonic interview. Of the 50 participants, only 23 participants initially consented to participate in the second phase of the study. Those participants that agreed in participating were contacted.

Of the 23 participants that initially consented, twelve participants could not be reached on the telephone number that they provided, and three refused to continue participating in the study. Even though the optimal sample size for conducting interviews is ten to twelve (Creswell, 2003), only eight participants were willing to participate in the telephonic interview in the second phase of the study.



#### **3.5.1 METHODS USED FOR DATA COLLECTION**

A semi-structured interview guide was developed based on the findings of the WHODAS 2.0 from the first phase of the study. The interview guide was structured with four predetermined themes which were identified as the areas that participants reported most difficulty in from completing the WHODAS 2.0. The four pre-determined themes were: participation restriction, self-care, life activities and mobility. In the interview questions, there were also probing questions, which assist in guiding the participant so that the relevant information could be extracted. Probing questions were used to explain the underlying reasons why participants reported challenges in these specific domains.

Telephonic interviews are often used to explore the results of quantitative data that cannot be explained statistically in more depth. This qualitative method of data collection is used to capture the participant's feelings or experiences on a more personal level, or to explore certain findings in more depth in a non-threatening environment (Stewart and Shamdasani, 1990). Semi-structured telephonic interviews were deemed the most appropriate instrument of data collection as in this situation since the majority of the participants refused to partake in a face-to-face interview due to the following reasons:

1. Participants stayed too far away from the venue where the interview was to be conducted, and the researcher could not do home visits.
2. Participants had difficulty accessing public transport, despite the fact that transport would be paid for by the researcher.



### **3.5.2 PROCEDURE FOR DATA COLLECTION**

In Phase One, the WHODAS 2.0 answers and the demographic details were analysed. In Phase Two, using the demographic details and questions derived from the answers of the WHODAS 2.0, a telephonic interview was conducted. The participants were conveniently selected for the telephonic interview. Due to the lack of numbers in participants, only eight participants responded and gave consent for the telephonic interview. The participants were then contacted telephonically, where consent was again asked over the phone, and if the participant still agreed the interview would begin.

### **3.5.3 ANALYSIS OF QUALITATIVE DATA**

In the telephonic interview, the participants engaged in the different topics and spoke about their problems and struggles that they experienced. During the interview, permission to record audio was granted, and the interview was recorded. Once the interview was done, the audio recording was transcribed verbatim by the researcher and the researcher's assistant. Within the four pre-determined themes, the qualitative data was then analysed using Creswell's (2007) seven step process of thematic analysis.

The seven steps include:

1. Organising and preparing data for analysis
2. Reading through all the data
3. Coding the data
4. Collapsing the codes into categories
5. Grouping similar categories into themes
6. Inter-relating themes
7. Interpreting the meaning of the themes

Similar phrases or words were coded and grouped together in order to form categories. Similar categories were then collapsed into sub-themes that were situated within the pre-determined themes from the WHODAS 2.0.

### **3.5.4 TRUSTWORTHINESS OF QUALITATIVE DATA**

Credibility: Peer examination was done to ensure credibility. The study utilised a peer scrutinising method, where the study was submitted for review by another researcher who gave comment on

the interview guide, type of probing questions asked during the interview and how the interview was conducted. After the feedback and suggestions, the researcher made appropriate changes (Creswell, 2003). The comments stated that the questions asked by the research were too structured and the questions needed to be broad. At first the second phase of the study was meant to be a face-to-face interview, but due to limited amount of funding and transport issues, it was changed to a telephonic interview.

Transferability: Transferability allows the study to be applied in other research settings and contexts. To facilitate transferability a detailed description of the study has been written. This detailed description includes the target population and the study in order to enables other researchers to transfer the study to another setting and participants.

Dependability: A very detailed description has been laid out in order for the method and/or tools used in this study to be explained. This could ensure that other researchers could use this methodology and could obtain the same or similar results.

### **3.5 RESEARCH ETHICS STATEMENTS**

Ethics clearance has been obtained from the University of the Western Cape, Research Ethics committee and permission to access patients has been obtained from the Medical Manager at TBH. Permission has been obtained online from the World Health Organisation (WHO) in order to use the WHODAS 2.0 for research purposes. Then written informed consent [Appendix F] has been obtained from all participants, as well as permission to audio record their voices during the telephonic interviews. The participants were provided with an information sheet [Appendix G] that

included explicit information such as: objectives and aim of the study, their right to withdraw, confidentiality of information and their personal details, and that they would have been referred for counselling if necessary. It was explained to all the participants that information would be kept confidential, although the participants were not anonymous, because they were contacted for the telephonic interview. If any patient was traumatised by the sharing of their experiences in the telephonic interview, they would have been referred for psychological counselling. All surveys will be kept safely and locked up away from public. Access is given only to the researcher and the study supervisor. Study results will be disseminated to TBH and the private sub-acute hospital.

### **3.7 SUMMARY OF THE CHAPTER**

In this chapter, the methods of data collection method were described and justified. The data collection and analysis steps are explained in detailed, covering the research design, population sample strategy, sample size and the instruments used for data collection. This chapter also includes a description of the measures followed to ensure scientific rigor and the ethical principles adhered to. The results of the quantitative phase of the study will be outlined in the next chapter.

## CHAPTER 4

### RESULTS

#### 4.1 INTRODUCTION

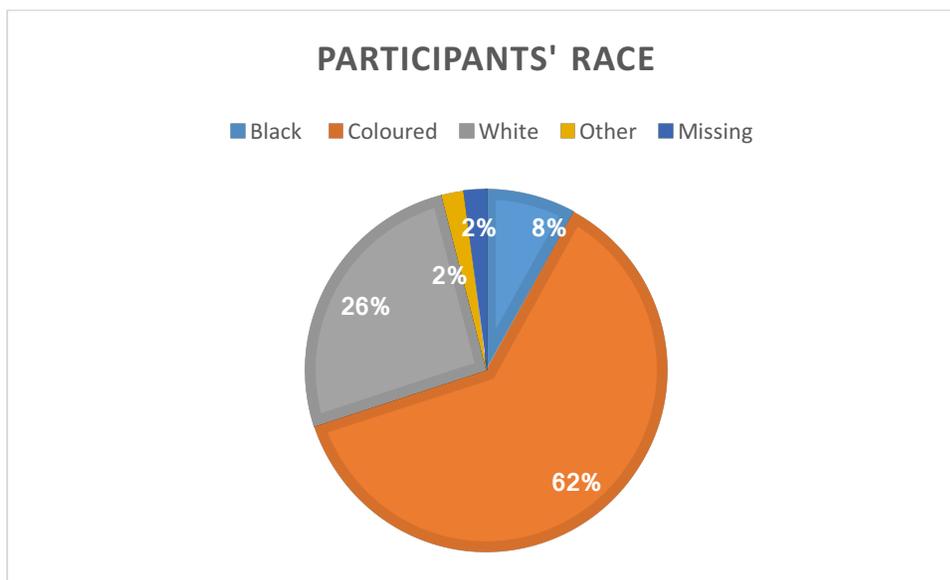
In this chapter, the results of both the quantitative and qualitative data will be presented. The quantitative results will first be presented, and it will be followed by the qualitative results.

#### 4.2 QUANTITATIVE DATA

##### 4.2.1 DESCRIPTION OF THE STUDY SAMPLE

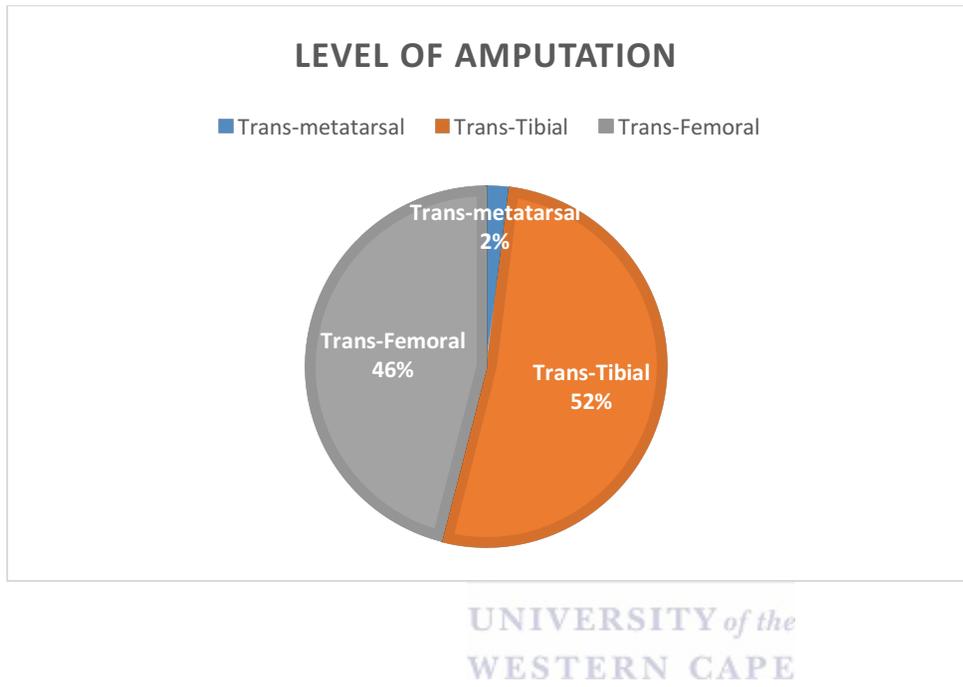
A total of fifty (50) participations were included in the study sample. In this study 72% (n = 36) of participants were male, and 28% (n = 14) were female. The mean age of participants was 57 years old (SD  $\pm$ 12 and range is 23 – 77). When considering the participants' racial distribution, 62% (n = 31) were coloured, 26% (n = 13) were white, 8% (n = 4) were black and 4% (n = 2) of the participants did not complete this question (*Figure 4.1*).

Figure 4.1 Ethnic distribution of the participants



The majority of participants (52%) suffered a trans-tibial amputation (*Figure 4.2*) and only 14% (n = 7) had a prosthesis.

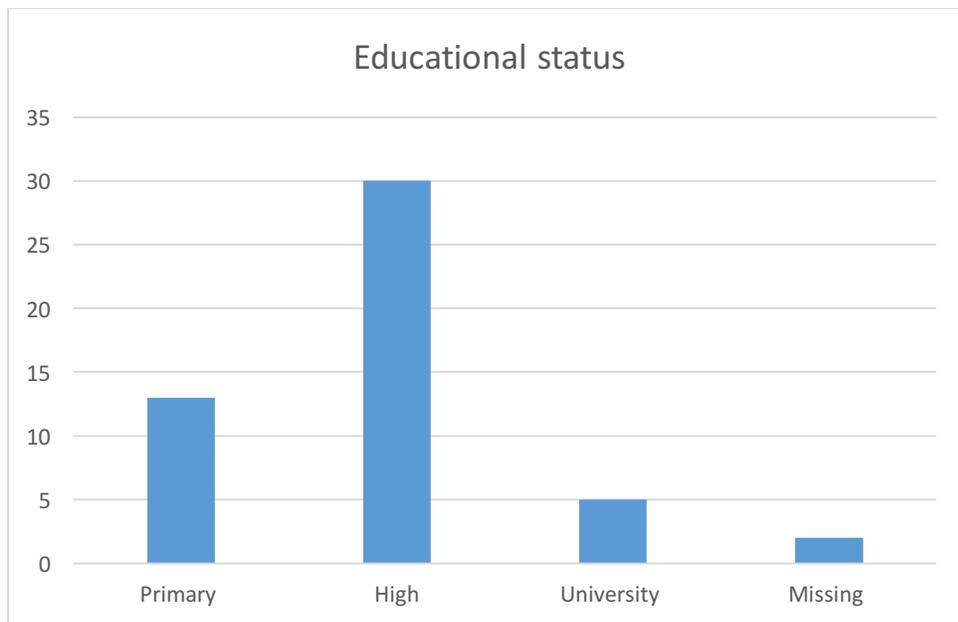
Figure 4.2 Participants' level of amputation



#### 4.2.2 SOCIO-ECONOMIC STATUS

The majority of participants (60%) stated that high school was their highest level of education, and only 10% (n = 5) completed tertiary education (*Figure 4.3*).

Figure 4.3 Participants' highest level of education



Of the total population, 56% (n = 28) earned R1400 or less per month and only 28% (n = 14) has a disability grant (Figure 4.4).

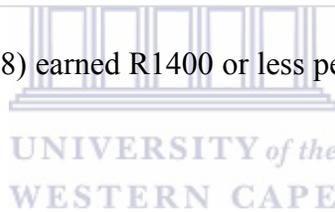
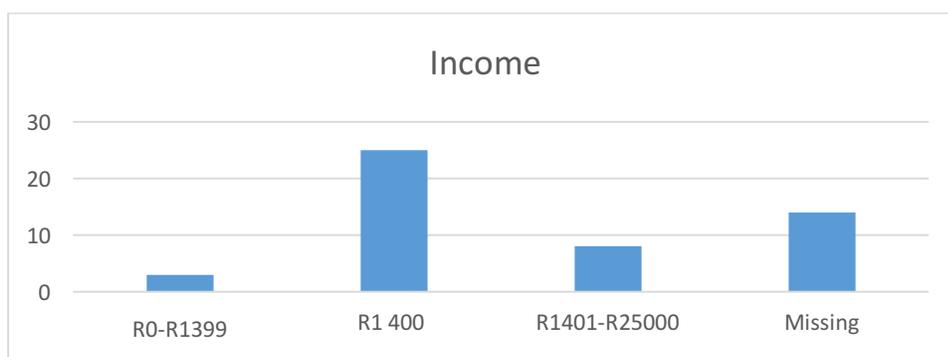


Figure 4.4 Participants' income status



Only 8% of the participants (n=4) were employed at the time of data collection. In this study, 14% (n=7) of the participants had a prosthesis. Out of these seven participants, only one was employed (Figure 4.5). The rest were all retired, had a disability grant or have no work.

Figure 4.5 Prosthetic use and employment

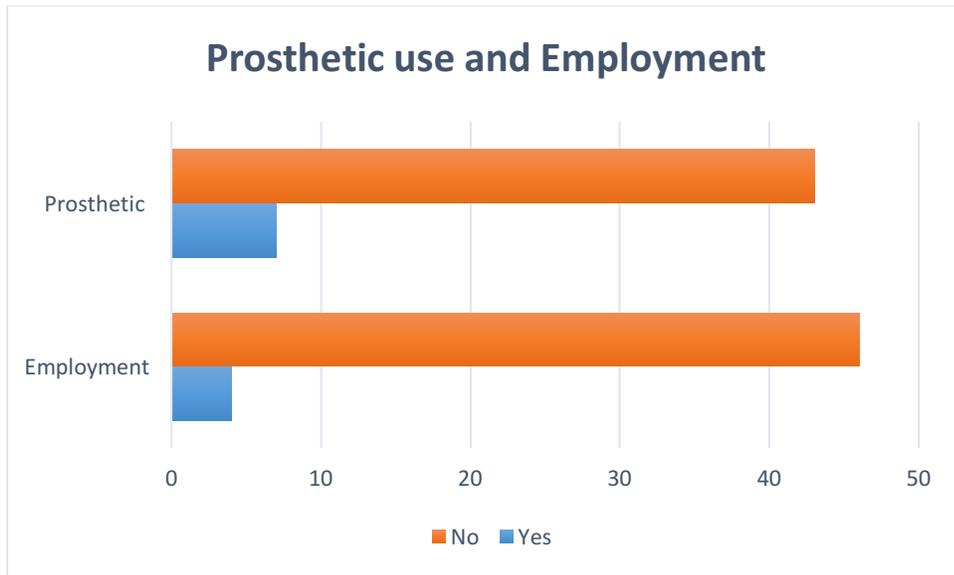
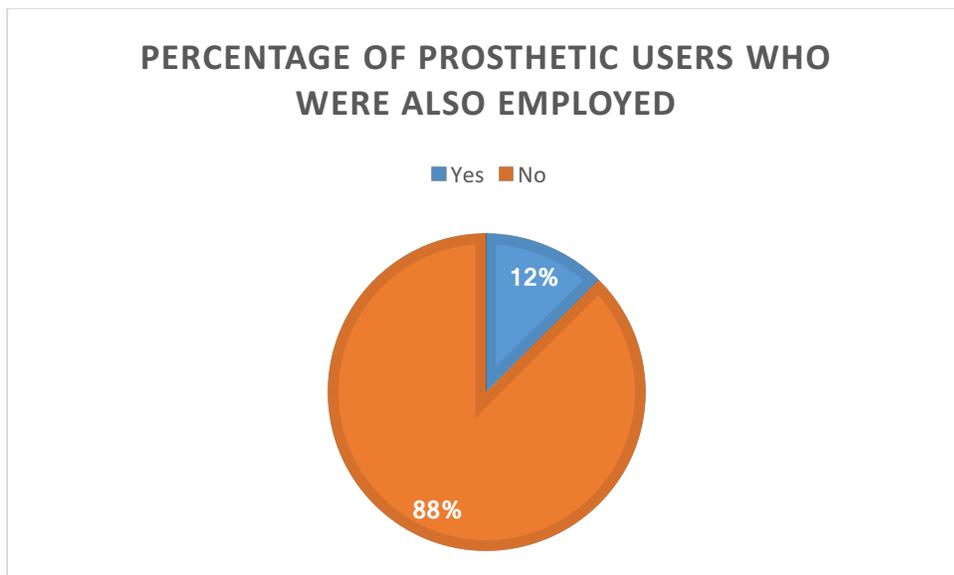


Figure 4.5 displays how many of the participants had a prosthesis and how many were employed.

In figure 4.6, the employment rate is demonstrated, where 88% (n=7) was unemployed.

Figure 4.6 Prosthetic users who are also employed



### **4.3 RESULTS FROM WHODAS 2.0**

The WHODAS 2.0 is a Likert Scale Survey consisting of the following options: none, mild, moderate, severe and extreme difficulty (WHO, 2001). For the purpose of this study, the Likert scale classification has been grouped to: low difficulty (none and mild) high difficulty (moderate, severe and extreme difficulty) and missing data (did not or cannot answer).

#### **4.3.1 UNDERSTANDING AND COMMUNICATION**

When the WHODAS 2.0 survey was answered, all sections of the survey were answered, even though the main focus of this study was on participation restrictions. In the WHODAS 2.0 the section of “Understanding and Communication” was answered, but as expected, no participants reported any difficulty in terms of understanding and communication.

#### **4.3.2 PARTICIPATION RESTRICTION OF PARTICIPANTS**

Participation restriction of the participants were determined by using the WHODAS 2.0 (WHO, 2001). The instrument was filled in, in its entirety although the study aimed to determine the participation restriction of the study sample. None of the participants reported any difficulty with understanding and communication and the information related to participation restriction will be outlined below.

#### **4.3.3 MOBILITY**

In this study, 75% (n = 35) of the total participants had moderate to extreme difficulty with standing for a long period of time. In addition, 92% (n=46) of the participants struggled with long distance walking. (Table 4.2)

**Table 4.1: Classification of WHODAS 2.0 grouping**

<b>Classification</b>	<b>Explanation</b>
Low Difficulty (LD)	Participants who experienced “none” and “mild” difficulty on the Likert Scale were classified as having a low level of difficulty (LD) with tasks.
High difficulty (HD)	Participants who experienced “moderate”, “severe” or “extreme difficulty” were classified as having a high level of difficulty (HD)
Missing data (MD)	Did not answer or N/A

Table 4.2: Getting around (Mobility)

<b>WHODAS 2.0: Scoring item</b>	<b>LD</b>		<b>HD</b>		<b>MD</b>	
	<b>N=5</b>	<b>%</b>	<b>N=5</b>	<b>%</b>	<b>N=50</b>	<b>%</b>
<u>Standing for a long period, such as 30 minutes?</u>	15	30	35	70	0	0
<u>Standing up from sitting down?</u>	32	64	18	36	0	0
<u>Moving around inside your home?</u>	37	74	13	26	0	0
<u>Getting out of your home?</u>	33	66	17	34	0	0
<u>Walk a long distance such as a kilometre (or equivalent)?</u>	4	8	46	92	0	0

#### 4.3.4 HOUSEHOLD RESPONSIBILITIES AND LIFE ACTIVITY AT SCHOOL OR WORK

Approximately half of the participants (52%) struggled with doing their household tasks. Furthermore, 80% of the participants (n=40) struggled to do their household tasks quickly (Table 4.3). Most of the participants in this study (n=46) either did not work or went to school or did not fill in this section.

Table 4.3: Life Activities

<b>WHODAS 2.0: Scoring items</b>	<b>LD</b>	<b>%</b>	<b>HD</b>	<b>%</b>	<b>MD</b>	<b>%</b>
Taking care of your <u>household responsibilities</u> ?	29	58	21	42	0	0
Doing most important household task <u>well</u> ?	24	48	26	52	0	0
Getting all the household work <u>done</u> tasks well?	18	36	32	64	0	0
Getting your household work done as <u>quickly</u> as needed?	10	20	40	80	0	0
Your day-to-day <u>work/school</u> ?	3	6	1	2	46	92
Doing your most important work/school tasks <u>well</u> ?	2	4	2	4	46	92
Getting all the work <u>done</u> that you need to do?	2	4	2	4	46	92
Getting your work done as <u>quickly</u> as	1	2	3	6	46	92

#### 4.3.4 PARTICIPATION IN SOCIETY

A total of 64% of the participants (n=32) were severely emotionally affected by the amputation. When reviewing the effect on family, 60% of the participants indicated that they felt that they (n=30) had caused problems to their family members as a result of their amputation. The majority of participants (62%) also reported difficulty in participating in leisure activities independently (Table 4.4).

Table 4.4: Participation in Society

<b>WHODAS 2.0: Scoring items</b>	<b>LD</b>	<b>%</b>	<b>HD</b>	<b>%</b>	<b>MD</b>	<b>%</b>
How much of a problem did you have in <u>joining in community activities</u> (For example festivities, religious or other activities) in the same way as anyone else can?	36	72	13	26	1	2
How much of a problem did you have because of barriers or hindrances in the world around you?	37	74	12	24	1	2
How much of a problem did you have living with dignity because of the attitudes and actions of others?	36	72	14	28	0	0
How much time did you spend on your health condition, or its consequences?	34	68	16	32	0	0
How much have you been emotionally affected by your health condition?	18	36	32	64	0	0
How much has your health been a drain on the financial resources of you or your family?	26	52	23	46	1	2
How much of a problem did your family have because of your health problems?	19	38	30	60	1	2

How much of a problem did you have in doing things by yourself for relaxation or pleasure?	19	38	31	62	0	0
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For the first phase of the study, four independent chi-squared tests were conducted: The first independent chi-square test was performed in order to determine if there was any statistical significant relationship between the level of amputation (independent variable) and having difficulty with mobility (dependent variable).

#### 4.3.5 FACTORS INFLUENCING PARTICIPATION RESTRICTION

Factors that could potentially influence participation restrictions was investigated. These factors included level of amputation and prosthetic use. These are outlined below.

The second independent chi-square test was done in order to determine if there was any statistical significant relationship between the level of amputation (independent variable) and having any participation restrictions (depend variable). The third independent chi-square test was performed to identify any statistical relationship between participation restriction (independent variable) and difficulty with mobility (dependent variable). The last chi-square test was test so that the statistical relationship between a prosthesis and non-prosthesis user (independent variable) and having difficulty with mobility (dependent variable).

#### 4.3.6 CORRELATIONS BETWEEN CATEGORICAL VARIABLES

When considering the level of amputation in relation to difficulty experienced with mobility, 43% (n = 13) of persons with a trans-femoral amputation and 35% (n = 9) of persons with a trans-tibial amputation experienced difficulty with mobility. In the first independent chi-square test no

significant relationship was established between these categorical variables with a T value of 0.525131 and a P value of 0.525131 (Table 4.5).

Table 4.5 Level of amputation and mobility

<b>Level of amputation</b>	<b>Mobility difficulty (Y)</b> <b>n = (%)</b>	<b>Mobility difficulty (N)</b> <b>n = (%)</b>	<b>Marginal row totals</b> <b>n = (%)</b>
Transfemoral	10 (20%)	13 (27%)	23 (47%)
Trans-tibial	9 (18%)	17 (35%)	26 (53%)
Total	19 (39%)	30 (61%)	49 (100%)

The second independent chi-test no significant relationship was established between prosthetic use and difficulty with mobility with a T value of 2.2425 and a P value of 0.134262 (Table 4.6).

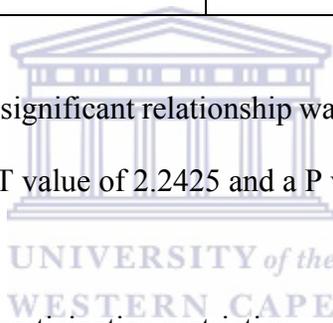


Table 4.6 Level of amputation and participation restriction

<b>Level of amputation</b>	<b>Participation Restriction (Y)</b> <b>n = (%)</b>	<b>Participation Restriction (N)</b> <b>n = (%)</b>	<b>Marginal row totals</b> <b>n = (%)</b>
Trans-femoral	5 (10%)	18 (37%)	23 (47%)
Trans-tibial	5 (10%)	21 (43%)	26 (53%)
Total	10 (20%)	39 (80%)	49 (100%)

In the third independent chi-square test, statistically significant relationship was established between difficulty with mobility and participation restriction with a T value of 6.2937 and a P value of 0.012117 (Table 4.7).

Table 4.7 Difficulty with mobility and participation restriction

<b>Participation Restriction (PR)</b>	<b>Mobility difficulty (Y)</b> n = (%)	<b>Mobility difficulty (N)</b> n = (%)	<b>Marginal row totals</b> n = (%)
PR (Y)	8 (16%)	3 (6%)	11 (22%)
PR (N)	12 (24%)	27 (54%)	39 (78%)
Total	20 (40%)	30 (60%)	50 (100%)

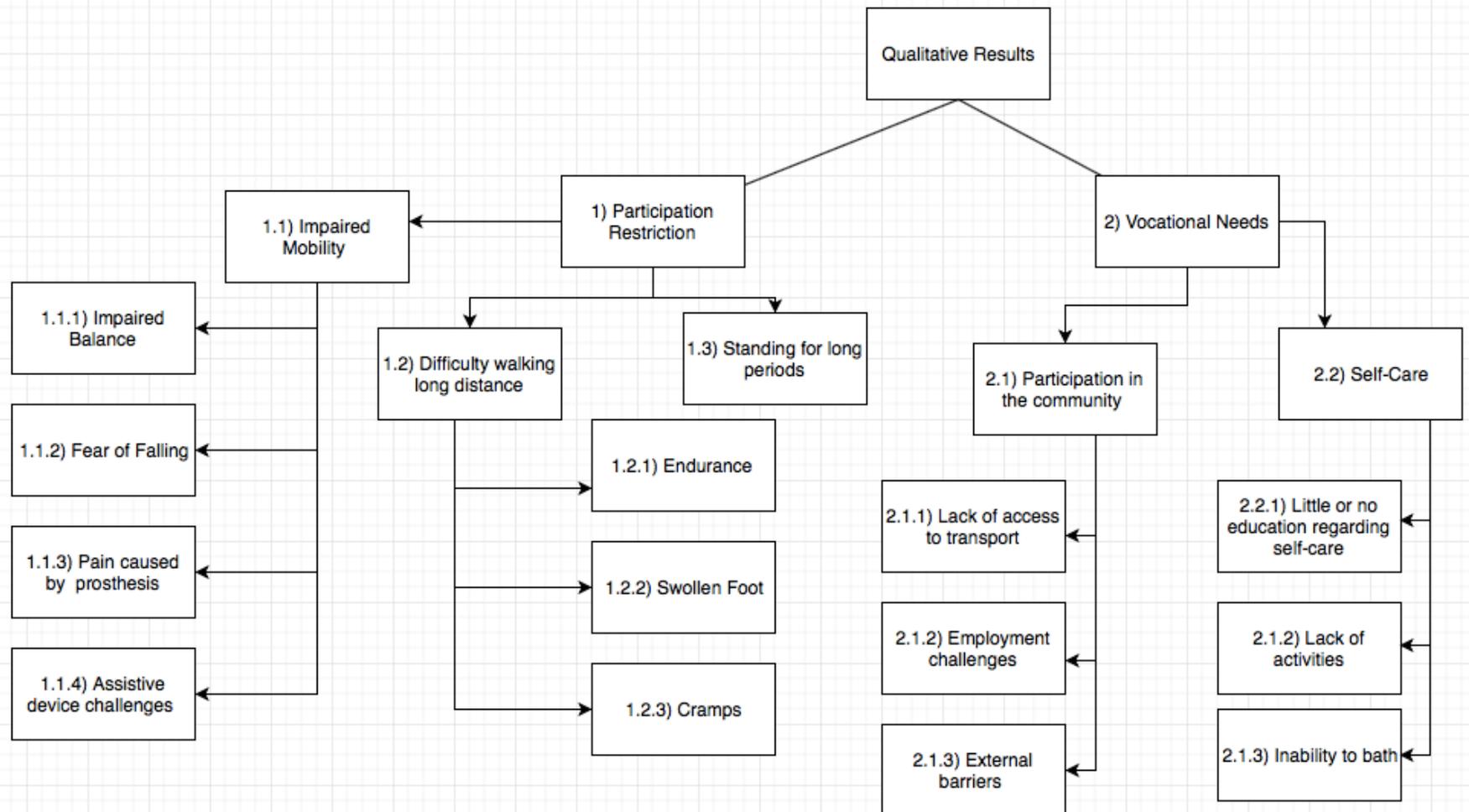
In the fourth independent chi-square test, no statistically significant relationship was established between difficulty with mobility and participation restriction with a T value of 2.2425 and a P value of 0.023227 (Table 4.8).

Table 4.8 Prosthesis use and mobility difficulty

<b>Prosthesis Users</b>	<b>Mobility difficulty (Y)</b> n = (%)	<b>Mobility difficulty (N)</b> n = (%)	<b>Marginal row totals</b> n = (%)
Prosthesis User	1 (2%)	6 (12%)	23 (46%)
Non-Prosthesis User	19 (38%)	24 (48%)	26 (52%)
Total	20 (40%)	30 (60%)	50 (100%)

## 4.2 RESULTS FROM QUALITATIVE DATA

Figure 4.7 Flow Diagram of Qualitative Results



## 4.3 QUALITATIVE DATA

To get a deeper understanding of the needs of individuals with a lower limb amputation with regards to the factors associated with participation restrictions and their vocational needs, the quantitative data collection and analysis was followed up with individual telephonic interviews. Qualitative data were analysed using thematic analysis within two pre-determined themes. The two themes were:

participation restrictions and vocational needs. Underlying reasons for difficulty with participating in society were explored with probing questions. These challenges were categorised into categories and sub-categories under the two main themes.

Data obtained from the quantitative phase of the study and the WHODAS 2.0 informed the categories within the “participation restriction” theme.



### 4.3.1 Description of participants

All the participants that indicated their willingness (in phase 1 of this study) to be contacted, was approached for participation in the qualitative phase of the study. Out of 23 participants, only eleven (11) could be reached of whom two (2) declined participation in the second phase. Therefore, eight (8) participants were telephonically interviewed.

### 4.4.1 PARTICIPATION RESTRICTIONS

The main categories that were identified within this theme were:

1.1) *Impaired mobility,*

1.2) *Difficulty walking long distance and*

### 1.3) Standing for longer periods of time.

Participants' challenges with mobility restricted their participation in activities such as going to the shop to buy groceries.

*Participant B: "No, not really. You see, if I have to shop, I can't walk a long distance."*

*Participant A: "It was quite difficult for me to walk when I got home."*

On further exploration of the underlying reasons for 1.1) **impaired mobility**, the sub-categories of 1.1.1) *impaired balance*, 1.1.2) *fear of falling*, 1.1.3) *pain caused by the use of prosthesis* and 1.1.4) *assisted devices challenges* arose. Participants reported that they struggled to stand or walk due to difficulty maintaining their balance after the loss of their limb.

*Participant B: "... my balance is completely out..."*

*Participant F: "Yeah, yeah to balance myself [is a problem] yeah."*

*Participant G: "...it doesn't scare me. It's my balance is not so lekker...."*

They also noted that they are afraid of, or had experience with falling, which impaired their mobility.

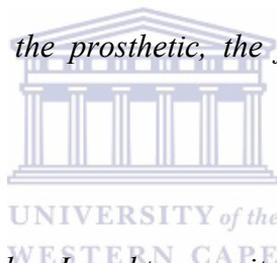
*Participant A: “Yes, it does help, but I’m scared that I’m going to fall. “*

*Participant A: “I’m too scared, I’m being honest now, I’m too scared. I must I say had a few nasty falls where I hurt my back, and I hurt my arm. “*

*Participant G: ...I have a couple of falls already...”*

Of the seven participants who used a prosthesis, all seven participants reported that the prosthesis caused them pain.

*Participant B: “Yeah the friction between your leg and prosthetic.”*



*Participant C: Yeah, when I used to wear it, the legs then it is sore under the stumps.”*

*Participant G: “Yeah, it hurts...”*

Furthermore, challenges from using assistive devices were explored. Participants stated that even with crutches they do not feel safe and has reported a few incidences of falling.

*Participant A: “I struggled with the crutches, because I had a few falls with the crutches.”*

Participants returned home with their assistive devices frequently reported that they struggled with mobility. These struggles were due to the limited amount of space in the house or community.

*Participant B: “No, no, no. I’ve got no problem moving around. Where I stay, I cannot use a wheelchair, I have to use a wheelchair if I go out or whatever.”*

*Participant C: “...there is no space or whatever to going through...”*

*Participant D: “Can’t get through that space yeah.”*

*Participant F: “Yes, inside the house when the wheelchair may be a little bit difficult to go there, then I use my crutches.”*

When exploring the reason why the participants could not walk for long distances, problems with 1.2.1) *endurance*, 1.2.2) *swollen foot* and 1.2.3) *cramps* were noted. Many participants reported that they had a low endurance tolerance.

*Participant C: No, I can’t walk so long, because I get tired very quickly.”*

*Participant A: “[Walking makes me] very tired.”*

*Participant F: "...it's, you know I can't walk with it without the frame. It tires me out easily."*

A participant also reported that their foot was swollen, and mobilising on a swollen foot was painful and uncomfortable for them.

*Participant G: "No, not really. It's just the [swelling] ... it doesn't feel so nice; my foot is sore underneath..."*

*Participant G: "...seems to be swelling over the foot."*

Another participant mentioned that he was experiencing cramps, which affected his mobility.



*Participant D: "No, no, just going on, just only the cramp that I'm getting."*

For some participants standing for long periods of time was a challenge. It is important that the participants are able to stand for a long period, as this directly affects their ability to do their activities of daily living (ADL's).

*Participants B: "Very difficult, because I had to hold onto something."*

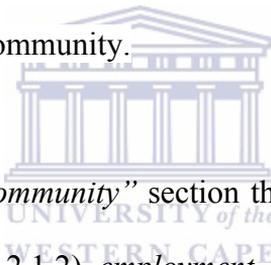
*Participant E: "No. I couldn't stand for a long time."*

*Participant G: “No, not really, my back hurts [when I stand for a long period of time].”*

*Participant C: “No, I can’t. Then I get sore by my stump. So I don’t wanna see that?”*

#### **4.4.2 VOCATIONAL NEEDS**

Two main categories were identified, namely 2.1) *participation in the community* and 2.2) *self-care*. In the “*participation in the community*” theme, numerous participants reported difficulty doing activities for themselves, either in their homes and/or getting around in the community.



In the “*participation in the community*” section the participants mentioned 2.1.1) *lack of access to transport*, 2.1.2) *employment challenges* and 2.1.3) *external barriers*. These factors hindered participants to interact in the community.

*Participant C: “But I’m just struggling with transport at the moment...”*

*Participant F: “...because I haven’t got transport or whatever to go...”*

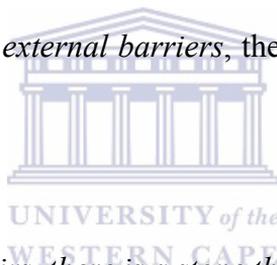
*Participant H: “...as it means travelling every day to the venue there to do the physio...”*

They also noted that there is a *lack of activities* to do when they are at home, that they get bored easily as there are no hobbies or leisure activities that keeps them busy.

*Participant C: “Yeah, I watch TV, but there are actually no activities at home. So... I just be there...”*

*Participant D: “No hobbies. So, I’m very bored...”*

Participants mentioned that even if they got transport, they still lack access to certain areas or buildings because of *external barriers*, these barriers include sand, stones and ramps.



*Participant D: “The stairs, there is a stone that is set up so man...”*

*Participant D: “No man, you see there is no ramps or whatever.”*

It was also noted that employment was a problem, either no one would employ them or they have difficulty finding a job.

*Participant C: “The only thing that I have a problem is finding a job...”*

*Participant B: “I can’t work, but I would love to. I can, If I, you see, this is a thing that lays heavy on my...”*

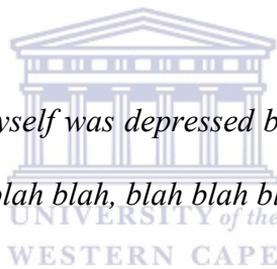
When exploring the *self-care* category, the difficulty that the participants faced was little to no education from the health professionals in the hospitals.

*Participant A: “No, no, no they never taught me, but I have ramps now my uncle made a ramp.”*

*Participant G: “No I didn’t get any physio.”*

With “*lack of activities*”, participants also reports of *depression* after having the limb loss.

*Participant A: Yea, I myself was depressed because I had to face the reality that I lost my leg, blah blah blah, blah blah blah. But I’m okay now. “*



Washing and cleaning is essential, yet the participants in the study struggled to get in or out of the bath, making them *unable to bath*.

*Participant B: “I can’t bath because I can’t get in and out of the bath, but I do shower, you see?...”*

*Participant F: “...I cannot actually bath but I’ve got a shower in, with a shower chair inside so I haven’t got problems with it.”*

## 4.5 SUMMARY OF CHAPTER FOUR

In this chapter, the results from the data analysis are presented. It was noted that majority of the participants (14%) suffered from trans-tibial amputations. 70% cannot stand for a long period of time, 80% struggled to do their house hold tasks quickly and 62% struggle to relax independently. Furthermore, the participants explained what was the impairments relating to the struggles. The main impairments included balance, fear of falling, assisted device challenges and lack of endurance.



# CHAPTER FIVE

## INTEGRATED DISCUSSION OF FINDINGS

### 5.1 INTRODUCTION

This chapter discusses the outcomes of the study and compares it with the salient literature in the field of lower limb amputations and rehabilitation. The chapter will discuss the participation restriction and factors associated with persons with unilateral lower limb amputations in Cape Town. The chapter will further outline a discussion regarding the vocational rehabilitation needs of the study sample.

### 5.2 PARTICIPATION RESTRICTIONS OF PARTICIPATIONS WITH LOWER LIMB AMPUTATIONS IN CAPE TOWN



Researchers have stated that disability should be viewed as an “interaction between health condition and environmental factors” (Gallagher, O’Donovan, Doyle & Desmond 2011). In order to provide solutions and/or suggestions for the improvement of conditions for individuals with lower limb amputations, it is therefore important for us to understand the environmental barriers and challenges they face. The World Health Organization provided an important framework in the form of the ICF, to improve our understanding of the relationship between individuals and their environment, participation and activities (WHO, 2001).

In the present study, the WHODAS 2.0 was used to give an indication of participation restriction of the study sample. Approximately one-quarter of

participants (26%) reported having a problem participating in community activities, however, 70% reported difficulty standing, and 92% reported having difficulty walking long distances. The difficulty in ambulation is alarming, as ambulation is often a requirement for community participation. It is therefore important that ambulation is listed as one of the prioritised goal for a person with a lower limb amputation. Standing for a long period of time is a struggle for the participants of this study as listed in the above. These results coincide with Bragaru et al., (2011) who stated that lower limb amputation impacts mobility significantly. Walking and standing are crucial activities of daily living. According to Manini (2011), walking and standing plays a large role in participation in society. This information is vital for the therapist to understand the underlying causes of mobility impairments, and can assist therapists to create a more specific rehabilitation programme for persons with lower limb amputation. In addition, therapist could also assist in improving the quality of life when the participant re-integrates back into the society.

On further exploration of the difficulties experienced with long standing or walking, the participants highlighted their fear of falling, lack of balance and endurance as possible reasons as illustrated with the following quotes: *“No, not really. You see, if I have to shop, I can’t walk a long distance”* and *“Yeah, yeah to balance myself [is a problem] yeah”*. These finding corresponds to that of Steadman, Donaldson & Kalra (2003), who stated that physical balance is an essential part of walking and standing. These authors further stated that a person with poor balance will not be able to walk or stand independently and safely. In addition, poor balance also leads to a state of anxiety, and induce the fear of falling. According to Steadman, et al

(2003) endurance, balance and fear are all factors that should have been treated or dealt with during the acute phase of rehabilitation. From this result, it could be established that the study population did not receive adequate rehabilitation as they are still struggling with balance. Hence this would be a recommendation to lengthen the rehabilitation periods post amputation.

Majority of participants also reported feeling like they are causing a problem for their family members (60%) and that they cannot relax or do activities independently (62%). This could be indicative that participants were dependent on their family members to assist them to participate in community activities. When exploring this in more depth during the interviews, participants reported challenges with mobilising with crutches, which would increase their dependence on a wheelchair and family members and impaired their ability to participate in the community. These challenges were attributed to poor balance as well as a fear of falling, which are two of the basic aims of rehabilitation of a person with a lower limb amputation.

### **5.3 POOR MOBILITY**

Standing for a long period of time is a struggle for the participants of this study. During the telephonic interviews, participants explained why it was difficult to stand or walk for a long period of time. The majority of participants (71.4%), stated that a lack of endurance, poor balance and fear of falling as part of the cause for their inability to stand or walk. Due to the amputation, participants have self-identified that their balance was poor after the amputation and as a result they were too scared to walk. The notion that poor balance negatively affected their mobility corresponds

to Steadman et al (2003), who stated that physical balance is an essential part of walking and standing. A person with poor balance will not be able to walk or stand independently and safely. In addition, poor balance also leads to a state of anxiety, and induce the fear of falling (Steadman, et al 2003). According to Steadman et al (2003), endurance, balance and fear are all factors that should have been treated or dealt with during the acute phase of rehabilitation. These findings coincide with Bragaru et al. (2011), who stated that lower limb amputation significantly impacts mobility. Walking and standing are crucial activities of daily living and plays a large role in participation in society Manini (2011).

In order to try and explain the difficulty with mobility in more depth, an independent chi-squared test was done to determine if there is a relationship between the level of amputation and the mobility difficulty experienced by the person with a unilateral lower limb amputation. The chi-square test resulted with a P-value of 0.525131 and a T-value of 0.4038. The P-value for this test is greater than 0.05, therefore it cannot be concluded that there is a significant relationship existing between these two variables. The above result is contradictory to the literature, as mobility is affected by the level of amputation. According to Schmalz, Blumentritt & Jarasch (2002), the higher the amputation the more energy is required during the phases of gait, which will affect mobility negatively. Therefore, it is expected that higher the amputation the more the participant will be affected. It must be taken into consideration when treating and rehabilitating high level of amputations, as they are more likely to suffer from immobility.

## 5.4 EMOTIONAL AND PSYCHOLOGICAL FACTORS

From the WHODAS 2.0, 64% (n = 32) of participants reported moderate to extreme negative emotional experiences during and after their amputation, and this negatively influenced their participation in society. When exploring this in more depth during the interviews, participants reported feeling depressed because they lost their leg. The increased dependency on family as a result of difficulty with mobility could potentially also negatively impact on their emotional state. Psychological factors are important to consider for successful rehabilitation of persons with a unilateral lower limb amputation. It is well documented that amputation affects not only a person's physical function, but emotional status as well (Lehohla, 2011; Yazicioglu et al., 2007). Lehohla (2011) and Burger and Marincek (2009) both stated that amputation has a definite negative impact on physical image and affects emotions. It has been noted that with a poor self-image, members in the society feels excluded and inferior to others. Two main factors affect the recovery of a person with a unilateral lower limb amputation, the first is inability to mobilise due to physical constraints, second is the lack of internal motivation of the person themselves.

Psychological impact is traumatic for persons with lower limb amputations. It was understood that the participants suffer from fear post-amputation due to the numerous amount of falls post amputation. This finding is in agreement with Yazicioglu et al. (2007), who stated that fear of falling dramatically affects the ambulation and mobility of the persons with a lower limb amputation. Further

exploring the psychological factors, it was discovered in the second phase of the study that the participants had developed a fear of falling. The psychological fear of falling in this study was rooted in the self-perceived and reported inability to balance. In this study, most of the participants reported at least one or many falls, and now have developed a fear of falling. A fall does not only demolish a person's confidence in their own independence, but it also causes physically pain. These two factors combined resulted in participants in this study preferring to avoid walking and standing and using their wheelchair. This psychological barrier can be addressed by adequate rehabilitation and does not need to involve a psychologist. Early post-operative rehabilitation should be aimed at improving balance, proprioception, prescription of an appropriate assistive device and mobility training with the device. If these components of rehabilitation were not adequately addressed, a person with a lower limb amputation might not have the skills to mobilise, or feel confident enough to mobilise and consequently not mobilise due to the fear of falling.

In terms of motivation, if the persons with a lower limb amputation is demotivated, regardless of their ability to mobilise, they will not mobilise. Therefore, psychological counselling, therapy, as well as family support play an important role to ensure improved functional outcomes for the patient. It is also vital to prepare the patient before the amputation, making them aware of the possible outcomes and effect on their function. Esquenazi and DiGiacomo (2001), stated that pre-operative measures are part of the nine rehabilitation steps of a persons with a unilateral lower limb amputation.

## 5.5 ENVIRONMENTAL BARRIERS

In the WHODAS 2.0 only 24% (n=12) participants reported experiencing environmental barriers to participation in society. However, from the interviews it was evident that the poor mobility combined with the fear of falling, resulted in the fact that participants preferred using their wheelchair. Even though many buildings are becoming wheelchair-friendly, in this study where participants were largely wheelchair dependent, the external environment still presented a barrier to participating in society. According to literature, a higher percentage of persons with a unilateral lower limb amputation experienced physical barriers or challenges (Gallagher, O'Donovan, Doyle and Desmond, 2011). Persons with a unilateral lower limb amputation also then reported to experiencing some participation limitations due to the physical barriers (Gallagher et al, 2011). Gallagher et al (2011) continued that the greatest challenge for persons with a unilateral lower limb amputation was physical or structural environment issues. As in the telephonic interviews, there were participants who struggled to mobilise around their community due to barriers. The barriers mentioned include stairs, lack of transport, lack of ramps and different material on the road surface. It is important to have access and a sufficient level of mobility in order to partake in community activity. It was the possibility of mobility with a combination of external barriers that resulted in the participants not being able to partake in community participation.

According to the results of the WHODAS 2.0, 74% (n=37) of participants did not experience any barriers that hindered their function. During the telephonic interview, it was explored in more depth. The participants responded that they had limitations

due to the confined spaces and lack of access to certain buildings. This could be that when the participants answered the WHODAS 2.0 they were not aware of what the question was actually asking, or they misunderstood the question. In terms of the International Classification of Function, Disability and Health (ICF), according to Gallagher et al. (2011), there is very little literature on ICF and amputation where the research will focus on participation.

## **5.6 TIME SPENT ON HEALTH CONDITION**

In the first phase, it was noted that the majority of participants (68%) did not feel that the time that they had to spend on their health negatively impacted their participation in society. This counter-intuitive finding could potentially be explained by the fact that 92% (n=46) of the participants were unemployed, which means that they had enough time to spend on their health.



## **5.7 PERFORMING HOUSEHOLD TASKS**

It was found that 64% (n=32) of the participants struggled to do all the household tasks, and furthermore, 80% (n=40) of participants struggled to do all the household tasks quickly, although this report could be due to the task being difficult and does not relate to the time dedicated for the task. Although when an explanation for this was sought through the telephonic interview, the majority (86%) of the participants discussed that the speed to finishing a task does not bother them anymore, which concludes that this is not a major restriction and did not really affect their quality of life or participation in society.

## **5.8 LACK OF INDEPENDENCE IN LEISURE ACTIVITIES**

In the WHODAS 2.0, 62% (n=31) participants had a problem doing things by themselves for relaxation or pleasure. Reviewing the data in the second phase, the participants complained of pain when using their prosthesis, cramps and swollen feet. During the telephonic interview participants mentioned that they were unable to get in and out of the bath, possibly due to the lack of education and mobility of the participants. Lastly, there are little to no activities for the participants to do in their community. This could be directly related to the fact that they have poor ambulation, as they are limited to certain areas. These factors could all hinder the ability for the participant to be able to relax or do pleasurable activities. An alarming 52% (n =26) of the participants struggled with doing their household tasks. It was further noted that they struggled to complete their household responsibilities quickly. In the second chi-square test, where the relationship between participation restriction and level of amputation was tested. The test resulted in a P-value of 0.827878 and a T-value of 0.0473. The second chi-square also showed no significant relationship due to the p-value >0.05.

## **5.9 EMPLOYMENT AND PARTICIPATION RESTRICTIONS**

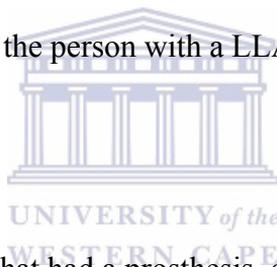
In this study, only 8% (n = 4) of the participants were employed at the time of data collection. The loss of a limb is considered a severe disability, but generally two-thirds of persons with a lower limb amputation are still able to work in a modified environment (Burger and Marincek, 2009). When considering employment and schooling, an interesting finding in the first phase of this study is that 92% (n=46) of the participants were neither at work nor at school, therefore this section was

poorly answered. On further exploration, 74% (n=37) of the participants were retired, 24% (n=12) participants wanted to work, but either could not find employment, or they could not fulfill the job requirements due to their low endurance and functional ability and the remaining 2% (n=4) of the participants left this section open. It is possible that the employment they looked at was more labour and hand work, as 60% (n=30) of the participants only finished high school, therefore they might not reach the job requirements. With limited schooling, coupled with a unilateral lower limb amputation, it will be difficult to find employment, thus the majority of the participants are unemployed. Literature states that 25% of South Africans are unemployed, which corresponds with our study sample, there is however no consensus whether this is due to lack of job opportunities or if South Africans are unable to work (World Bank, 2014). In this study sample, even though 24% (n=12) reported a willingness or need to work, the majority of participants also reported severe limitation in balance, mobility and endurance which would limit their ability to work. Exploring the needs and struggles in the vocational rehabilitation phase is important, as that could guide the therapist and careers in their rehabilitation programme.

Fisher, Hanspal & Marks (2003) noted that the majority of patients with upper limb amputation return work, but not many of persons with a lower limb amputation return to work. In the Fisher et al (2003) study, it was also noted that vocational rehabilitation and employment includes components that needs to be addressed by the therapist. These components are: age, prosthetic use, and availability and accessibility of vocational services. The government and labour law department

should be made aware of this statistic of unemployment of persons with lower limb amputation, as it will contribute to the disability and poverty cycle.

In order to break the cycle, social work and other health professionals prepare the person with a disability for employment, raise awareness and link persons with disability with the employment sector. Even though this specific study sample did not have a normal distribution, return to work is a vital part of vocational rehabilitation, but very little attention is currently given to it in conventional rehabilitation programmes. Obtaining information on the participation restrictions and vocational needs of persons with lower limb amputations can assist rehabilitation staff to increase the person with a LLA's chances of returning to their previous employment.



Out of the seven participants that had a prosthesis, only one was employed.

This finding was alarming as it was expected that prosthetic users were more capable of working. Therefore, the employment rate for prosthetic users should be more when compared to non-prosthetic users. This finding was different to the literature as according to Webster, Hakimi, Williams, Turner, Norvell & Czerniecki (2012), a prosthesis should assist persons with a unilateral lower limb amputation to work and do activities of daily living. In terms of the South African context, it could be different due to the high unemployment rate in South Africa of able-bodied people. Hence, people with a disability could suffer even more from the high unemployment rates. Secondly, in the telephonic interview, it was noted that prosthetic owners did not use their prosthesis, the reason being that the participant had pain and discomfort

when using the prosthesis. In supposition, these two reasons could result in the unemployment of persons with lower limb amputation.

## **5.10 PROSTHESIS AND MOBILITY**

In this study, 86% (n=43) of participants did not have a prosthesis. Another important finding in Phase One was that, of the seven participants that had a prosthesis, 14% (n=2) refused to use their prosthesis. In Phase Two of the study, the participants stated in the interview that prolonged use of their prosthesis causes discomfort and irritation on the participant's stump, impairing their mobility, and ultimately their participation in society. These results contradicted the literature as according to Webster et al (2012), since the prosthesis acts as a replacement of the participant's lost limb, the use of a prosthesis improves the mobility and quality of life of the persons with a lower limb amputation. It is also well known that there are large fluctuations in residual limb volumes and skin irritation in primary (first time) prosthetic users Meulenbelt, Geertzen, Jonkman & Dijkstra (2009).

Therefore, it is crucial to explore if participants who had a prosthesis used it, and what the challenges were with wearing it. From the qualitative findings, it would suggest that these persons were not adequately followed up, or that there is a lack of prosthetic rehabilitation. The clinical implication of this finding is that therapists should regularly follow up on the comfort and use of a prosthesis. if a patient has one, in order to refer them for adjustments or fitting of a new prosthesis.

A third chi-square test was done to explore if there is a relationship between the prosthesis users and non-prosthesis users and the mobility difficulty experienced by

the person with a unilateral lower limb amputation. The chi-square test resulted with a P-value of 0.134262 and a T-value of 0.012117. As the P-value for this test is greater than 0.05, it cannot be concluded that there is a significant relationship existing between these two variables. The chi-square test confirms that there are no correlations between the two variables, which is contradictory to the literature. As stated above, a prosthesis is an assistive device that facilitates and enables a person with unilateral lower limb amputation to ambulate (Webster et al., 2012).

### **5.11 ASSISTIVE DEVICE AND MOBILITY**

Surprisingly, participants also refused to use assistive devices such as the walking frame, rollator frame and crutches. On further exploration in the telephonic interview, it was discovered that participants struggled to use the assistive devices. There were two main underlying reasons why the participants did not use the assistive device. The participants first explained that they had a limited time in the hospital to get used to the assistive device. Secondly, the participants struggled with their balancing capabilities, resulting them having numerous falls. These two factors influenced them to not use their assistive device, as they felt safer in their wheelchair. After identifying this factor, it is a note to the therapist to not discharge or let persons with lower limb amputation leave the facility without having appropriate training. That the therapist should ensure that the amputee is capable and safe using the assistive device.

Understanding the underlying causes of mobility impairments for persons with a lower limb amputation is vital in assisting therapists to create a more specific

rehabilitation programme for persons with lower limb amputation. In addition, reintegration back into society will result in an improved quality of life for persons with a lower limb amputation.

## **5.12 SUMMARY OF CHAPTER FIVE**

In this chapter, the results of the study were explored and evaluated. The chapter reviews the possible findings and relationship between variables, and also highlights the important link relating to the objectives. The content also covers the possible innovations that could be used to address the matters found in the result of the study.



# CHAPTER 6

## CONCLUSION, CHALLENGES AND RECOMMENDATIONS

### 6.1 INTRODUCTION

This chapter serves to provide an overview of the study and to draw conclusions from the findings of this study in relation to the research questions, aim and objectives. The challenges experienced during the study will be discussed, and recommendations for future research are made.

### 6.2 OVERVIEW OF THE STUDY

This study focused on the domain of participation restrictions within the ICF framework. Vocational rehabilitation is one of Esquenazi's (2004) nine phases of amputation rehabilitation. Participation restrictions and vocational rehabilitation was explored within the context of these two frameworks. The study further explored the possible relationships between variables such as level of amputation, severity of participation restrictions, prosthetic and non-prosthetic users and mobility.

This study applied a mixed methods approach and a sequential explanatory design. Quantitative and qualitative study methods were employed to ensure an in-depth understanding of the restrictions experienced by persons with a unilateral lower limb amputation. This information could assist in changing rehabilitation programmes to assist future persons with lower limb amputations to reintegrate back into society.

The first phase of the study utilised the WHODAS 2.0 which determined the participation restrictions that persons with an amputation experienced. In this phase, the majority of the participants struggled with mobility, doing housework, staying alone at home, psychological impact and problems caused to family.

On further exploration, and making use of telephonic interviews with the individual participants, the impairments, struggles and restrictions that prevented them from reintegrating into society was discovered. In this phase, participants reported that their impaired mobility was due to impaired balance, fear of falling and pain cause by assistive devices. In terms of vocational needs, the struggles were highlighted as little or no education, lack of employment opportunities for those who wanted to work and lack of leisure activities to participate in. Furthermore, they experienced challenges with transport and access to health professionals.

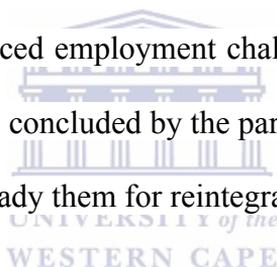
### **6.3 SUMMARY OF THE MAIN FINDINGS OF THE STUDY**

In the first phase of the study, 56% (n=28) of the participants only completed high school. Regarding employment, only 8% (n=4) were employed after the amputation had occurred. In addition, only 12% (n = 7) of the participants were prosthesis users.

From the WHODAS 2.0 that was used in the first phase, in the mobility section, 70% (n=35) of the participants struggled to stand for a long period of time. Furthermore, 92% (n=46) of the participants struggle to walk long distances. Reviewing the life activity section, it was discovered that 80% (n=40) of the participants struggled to

do all their household tasks quickly, where 64% (n=32) struggled to do the task without a time constraint. In the participation in society section, it was noted that 64% (n=32) of participants had been emotionally affected, 60% (n=30) have caused problems to the family and 62% (n=31) struggle to relax independently.

The third most common challenge was that the space provided either at home or in the community was not enough for participants to be mobile. Either the space was too constricted or there was no access to that area due to barriers, such as stairs or steep ramps. Furthermore, participants struggled with the given assistive devices, whether it was the walking frame or the crutches, thus participants develop fears of falling. Lastly, participants faced employment challenges, due to their inability to meet the requirements. It was concluded by the participants that the treatment they received was not enough to ready them for reintegration into their community.



The main finding in this study was that the participants struggled with the ability to mobilise, which negatively affected their participation in society. Participants in Phase Two of the study reported that they require a longer rehabilitation period during their stay at the hospital, as they are getting discharged before they are fully independent.

A total of three chi-squared tests were done, to determine if there are any relationships between the variables. The chi-square that was done for participation restriction and level of amputation showed no significant relationship due to the p-value being  $>0.05$ , whereas the second chi-square test was done for the level of

amputation and mobility difficulty. The second chi-square also showed no significant relationship due to the p-value  $>0.05$ . The last chi-square test performed was done on mobility and participation restriction; this test showed a positive relationship between the two variables.

#### **6.4 STUDY LIMITATIONS**

#### **6.5 CHALLENGES AND LIMITATIONS DURING THE STUDY**

The study had many limitations and challenges due to the limited permission granted by the DOH. The ideal sample size for participants for this study was 222, but due to the long period of delays in different facilities, and limited permission to only access two healthcare institutions (Tygerberg Hospital) and sub-acute private hospital, only fifty (50) participants were recruited for the study over a period of twelve months. This severely affects the generalizability of this study. In order for this study to be generalizable the ideal sample size needs to reach 222 participants (Yamane's formula). A major limitation in addressing the objective of establishing vocational needs in relation to employment in this study, was the demographics of the participants in the second phase of the study. The majority of participants who participated in the interviews where vocational needs were explored, were retired and those who wanted to work had no other vocational rehabilitation needs other than a lack of employment opportunity. This limited the questions that could be asked in relation to employment as an integral part of vocational rehabilitation. Subsequently more emphasis was placed on recreational activities such as hobbies and sport as part of vocational needs, which were more appropriate for this specific study sample.

Once permission was granted the first phase of the study was initiated, another problem was that the participants were difficult to follow up due to missing or incorrect contact numbers being documented in the medical folders, or participants not answering their phones. Due to the communication error, the number of participants participating in the telephonic interview were affected. Even though data saturation was reached, ten to twelve participants would have been more representative of the study population. In addition to our low participant sample size, many participants also refused doing the telephonic interviews, which reduced the available sample for the second phase of the study.

## **6.6 RECOMMENDATIONS BASED ON THE STUDY FINDINGS**

The rehabilitation period should have been longer so that participants are well equipped and have good balance, endurance and the ability to stand and walk for longer periods. In this study, participants struggled to transfer in and out of the bath; this falls under activity of daily living(ADL), as participants could alternatively shower. It is therefore important to educate the participants in how to (First) transfer from one surface to another (second) transfer in and out of the bath. Consequently, a pre-operative home visit should have been implemented so that the participant's family could have adjusted the house accordingly.

Furthermore, many person with lower limb amputation either had a lack of knowledge or lacked interest in further knowledge about prosthesis. Several persons with lower limb amputation expressed their desire and need of the prosthesis in order

to participate in physical and sporting activities, hence the importance of educating the participants and future persons with a unilateral lower limb amputation about prosthesis.

## **6.7 RECOMMENDATIONS**

### **6.7.1 RECOMMENDATIONS FOR RESEARCH**

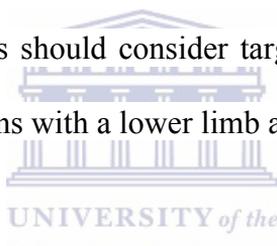
- Researchers should target multiple facilities and rehabilitation centres within the province to increase the sample size within the Western Cape.
- A future study should be conducted where other provinces in South Africa should be included, for a more generalisable population.
- Demographic details should have a description of their employment (if employed).
- Demographic details could include previous functional levels so a comparison of ADL's and function could be included.
- Demographic details should include previous employment status in order for a comparison to be done at the end of the study.

### **6.7.2 CLINICAL RECOMMENDATIONS**

In the clinical setting, it is recommended that the hospital should provide rehabilitation to people with lower limb amputations within their area of residence. For those who cannot access a care centre, either due to transport or physical issues, access to home visits is recommended. Many participants struggled to access rehabilitative care due to transport and accessibility difficulties. Home visit

rehabilitation programmes' main focus is to educate and facilitate their ability to reintegrate back into the community. During these home visits the health care professional should consider looking at the QOL and ADL's that the persons with lower limb amputation would struggle with and address these. Home visit rehabilitation programmes should also include pre-operative home visits, in order for families to make the possible changes as soon as possible.

Therapists should explore educating caregivers, mid-level care workers and families to empower them to assist in the community and residential areas. From the study, the majority of the participants struggled with balance, bathing, poor endurance and mobility. Health professionals should consider target these specific areas to help improve the function of persons with a lower limb amputation.



The rehabilitation programme should include strengthening, improving endurance, balance, proprioception, confidence, psychological consultation and home visits to ensure that their home environment is suitable for the participant. In addition, further intervention is required for employment, therefore social workers should be involved in assisting with person with lower limb amputation for employment, as the participants find it difficult for them to approach and find employment for themselves. According to Steadman, et al., (2003) endurance, balance and fear are all factors that should have been treated or dealt with during the acute phase of rehabilitation.

Balance should be targeted and exercised so that the participant would be safe and able to mobilise independently. Many participants reported fear of falling or have had falls. Improving balance will prevent and decrease the falls which could negatively affect mobility and independency. Endurance should be focused on as well, as participants describe that they struggle to mobilise long distance because of poor endurance. To improve mobility and independency, endurance should be a focus of rehabilitation before discharge.

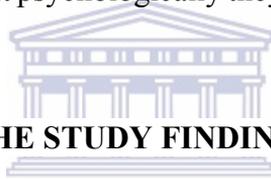
Mobility is an issue with the participants, reasons due to the abovementioned underlying causes. Another factor that influenced mobility in the participants was their assistive devices. Many expressed that they were not educated and felt unsafe with using the device. Therefore, another aspect to target would be to ensure that the participant should feel safe and educated on the use of the assistive device they are equipped with before being discharging the patient. Otherwise, as indicated in the study, it would result in a lower functional assistive device (e.g. wheelchair).

Furthermore, social workers and government should look into amending employment or re-employment policies for the post-operative amputation. As from the study, participants suggested that post-operation they would still prefer to work, but they cannot, as they do not meet the basic requirements for employment. Therefore, those who cannot meet the working requirements, should either receive further assistance in vocational rehabilitation or a lower function job should be organised for persons with lower limb amputations.

It is important for researcher and therapist in future to consider the following when a person with lower limb amputation is encountered:

- Ensure participants are educated and informed of the outcome or possible impairments that an amputation could cause, so that participants are not in fear.
- Ensure participants are able to safely mobilise with the assistive device that they are given before they are discharge, improving their balance and endurance is essential.

Lastly, many participants suffered from emotional problems, having the people with lower limb amputations see a psychologist should be part of the rehabilitation process. This would ensure that psychologically they are not hindering their progress.



## **6.8 CONCLUSION OF THE STUDY FINDINGS**

The difficulty in mobilising independently negatively affected their participation in society and vocational activities such as work, hobbies, employment and sport. The main restrictions reported were difficulty with standing and walking long distances. The underlying reasons reported which could be addressed by adequate rehabilitation was poor balance, endurance and the fear of falling that developed after the amputation.

The above mentioned impairments and participation restrictions, combined with the deeper insight gained into the reasons for these impairments can assist to inform and develop patient-centred vocational rehabilitation programmes for persons with a unilateral lower limb amputation.

## 6.9 SUMMARY OF CHAPTER SIX

This chapter covered the limitations of the study, summaries the finding of the study, clinical implications and recommendations of the study. This chapter also covers the information that could be used for the health professionals to assist persons with unilateral lower limb amputation in rehabilitation.



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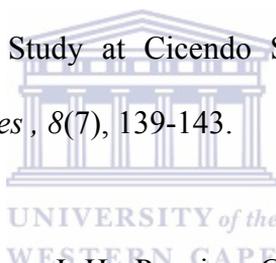
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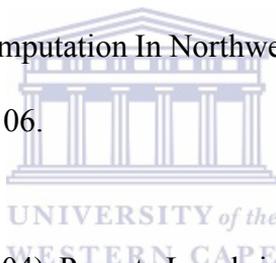
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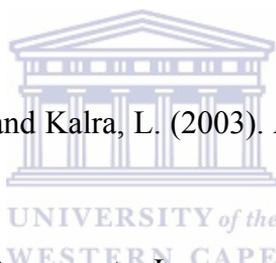
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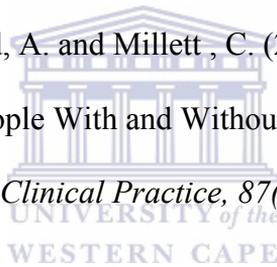
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86(10):800-5.



Dear Mr Yu,

With thanks we acknowledge receipt of the WHODAS 2.0 user agreement. We are pleased to grant you herewith a non-exclusive, royalty free, non-commercial license to use the WHODAS 2.0 and related material for the purpose outlined in the user agreement.

Attached you will find the WHODAS 2.0 instrument versions and an order form for the WHODAS 2.0 manual which provides further background information on the population norms, scoring algorithm, development history, psychometric properties and applications. Additional available translations may be accessed through our website at [http://www.who.int/classifications/icf/form\\_whodas\\_downloads/en/](http://www.who.int/classifications/icf/form_whodas_downloads/en/).

Also attached are the SPSS Algorithms, should you wish to use them in your analysis.

Thank you for your interest in the work of the World Health Organization, and in the WHO Disability Assessment Schedule 2.0.

Sincerely,

Dr Nicole M. Homb  
Postdoctoral Fellow

Classifications, Terminologies and Standards (CTS) World Health Organization | Avenue Appia 20 |  
1211 Geneva | Switzerland





# WHODAS 2.0

WORLD HEALTH ORGANIZATION  
DISABILITY ASSESSMENT SCHEDULE 2.0

## 36-item version, self-administered

This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think back over the past 30 days and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, please circle only one response.

In the past <u>30 days</u> , how much <u>difficulty</u> did you have in:						
<b>Understanding and communicating</b>						
D1.1	<u>Concentrating</u> on doing something for <u>ten minutes</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
D1.2	<u>Remembering</u> to do <u>important things</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
D1.3	<u>Analysing and finding solutions</u> to <u>problems</u> in day-to-day life?	None	Mild	Moderate	Severe	Extreme or cannot do
D1.4	<u>Learning a new task</u> , for example, learning how to get to a new place?	None	Mild	Moderate	Severe	Extreme or cannot do
D1.5	<u>Generally understanding</u> what people say?	None	Mild	Moderate	Severe	Extreme or cannot do
D1.6	<u>Starting and maintaining a conversation</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
<b>Getting around</b>						
D2.1	<u>Standing for long periods</u> , such as <u>30 minutes</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
D2.2	<u>Standing up</u> from sitting down?	None	Mild	Moderate	Severe	Extreme or cannot do
D2.3	<u>Moving around</u> <u>inside your home</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
D2.4	<u>Getting out of your home</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
D2.5	<u>Walking a long distance</u> such as a <u>kilometre</u> [or equivalent]?	None	Mild	Moderate	Severe	Extreme or cannot do

*Please continue to next page ...*

In the past <u>30 days</u> , how much <u>difficulty</u> did you have in:						
<b>Self-care</b>						
D3.1	<u>Washing your whole body?</u>	None	Mild	Moderate	Severe	Extreme or cannot do
D3.2	Getting <u>dressed</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
D3.3	<u>Eating</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
D3.4	Staying <u>by yourself</u> for a <u>few days</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
<b>Getting along with people</b>						
D4.1	<u>Dealing with</u> people <u>you do not know</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
D4.2	<u>Maintaining a friendship</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
D4.3	<u>Getting along</u> with people who are <u>close to</u> you?	None	Mild	Moderate	Severe	Extreme or cannot do
D4.4	<u>Making new friends</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
D4.5	<u>Sexual activities</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
<b>Life activities</b>						
D5.1	Taking care of your <u>household responsibilities</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
D5.2	Doing most important household tasks <u>well</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
D5.3	Getting all the household work <u>done</u> that you needed to do?	None	Mild	Moderate	Severe	Extreme or cannot do
D5.4	Getting your household work done as <u>quickly</u> as needed?	None	Mild	Moderate	Severe	Extreme or cannot do

***Please continue to next page ...***

If you work (paid, non-paid, self-employed) or go to school, complete questions D5.5–D5.8, below. Otherwise, skip to D6.1.

Because of your health condition, in the past <u>30 days</u> , how much <u>difficulty</u> did you have in:						
D5.5	Your day-to-day <u>work/school</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
D5.6	Doing your most important work/school tasks <u>well</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
D5.7	Getting all the work <u>done</u> that you need to do?	None	Mild	Moderate	Severe	Extreme or cannot do
D5.8	Getting your work done as <u>quickly</u> as needed?	None	Mild	Moderate	Severe	Extreme or cannot do

<b>Participation in society</b>						
In the past <u>30 days</u> :						
D6.1	How much of a problem did you have in <u>joining in community activities</u> (for example, festivities, religious or other activities) in the same way as anyone else can?	None	Mild	Moderate	Severe	Extreme or cannot do
D6.2	How much of a problem did you have because of <u>barriers or hindrances</u> in the world around you?	None	Mild	Moderate	Severe	Extreme or cannot do
D6.3	How much of a problem did you have <u>living with dignity</u> because of the attitudes and actions of others?	None	Mild	Moderate	Severe	Extreme or cannot do
D6.4	How much <u>time</u> did <u>you</u> spend on your health condition, or its consequences?	None	Mild	Moderate	Severe	Extreme or cannot do
D6.5	How much have <u>you</u> been <u>emotionally affected</u> by your health condition?	None	Mild	Moderate	Severe	Extreme or cannot do
D6.6	How much has your health been a <u>drain on the financial resources</u> of you or your family?	None	Mild	Moderate	Severe	Extreme or cannot do
D6.7	How much of a problem did your <u>family</u> have because of your health problems?	None	Mild	Moderate	Severe	Extreme or cannot do
D6.8	How much of a problem did you have in doing things <u>by yourself</u> for <u>relaxation or pleasure</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do

**Please continue to next page ...**

Overall, in the past 30 days, <u>how many days</u> were these difficulties present?	<b>Record number of days</b> ____
In the past 30 days, for how many days were you <u>totally unable</u> to carry out your usual activities or work because of any health condition?	<b>Record number of days</b> ____
In the past 30 days, not counting the days that you were totally unable, for how many days did you <u>cut back</u> or <u>reduce</u> your usual activities or work because of any health condition?	<b>Record number of days</b> ____

ompletes the questionnaire. Thank you.



## Appendix C: Demographic detail form

### Demographic questionnaire:

Thank you for your participation in this study. Please complete the follow questionnaire:

~ Thank you for your participation of this study! ~

Name:				Address:			
Surname:							
Title	Mr.	Mrs.	Miss				
				Postal code			
Contact details:							

Gender	Male		Female			
Age	UNIVERSITY of the WESTERN CAPE					
Highest level of education completed?	Primary School	High School		University		
What is your religion?						
Race	Black	Colored	White	Asian	Other	
Monthly Income (Rands)						
Are you currently employed?	Yes			No		
Do you have a disability grant?	Yes			No		
How many people live with you?						
Are you married?	Single	Married		Widow		
At what level was your leg amputated?						
Are you currently using a prosthetic leg (false leg)?	Yes			No		
Would you be willing to join us for a group discussion about your experiences after losing your leg?	Yes			No		

## Appendix D: Ethical clearance



### OFFICE OF THE DEAN DEPARTMENT OF RESEARCH DEVELOPMENT

UNIVERSITY of the  
WESTERN CAPE

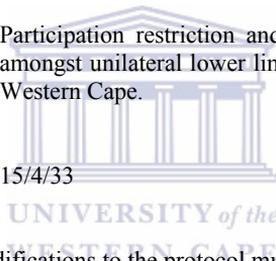
08 June 2015

#### 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:  
Mr TW Yu (Physiotherapy)

Research Project: Participation restriction and vocational needs amongst unilateral lower limb amputees in the Western Cape.

Registration no: 15/4/33



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*

**Appendix E: Permission from Tygerberg Hospital**



**Western Cape  
Government**

Health

**Tygerberg Hospital**

**REFERENCE: Research Projects**

**ENQUIRIES: Dr G G Marinus**

**TELEPHONE: 021 938-6267**

**ETHICS NO: 15/4/33**

Participation restriction and vocational needs amongst unilateral lower limb amputees in the Western Cape.

Dear Mr Yu Tak Wing

**PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL**

In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.

A handwritten signature in black ink, appearing to read 'D Erasmus', enclosed within a large, hand-drawn oval.

**DR D ERASMUS  
CHIEF EXECUTIVE OFFICER**

*Date: 24 August 2015*

**Appendix F: Consent form**



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Private Bag X 17, Bellville 7535, South Africa

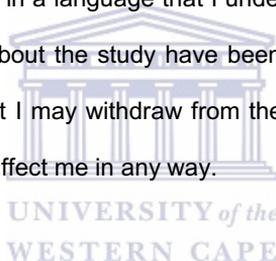
Tel: +27 21-959 2542, Fax: 27 21-959 1217

E-mail: [kaisterkai@gmail.com](mailto:kaisterkai@gmail.com)

**CONSENT FORM**

**Title of Research Project:** Participation restrictions and vocational needs amongst unilateral lower limb amputees in the Western Cape.

The study has been described to me in a 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:** Liezel Wegner

**University of the Western Cape**

**Private Bag X17, Belville 7535**

**Telephone:** (021)959-2542

**Fax:** (021) 959-1217

**Email:** [liwegner@uwc.ac.za](mailto:liwegner@uwc.ac.za)



# UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959, Fax: 27 21-959

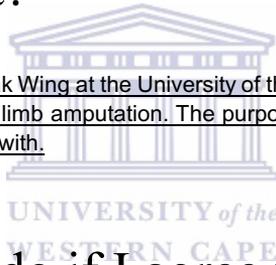
E-mail: [kaisterkai@gmail.com](mailto:kaisterkai@gmail.com)

## INFORMATION SHEET

**Project Title:** Participation restrictions and vocational needs amongst unilateral lower limb amputees in the Western Cape.

### What is this study about?

This is a research project being conducted by Yu Tak Wing at the University of the Western Cape. We are inviting you to participate in this research project because you had a lower limb amputation. The purpose of this study is to gain an understanding of what people who have suffered an amputation struggle with.



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

Initially you would just need to complete two questionnaires. The first one will ask you about personal information such as your age, gender and contact details and the second one would ask you about activities of daily life, and how you function with your disability. This should not take you more than half an hour to complete.

If you are willing to participate in a discussion in a group, you might be selected and asked to join a group of other people who also suffer a lower limb amputation to discuss what your experiences are in relation to work, hobbies and sports participation. As you are part of this group your voice will be recorded so that we can make sure that we remember everything that you have shared.

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

We will do our best to keep any information gathered for this study strictly confidential, the questionnaire and survey which you completed would be safely locked away where only I and/or my supervisor will have access to. If any information is to be used in the study, your personal details will be removed so that you will not be recognized. We would not have names displayed when results are shown, we will use code to classify different data collected.

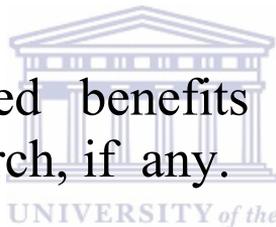
## What are the risks of this research?

Part 1: There will be no risk or disadvantages in this part of the study. Part 2: Since we will be in a group talking you will be sharing your experiences which could be sensitive and personal and this could make you uncomfortable. If you are in any way traumatised by sharing your experiences you will be referred for counselling. Otherwise there is no known health risk or dangers in participating in this study.

## 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 struggles of the amputees (like yourself) in the Western Cape. We hope that, in the future, other people might benefit from this study through improved understanding of the struggles that amputees experience.

Describe the anticipated benefits to science or society expected from the research, if any.



The information we collect will benefit doctors and therapists involved in the rehabilitation of people who suffered lower limb amputees.

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

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

## What if I have questions?

This research is being conducted by **Yu Tak Wing, at the Physiotherapy Department** at the University of the Western Cape. If you have any questions about the research study itself, please contact Yu Tak Wing at: 072 130 7578 or [kaisterkai@gmail.com](mailto:kaisterkai@gmail.com)

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

Study supervisor: Ms L. Wegner 021 959 5393

Head of Department: Dr N. Mlenzana 021 959 2542

Faculty of Community and Health Sciences (Dean): Prof Jose

Frantz Telephone: 021 959

2852

Email: [jfrantz@uwc.ac.za](mailto:jfrantz@uwc.ac.za)

University: University of the Western Cape

Address: Private Bag X17

Bellville 7535



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WESTERN CAPE

## Appendix H: Telephonic interview questions

### *Telephonic interview questions*

#### A: Participation restrictions

1. Can you please tell me what you are struggling with since you have lost your leg?
2. Did receive rehabilitation (exercises) in the hospital?
  - a. Did you feel that it helped you to be more independent at home?
  - b. Can you recommend anything else that might help other people that should have been included?
3. Do you have a problem going out into your community?
  - a. Did you face any problems when you're doing tasks in your community?
  - b. Are there any barriers that hinder your assistive devices or movement?
  - c. Do you feel ashamed because of your disability?
  - d. Do they look down on you because of your loss of limb?
  - e. How did your family respond to your disability?
  - f. What do you want to do when you want to relax?
    - i. Do you have any hobbies / fun activities?
    - ii. Is there anything that makes it difficult to enjoy that activity?

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#### B: Self-care at home:

1. Do you have challenges when staying at home alone?
  - a. What makes it difficult for you to stay alone?
  - b. What do you struggle with when you stay alone?
  - c. Do you feel safe to do normal activities when no one is around you?
    - i. Eg: Bath / make tea / cook
  - d. Does your house require a lot of work for you to do?
  - e. Are you able to freely move around in your house?
    - i. With / without your assistive device

#### C: Life activities:

1. Is there any chores / house work that you cannot do after your amputation?
2. **Link the below**
  - a. What do you think you need to overcome the struggles?
  - b. Are there any struggles with the assistive device that you have currently?
  - c. What type of house hold responsibilities do you struggle with?
  - d. What hinders you is in doing the house hold tasks?
  - e. What is preventing you in doing your task quickly?
  - f. Does that affect your work / go to school:
    - i. Is there any difficulties in attending school / work?
    - ii. What would you recommend therapist do for improving your working abilities?

- b. How far
  - c. What makes it difficult to stand for a long period of time?
- 2. Is it challenging stand up from sitting?
  - i. Why do you struggle / what makes it difficult to stand up from sitting?
- 3. Is it challenging to stand up?
  - a. How long can you generally stand for before you need to sit down?
  - b. What do you struggle with when you try to move around at home?
  - c. What makes it difficult for you to walk long distances?
    - i. Why do you need this break?
    - ii. Why do you struggle



**Appendix I: Letter from editor of Master's thesis**



**LIENEKE BOESAK DEVELOPMENT PROJECTS**

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E-MAIL: [lienekeboesak@webmail.co.za](mailto:lienekeboesak@webmail.co.za)

Trading as:  
**Integrated Learning Systems**  
Reg No: 2012/172787/07

21 April 2017

This serves to confirm that the Master's thesis of **TAK WING YU** entitled: "**Participation Restrictions and Vocational Needs Amongst Persons With a Lower Limb Amputation in Cape Town, South Africa**" has been proof-read and edited for submission to the University of the Western Cape.

A handwritten signature in cursive script, appearing to read 'L Boesak', written over a horizontal line.

**LIENEKE BOESAK**