

**UNDERSTANDING THE REHABILITATION NEEDS OF PERSONS LIVING
WITH A LOWER LIMB AMPUTATION IN RURAL AREAS OF THE
OR TAMBO DISTRICT OF THE EASTERN CAPE, SOUTH AFRICA**

By

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ABSTRACT

Background Globally, the leading cause of lower limb amputation is diabetes mellitus. In South Africa, there is a rise in diabetes-related lower limb amputation with a marked increase in the number of persons with diabetes mellitus in rural areas. However, there is no information on the number of people who are living with a lower limb amputation. An amputation does not only have an impact on a person's physical functioning but can result in poor quality of life, dependence and exclusion from societal participation. Rehabilitation and prosthetic interventions are known to facilitate those with a lower limb amputation to return to independence in activities of daily living, improved quality of life and inclusion in society.

Access to health care is very challenging for persons living in rural areas. Challenges to accessing health care include limited rehabilitation staff, harsh terrain and far distances from services, a lack of access to transport, or the lack of confidence in the service provided by the healthcare institutions. For optimal and patient-centred outcomes, rehabilitation services are of paramount importance. Due to the challenges with providing services in rural areas, community-based rehabilitation is the ideal model for providing rehabilitation to persons with lower limb amputation in rural settings. In order to plan an appropriate community-based approach to rehabilitation, establishing the prevalence of disability and patient-specific needs are imperative.

Aims of the study: The aims of this study were firstly, to determine the period prevalence of people living with a lower limb amputation within the rural OR Tambo District of the Eastern Cape in order to determine the need for services and secondly, to gain a deeper understanding of the rehabilitation needs of persons living with a lower limb amputation within the rural OR Tambo District of the Eastern Cape.

Setting: The study was conducted in the OR Tambo District of the Eastern Cape, South Africa.

Approach: A mixed methods approach was taken: Phase A is quantitative and Phase B is qualitative. The quantitative study was conducted at the tertiary Nelson Mandela Academic Hospital and the qualitative study was conducted within the Qandu and

Swazini villages of the Port St Johns Subdistrict of the OR Tambo District of the Eastern Cape. According to the hospital theatre records, 256 lower limb amputations were performed within a two-year period. Of these records, only 17 medical folders were made available. Relevant information pertaining to in-patient therapy, medical history and cause of amputation was extracted. The qualitative aspect utilised a case series study design to explore the rehabilitation needs that persons living with lower limb amputations in a rural setting experience.

Instruments: This was achieved by means of in-depth interviews as well as direct participant observation using photo elicitation and video-based fieldwork.

Analysis: In Phase A, data were analysed using the Statistical Package for the Social Sciences (SPSS version 22). Demographic details and data relating to causes of amputation were analysed descriptively by means and frequencies and presented as graphs and tables. In phase B, a process of selection of images, contextualisation and coding was done together with the participants. Audio-recordings of the participants' inputs in selection of photographs as well as the structured in-depth interviews were transcribed and were used to enhance the narrative-evolving video-based fieldwork.

Results: A total of 128 lower limb amputations were being performed annually within the OR Tambo District. The most common cause resulting in lower limb amputation within the district was complications of diabetes mellitus. The most common comorbidity associated with lower limb amputation was also diabetes mellitus. Participants in the case series (Phase B) reported poor functionality and activity limitations. They indicated that this had a negative impact on their daily activities, which in turn had a negative impact on the financial status of the family as well as on the individuals' psychological well-being. Participants were no longer the breadwinners in their families and this placed immense financial strain on the household. Environmental barriers limited community integration and access to healthcare services and this too had a negative impact on the physical and psychological well-being of the individuals. These barriers included decreased functional independence of participants, financial challenges, poor quality of transport services, difficult terrain and far distances. Despite general feelings of depression, participants expressed motivation and enthusiasm to regain their functional independence through rehabilitation and prosthetic assistance.

Conclusion and recommendations: Measures to manage and prevent diabetes mellitus in rural areas need to be developed to reduce the incidence of lower limb amputation. This could be achieved through education, health promotion and diabetic screening and foot care management within rural areas where access to health services are limited. Additionally, services should be decentralised to allow for better accessibility of rehabilitation services. A community-based approach to rehabilitation should be used to address the rehabilitation needs identified. There is an urgent need for governmental stakeholders, such as the Department of Health and the local municipality, to collaborate in order to eradicate environmental barriers. Such collaboration would allow for improved accessibility and utilisation of rehabilitation services. Lastly, there is a call for vocational training to expand employment opportunities for those living with a disability in this setting. This may reduce the impact of the disability and improve the functionality, quality of life and independence of persons living with a lower limb amputation.

Ethics: Permission to conduct this research was obtained from the Ethics Committee of the University of the Western Cape, the Eastern Cape Provincial Department of Health, and the Clinical Manager and Chief Executive Officer of the Nelson Mandela Academic Hospital in order to conduct the study in this district. Written informed consent was obtained in isiXhosa from all participants. This included consent for audio-recording, photography and video-recording. Each participant was issued with an information sheet written in isiXhosa explaining the above. All participants were made aware of the aims and objectives of the study, as well as the potential outcome. Any community member who was not one of the four case studies whose face would be captured on footage and visible also signed a release/consent form to use their image for research purposes. The release/consent form was explained to them in isiXhosa to ensure transparency.

Keywords: amputation, lower limb, rehabilitation, needs, causes, co-morbidities, rural

DECLARATION

I hereby declare that “Understanding the rehabilitation needs of persons living with a lower limb amputation in rural areas of the OR Tambo District of the Eastern Cape, South Africa” is my own work, and that I have not submitted it or any part of it for a degree at any university. All the sources that I have used or quoted have been indicated by means of complete references.

Signature: Date:

Sarah Manig



DEDICATION

I dedicate this work to the patients of rural Transkei who taught me more about resilience and perseverance through grace than they will ever know. This work is for you. Your beautiful faces and spirits dance around the fire you lit within me. *Ndiyabulela.*

To my colleagues who stood by me, Alice Gelderbloom-Waddilove and Carly Sanford, your persistence and tenacity to always give your all despite challenging work environments inspired this work. Thank you.

My greatest “thank you” goes to my family. Mignon, Jessica, Christopher and Mark, thank you for being the backbone of my existence. Thank you for supporting and encouraging me during this time and allowing me to pour my heart and soul into it.

Lastly, to my two beautiful grandmothers, Wilma and Mary, I dedicate this work to you, for I am rooted in you both.

To everyone, I am because you are.

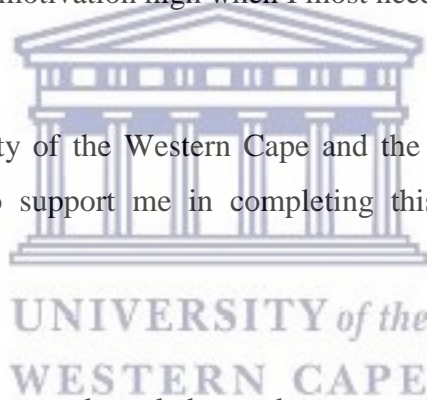
Thank you

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LIST OF ABBREVIATIONS

CBR – Community-based rehabilitation

CHC – Community Health Centre

CRPD – Convention on the Rights of Persons with Disabilities

EC – Eastern Cape

DM – Diabetes mellitus

GATE – Global Cooperation on Assistive Technology

HPCSA – Health Professions Council of South Africa

ICF – International classification of functioning, disability and health

KZN – KwaZulu-Natal

LLA – Lower limb amputation

NMAH – Nelson Mandela Academic Hospital

NRP – National Rehabilitation Policy

PAD – Peripheral arterial disease

WHO – World Health Organization



CHAPTER ONE: BACKGROUND

1.1. Introduction

This chapter provides background to the context of this study through exploring the relationship of disability – especially lower limb amputation (LLA) – and rehabilitative health care. This chapter also clarifies the problem statement, aims and objectives and the research questions of the study.

1.2. Background

The World Health Organization considers disability as an umbrella term to describe impairments, activity limitations or participation restrictions (WHO, 2011), that result from the interaction between a person with a health condition and environmental and personal factors. It is difficult to ascertain the exact statistics for lower limb amputation (LLA) globally, as not all countries keep records. However, LLA is considered a significant physical disability that affects many people throughout the world. The leading cause of LLA is diabetes mellitus (DM), followed by trauma (Lazzarini, O'Rourke, Russell, Clark, & Kuys, 2012). In South Africa, there is also a rise in diabetes-related LLA (Shaw, Sicree, & Zimmet, 2010).

LLA is associated with significant morbidity and mortality (Godlwana, Nadasan, & Puckree, 2008). An amputation does not only have an impact on a person's physical functioning but can also result in a poor quality of life, dependence and exclusion from societal participation (Godlwana, Stewart, & Musenga, 2012). Rehabilitation and prosthetic interventions are known to facilitate those with an LLA to return to independence in activities of daily living, improved quality of life and inclusion in society (Zidarov, Swaine, & Gauthier-Gagnon, 2009b).

Access to health care is very challenging for individuals living in rural areas. The difficulty in accessing health care, coupled with the increase in incidence of DM, further increases the risk for LLA. Challenges to accessing health care include limited rehabilitation staff, harsh terrain and far distances from services, a lack of access to transport, or the lack of confidence in the service provided by the healthcare institutions (Ennion & Rhoda, 2016; Godlwana et al., 2008; (Goins, Williams, Carter, Spencer, & Solovieva, 2005). There is currently no information available about the

actual number of persons with LLAs in South Africa, but there is an increase in persons with an amputation and this will require increased rehabilitation services (Dunbar, Hellenberg, & Levitt, 2015).

Due to immense staff shortages in rural areas, many healthcare facilities that are situated in rural areas rely on only one allied health professional to provide all rehabilitation services (Roots, Brown, & Bainbridge, 2014). The staff shortages and challenges associated with access to health services calls for the implementation of a community-based rehabilitation (CBR) approach, as advocated by the World Health Organization (WHO, 2010). In order to explore the possible implementation of a CBR approach in prosthetic rehabilitation in rural settings, the demand for such a programme should be identified by establishing the prevalence of lower limb amputations as well as exploring the rehabilitation needs of someone who has sustained a major LLA.

According to the World Health Organisation, CBR is aimed at addressing the needs of persons with disabilities and their family members in the areas of health promotion, prevention, medical care, rehabilitation and assistive devices. CBR also works with individuals and their families to facilitate their access to health services (WHO, 2010). In this study the participants' needs were explored in alignment with the "Health" component of the CBR matrix, in terms of rehabilitation and the needs regarding assistive devices (WHO, 2010). This provided insight to the need for rehabilitation services and assistive devices as well as the contextual challenges identified by patients in accessing services and using devices.

Challenges with rehabilitation services in South Africa are preventing optimal rehabilitative and prosthetic care. With the rise in diabetes-related LLA, the healthcare system struggles with both preventative and post-operative care. Staff shortages, lack of equipment and inaccessibility of health care services are some barriers to providing effective rehabilitative and prosthetic services identified by healthcare professionals in South Africa (Ennion & Rhoda, 2016). From the user's perspective, environmental barriers such as difficulty in accessing health care, termination of home-based care, poor communication between service providers, and time-related challenges have been found to be restricting efficient rehabilitation (Visagie & Swartz, 2016; M'kumbuzi & Myezwa, 2016).

Living with an LLA poses an increased risk of morbidity and mortality as mentioned above. The challenges of access to healthcare services in rural settings of South Africa are large and someone living with an LLA is further marginalised compared to an able-bodied person living in the same environment. This is due to the associated difficulties of mobilisation associated with an LLA, thus resulting in worse overall outcomes for a person with an amputation. Therefore, a CBR approach might be useful to overcome these challenges. To inform a sustainable CBR strategy, a needs analysis of the perceptions and rehabilitative needs of those living with an LLA in such a setting had to be established.

1.3. Problem statement

There is currently no information available about the prevalence of LLA in rural settings in South Africa. There is, however, a marked increase in the number of persons with DM, and therefore an increase in the number of persons with an LLA can be expected as well (Pillay, Lutge, & Aldous, 2016). To meet the rehabilitation demands of persons with amputations, more rehabilitation services will be required. There is, however, already a shortage of rehabilitation staff servicing rural areas in South Africa. A CBR approach to prosthetic rehabilitation might be useful to overcome the lack of professional rehabilitation staff (WHO, 2010). In order to implement a CBR approach, the demand for the service and the patients' rehabilitation needs first have to be identified (Moulton, Miller, Offutt, & Gibbens, 2007).

1.4. Research questions

The questions that guided this research were formulated as follows:

Question 1: How many LLAs were performed in the OR Tambo District of the Eastern Cape of South Africa in the years 2016 and 2017?

Question 2: What were the most common causes that resulted in the LLA?

Question 3: What are the daily experiences and rehabilitation needs of a person with a trans-tibial or trans-femoral LLA?

Question 4: What is the impact of a prosthesis on the functional outcomes for a person with an LLA?

1.5. Aim of the study

The overall aim of this study was to collect information that could assist in indicating the need for and inform a CBR intervention for persons with LLA in a rural setting. More specifically, the study sought to determine the period prevalence of people living with an LLA within the rural OR Tambo District of the Eastern Cape. A further aim of the study was to explore and visually depict the rehabilitation needs of people living with an LLA within the rural OR Tambo District of the Eastern Cape.

1.6. Objectives of the study

The objectives of the study were the following:

- To determine how many LLAs were performed in the OR Tambo District of the Eastern Cape of South Africa in the years 2016 and 2017
- To determine what were the most common causes that resulted in the LLA
- To explore and describe what the daily experiences and rehabilitation needs are of persons with an LLA in this setting
- To explore and describe what the impact of a prosthetic limb is on the activities of daily living for a person living with an LLA in this setting

1.7. Significance of the study

Community based rehabilitation programmes support persons with disabilities in attaining their highest possible level of health, working across five key areas within the “Health” component of the matrix: health promotion, prevention, medical care, rehabilitation and assistive devices. This research focused only on the needs of persons with LLAs in a rural setting in terms of rehabilitation and assistive devices. Understanding the participants’ perceptions regarding rehabilitation services and their rehabilitation needs will inform the development of an appropriate CBR programme and highlight needs for intervention. A person who has lost a limb is completely dependent on an assistive device for mobility. It is therefore crucial to understand what assistive devices persons with an LLA are using, their perceptions of the device, challenges pertaining to effective use of the device and finally their perceptions of prosthetic service delivery. The findings of this study can potentially provide a

foundation for future research and projects to implement programmes in this specific domain of the CBR matrix.

The Convention on the Rights of Persons with Disabilities (CRPD) and the Global Cooperation on Assistive Technology (GATE) initiative guide policy makers to design suitable protocols to improve services to persons with disabilities for equal opportunities for all. However, in order for policy makers to draw up the said documents, research has to be done within rural environments across the country where persons with disabilities are residing. Research needs to be context-specific and an understanding for a particular problem will direct where the focus should shift for that particular need. The latest research in South Africa is exploring challenges pertaining to rehabilitative or prosthetic service delivery and the perceptions related to quality of life and function of someone living with an LLA in both rural and urban areas. While the general concerns and challenges are similar across the country, it is difficult to gauge the experiences or challenges from text. The gap in research is that there is no context-specific evidence that highlights the rehabilitation needs of someone living with an LLA. Therefore, appropriate strategies cannot be implemented until the concerns of persons living with an LLA in these specific environments are documented. Only then will it be possible to implement sustainable plans. An understanding of the environment and people's needs are essential.

Furthermore, the methods used in this study contribute to the significance of the study. The methods chosen to collect data for this study are direct participant observation using photo- and video-based fieldwork. These methods were aimed at bridging the gap between theory and the actual daily experiences of participants in this study, giving them a voice which might not otherwise be heard.

CHAPTER TWO: LITERATURE REVIEW

2.1. Introduction

This chapter provides an overview of the relevant literature pertaining to this study, and more specifically it covers the international and national policies relating to disability, predictors and causes of LLA, primary health care and challenges pertaining to rehabilitation service delivery in South Africa. It also presents an overview of prosthetic service delivery in South Africa.

2.2. International and national policies relating to disability:

The current guiding policies in South Africa are the National Rehabilitation Policy (NRP) of South Africa (“Rehabilitation for all”, 2000), the United Nations Convention for the Rights of Persons with Disabilities (United Nations, 2006) and the World Health Organization’s Community-Based Rehabilitation Guidelines (WHO, 2010; Mji et al., 2013). These policies and guidelines set objectives for effective and accountable rehabilitation services (Mji et al., 2013).

Rehabilitation is understood to be a fluid construct rather than a fixed entity. It changes with the development of theories and socio-political understandings with particular reference to disability. Initially, rehabilitation followed a medical model approach to the provision of services. The medical model approach aims to return impaired bodies to societal normativity (Simmons, Blackmore, & Bayliss, 2008); Mji et al., 2013). (Tremain, 2005) suggests that the medical model approach follows a hierarchical trend. He proposes that persons with disabilities have been forced into a passive role by health professionals who make decisions for rather than with them.

This understanding and practice of rehabilitation has shifted toward a social model and uses an integrated approach to rehabilitation. One of the main criticisms of the medical model is that it places sole responsibility for change on the individual and has no understanding for the barriers that inhibit the full social integration of the affected person. A barrier could be either physical (geography/landscape) or attitudinal, for example, discrimination (Mji et al., 2013).

The social model brought about a change in the understanding of disability as a whole (Rule, Lorenzo, & Wolmarans, 2006). Disability is understood to have as much to do with discrimination and social exclusion as with health and pathology (Albert, 2004)

(Barnes & Mercer, 2005). With this understanding, the social model encourages the focus for rehabilitation on intervening in the environment in attempting to facilitate the full integration of persons with disabilities into local communities (Mji et al., 2013).

The rise of the disability rights movement and the social model has played an influential role in the enhancement of disability legislation and the structure and implementation of rehabilitation services (Mji et al., 2013). The same study explains that in South Africa the outset of the Integrated National Disability Strategy, which was based on the United Nations Standard Rules for the equalisation of opportunities for persons with disabilities shaped the foundation for the NRP (Mji, et al., 2013). This is evident in the wording of the goal of the NRP, which stipulates that “this policy is to improve accessibility to all rehabilitation services in order to facilitate the realization of every citizen’s constitutional right to have access to health care services” (Republic of South Africa. Department of Health , 2000, p. 2).

The goal of rehabilitation for someone living with an LLA is to become mobile once again. In order to achieve this goal, the appropriate assistive device is crucial. Without it, the person will not reach optimal function. When considering someone living with an LLA, the appropriate assistive device would include an option of crutches, prosthetics or wheelchairs. It is evident that without the appropriate assistive device, a person living with an LLA will not reach their optimal functional level. This would be in breach of the NRP as well as section 27 of the South African Constitution that guarantees access to healthcare services, to which rehabilitation is integral.

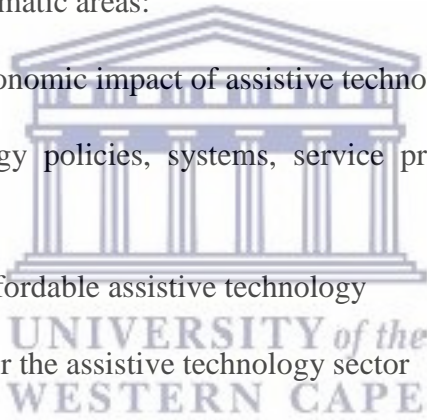
The Convention for the Rights of Persons with Disabilities (CRPD) and its Optional Protocol were adopted by the United Nations General Assembly in 2006 and entered into force in 2008. The Convention for the Rights of Persons with Disabilities aims to ensure that persons with disabilities – a group often rendered ‘invisible’ in legislation, policies and practices – are able to enjoy their human rights on an equal and equitable basis. The Convention for the Rights of Persons with Disabilities requires governments to meet the assistive technology needs of citizens (Mannan, Gowran, Donnelly, & Smith, 2017).

Over 80% of countries globally ratified the CRPD. South Africa is one of 161 countries to have signed the convention. This highlights that there is consensus to

improve health care to persons with disabilities globally. However, while South Africa has supported this notion, there is a major discrepancy between policy and service provision in this country.

The Global Priority Research Agenda formulated by the GATE initiative prioritises user involvement in all aspects of research, policy development, system design and service provision. This point is supported by the CRPD which is renowned for the involvement of persons with disabilities to form part of all decision-making processes.

To address the substantial gap between the need for and provision of assistive technology (a component crucial to the rehabilitation service), the World Health Organization (WHO) launched the GATE in 2014. GATE, in partnership with organisations of and for persons with disabilities, has developed a global priority research agenda in five thematic areas:

- 
1. Effects, cost and economic impact of assistive technology
 2. Assistive technology policies, systems, service provision models and best practices
 3. High-quality and affordable assistive technology
 4. Human resources for the assistive technology sector
 5. Standards and methodologies for the assessment of assistive technology need and unmet needs (WHO, 2017, p. 2).

The GATE initiative has prioritised research and innovation as a key focus area to improve access to ATs for persons with disabilities. GATE identified the global priority research areas as essential to improving development and implementation of a certification framework and increasing access to AT. If there is no substantial change to the current situation the gap between the need and the unmet need will increase, further marginalising those without access to quality AT and undermining their ability to be productive and enjoy fundamental human rights (WHO, 2017).

The United Nations Millennium Declaration was signed in September 2000. The Declaration was developed to commit world leaders to combatting poverty, hunger, disease, illiteracy, environmental degradation, and discrimination against women. The

Millennium Development Goals are derived from this Declaration, and all have specific targets and indicators. The United Nations Millennium Development Goals are eight goals that all 191 United Nations members agreed to strive to achieve by 2015.

The Sustainable Development Goals build on the Millennium Development Goals. The United Nations considers the Sustainable Development Goals to be “a universal call to action to end poverty, protect the planet and ensure that all people enjoy peace and prosperity” (Tebutt et al., 2016, p. 1). The 17 Sustainable Development Goals focus on key gaps in the progress made by the Millennium Development Goals and aim to stimulate global action to achieve the goals by 2030 (Tebutt et al., 2016).

A person living with an LLA is completely reliant on an appropriate assistive device for mobilisation to improve their functional outcomes. Although access to good quality and affordable assistive products has been mandated by the CRPD, only 10% of persons who require assistive devices have access to them (Tebutt et al., 2016). There is clearly a need for improved process of service delivery regarding assistive products.

Following from the GATE Great Summit, a draft position paper was formulated which included suggestions for action to improve services and access for persons with disabilities. The position paper was reviewed, discussed and refined. Two areas of action emerged as a way forward: 1) development of a competence framework and associated education and training programmes that aim to establish a set of process and skill-based competencies for assistive technology provision staff, assuring individual needs are met in specific contexts; 2) development and implementation of a certification framework that aims to provide guidelines that can be adhered to. The importance of context specific needs assessment was highlighted and was said to be crucial in providing an understanding of the assistive technology staff landscape. This approach supported the aims of this research study as it is essential to shape and strengthen credentialing frameworks through competencies and certification. These actions to address and support staff capacity building, together with the other GATE areas of focus on people, provision, policy and products, will contribute to increased access to appropriate assistive products and services globally (Smith et al., 2018).

Along with many other socio-economic rights, the right to access healthcare services is guaranteed by section 27 of the South African Constitution (Gaede & Versteeg, 2011). The legislation does not require the elected government to fully realise this mandate with immediate effect, since such a condition would be unreasonable given the resources required, and the poor state of health care and health inequities inherited from the previous dispensation. Rather, the Constitution requires the government to progressively realise this right within the confines of available resources. This imperative places the duty on the government to take all reasonable measures to address poor health outcomes and health services in rural communities. Progressive realisation implies that it is unconstitutional for access to health care to deteriorate. For this mandate to be realised in rural communities, the specific conditions of rural areas need to be considered when planning health services to ensure that policies and strategies relate to rural strategies (Gaede & Versteeg, 2011). Therefore, the research pertaining to this study could be invaluable in providing the necessary insight into a specific and well-known rural area of South Africa. The visual and videographic elements of the qualitative phase meet the call for insight into the specific conditions of rural areas which is needed to be considered when planning health services.

The White Paper on the Rights of Persons with Disabilities (Department of Social Development, 2016) indicates that there is a paucity of current data on the incidence of disability or quality of life of those with a disability in South Africa, which is why research needs to be done in the field to provide statistics, and comment on shortfalls and current service delivery. While the philosophies seem exemplary, there is no guide on the practicalities of implementation and this is a good reason for research to be done within the field of disability.

The White Paper (2016) also highlights how racial policies associated with the period of apartheid rule in South Africa found expression even in the services that were provided to persons with disabilities; thus the pervasive racial policies resulted in persons with disabilities – especially black people – becoming one of the most marginalised sectors of our society who experience extreme levels of exclusion, prejudice, isolation and denial and/or lack of access to fundamental rights and services. South Africa has manifested hostility pertaining to the inclusion and service delivery to those persons with disabilities and this may be may be rooted in South Africa's history of holding difference 'apart' (apartheid), and in its struggle to

acknowledge the value of social inclusion in resource-poor areas. A stronger societal orientation toward, for instance, social justice, poverty relief, and employment may provide a platform for improved attitudes to persons with disabilities. The issue of access to health care for rural South African persons with disabilities is not therefore simply a disability issue, but a broader human rights issue for all (Vergunst, Swartz, Mji, MacLachlan, & Mannan, 2015). National policy dictates that rehabilitation be provided through the district health system according to the principles of primary health care, along a continuum from primary care through to tertiary and specialist services (Mji, et al., 2013).

2.2.1 The International Classification of Functioning, Disability and Health

Discourses surrounding the dualism between impairment and disability have caused a major shift in the conceptualisation of rehabilitation. In recognition of this change, the International Classification of Functioning, Disability and Health (ICF) was developed as a way of understanding the complex interaction between features of the biological, psychological, cultural and social factors of disability (WHO, 2001; Mji et al., 2013). Also known as the biopsychosocial model, this model defines disability as the outcome of the interaction between a person's health condition and the context in which the person finds themselves (Mji, et al., 2013). This context includes external environmental factors (e.g. access to assistive devices, physical accessibility, societal attitudes), and those factors internal to the person (e.g. age, sex, coping skills, personality) (Mji et al., 2013).

The ICF, which was developed by the WHO as part of the classifications index, is a multipurpose classification system used to create a common language pertaining to health and health-related issues among various disciplines and sectors of society. The ICF creates a scientific basis as well as a systematic coding scheme to study health and health-related states, outcomes and determinants, thereby creating a platform for comparison of data across countries and healthcare disciplines (WHO, 2001).

The ICF organises information in two parts: 1) *Components of Functioning and Disability* – the body component comprises two classifications, one for functions of body systems and structures and one for the activities (the execution of a task or action by an individual) and participation (involvement in a life situation), and 2) *Components of Contextual Factor*, which is divided into environmental and personal factors. Environmental factors make up the physical, social and attitudinal

environment in which people live and conduct their lives. The ICF is an integral part of rehabilitation as it views the patient holistically, considering all perspectives pertaining to the person's life; therefore, it is patient-centred.

Disability refers to difficulties encountered in any areas of functioning mentioned above. The ICF can also be used to understand and measure the positive aspects of functioning such as body functions, activities, participation and environmental facilitation. The ICF emphasises environmental factors in creating disability, which is the main difference between this new classification and the previous International Classification of Impairments, Disabilities, and Handicaps. The ICF was considered an appropriate theoretical framework within which to interpret this study's findings, as the focus of this research was on understanding the relationship between the activity limitation, participation restriction and the environmental barriers that the person with a lower limb amputation experiences.

2.2.2 Community-based rehabilitation

As an essential component of healthcare services, rehabilitation provides a link between curative services and restoring the ability to enter or re-enter all facets of life (Visagie & Swartz, 2016). CBR was initiated by the WHO to aid in enhancing the quality of life for persons with disabilities and their families, meet their basic needs, and ensure their inclusion and participation within their communities and the rest of society. CBR started out as a strategy to increase access to rehabilitation services in resource-constrained settings and has since grown into a multi-sectoral approach working to improve the equalisation of opportunities and social inclusion of persons with disabilities. CBR is implemented through the combined efforts of persons with disabilities, their families and communities, and relevant government and non-government health, education, vocational, social and other services (WHO, 2010).

The WHO report on CBR notes how development initiatives have often been top-down, initiated by policy makers at locations far removed from community level, and designed without involvement of the community. It is now recognised that one of the essential elements of sustainable development is involvement of the community in all stages of the development process.

Rehabilitation involves a set of measures that enable persons with disabilities to achieve and maintain optimal functioning in their environments. Rehabilitation is

often initiated by the health sector but requires collaboration between all sectors. The focus should be on the modification of the impairment, compensation for loss of function, and the modification of the environment (WHO, 2010). In their study, Ennion and Rhoda (2016) note how multidisciplinary rehabilitation has been hailed as an integral part of ensuring optimal patient outcomes. They comment that it is usually the physiotherapist who is responsible for the physical rehabilitation process in developing countries.

It is evident that community-based rehabilitation is vital for improving and establishing developments that will assist with issues that surround disability within a resource-challenged environment. International frameworks such as the CRPD, the GATE initiative, the Sustainable Development Goals and the World Report on Disability all draw attention to the involvement of persons with disabilities in the decision-making processes as well as to draw particular attention to understanding the needs of persons with disabilities and the environmental factors involved. Given the resource constraints to providing rehabilitation in rural areas, and the mandate of the United Nations Convention for the Rights of Persons with Disabilities to provide equal services to persons with disabilities, the CBR framework is considered the ideal approach to address these challenges. To potentially utilise and implement this framework, persons with disabilities need to be involved in describing their needs, which was the main intent of this study.

2.2.3 Application of community-based rehabilitation to the current study

Persons with disabilities have challenges in accessing rehabilitation and assistive technology services and this has a negative impact on people, their quality of life and participation in society (Zidarov, Swaine, & Gothier-Gagnon, 2009; Godlwana & Stewart, 2013). The United Nations has recognised that this is a critical problem that must be addressed. In analysing the objectives of the NRP critically, it can clearly be seen that it is resolutely based on the strategy of CBR, whereby persons with disabilities should play a very active role in the planning, implementation and evaluation of rehabilitation services (Mji et al., 2013).

2.3. Incidence of disability internationally

Based on 2010 population estimates, approximately 785 million (15.6%) to 975 million (19.4%) persons 15 years of age and older were living with disabilities worldwide (World Health Organisation, 2004). Of these, around 110 million (2.2%) to 190 million (3.8%) experienced significant difficulties in functioning. Over one billion people (or about 15% of the world's population) were estimated to be living with disability. This is higher than WHO estimates from the 1970s, which suggested a global prevalence of around 10%.

Disability can be conceptualised on a continuum from minor difficulties in functioning to major impacts on a person's life. Disability is interpreted in relation to what is considered normal functioning, which can vary based on the context, age group, or even income group. This limits reliability of statistics. Estimates vary according to where the thresholds on the continuum of disability are set, and the way environmental influences are considered. Disaggregating these data further by sex, age, income, or occupation is important for uncovering patterns, trends, and other information about "subgroups" of people experiencing disability. The data collection method also influences results.

LLAs are associated with significant morbidity, mortality, and disability. An amputation is not merely the loss of a limb – it can mean disability, joblessness and a poor quality of life (Godlwana, Nadasan , & Puckree, 2008). Significant global variation exists in the incidence of lower extremity amputation, and it is critically important to investigate, establish and publish these figures (Godlwana et al., 2008). Ethnicity and social deprivation play a significant role but it is the role of diabetes and its complications that is most profound in causing an LLA (Moxey, et al., 2011).

2.4. Predictors of lower limb amputation

In 2008, Godlwana et al., investigated the global trends in the epidemiology of LLA and found that age, sex, gender, geographical site and level of education were definite predictors of LLA and particularly if the patient has already been diagnosed with DM. Moxey, et al., (2011) who have highlighted the significant role that ethnicity and social deprivation play as a predictor of LLA, explain the effects of social, economic

and geographical factors linked to ethnicity and how these factors can often prevent patients from accessing services and resources that may assist in limb salvage.

Similarly, a study by Regenbogen, Gawande, Lipsitz, Greenberg, & Jha, (2009) reported that race was a definite predictor for LLA. They found that LLAs were more likely to occur in African-Americans (45%) compared to Caucasians (20%), with African-American patients with diabetes and/or renal failure being most likely to seek surgical attention once gangrene had already set in. They reasoned that this may be as a result of lower incomes, lower educational levels and poor access to high quality primary health care, which is often associated with a rural setting.

2.5. Causes of amputation

Lower limb amputation occurs as a result of a wide range of diseases and trauma. The common causes of LLA globally is well known and include causes that are both trauma-related and non-trauma-related (Moxey et al., 2011; Dada, Yinusa, & Giwa, 2011; Canavan, Unwin, Kelly, & Connolly, 2007). There are, however, differences in the causes of LLA between developed and developing countries as well as between urban and rural settings (Chalya et al., 2012). The most common cause of LLA in developed countries is peripheral vascular disease, while trauma, infections, uncontrolled DM and malignancies are the most common cause in developing countries. Diabetes-related amputation is the leading cause of LLA with trauma being the cause of 0–57% of LLA globally (Lazzarini et al., 2012).

2.5.1. Trauma

In developing countries, trauma is one of the leading causes of LLA (Chalya et al., 2012; Thanni & Tade, 2007; Moxley et al., 2011). Chalya et al. (2012) found that most LLAs in Tanzania were caused by injuries related to motor vehicle accidents and Thanni and Tade (2007) found that the leading cause of LLA in Nigeria was also trauma and complications relating to traditional bone setting.

A study by Thanni and Tade (2007) examined the most frequent causes of amputation and found that the most prevalent causes in Nigeria were trauma (34%), complications following traditional bone setting (23%), malignant tumours (14.5%),

diabetic gangrene (12.3%), infections (5.1%), peripheral artery disease (2.1%), and burns (2.1%).

Thanni and Tade (2007) pointed out that an alarming number of LLAs in Nigeria were found to be the result of traditional bone setting. Traditional bone setting is an ancient technique used to correct bone deformities using splints made of bamboo, rattan cane and tied together with palm leaf or cotton thread (Dada et al., 2011). Dada et al., (2011) indicate that while traditional bone setting is a highly practised form of orthopaedic intervention in Nigeria, it is not associated with successful outcomes and frequently leads to LLA, lifelong deformities and sometimes death. It is important to note that in developing countries traditional care in the management of diseases and afflictions is high despite the availability of modern medical care services (Dada et al., 2011) and there is a need for research into the integration of traditional and modern medical beliefs.

Moxey et al. (2011) concur that geographical site, social deprivation and economic status stand as predisposing factors for amputation. The United States Department of State Bureau of Democracy, Human Rights and Labor (2016) compiled a report on the state of Nigeria in alignment with human rights. The compilers of the report commented on the state of civil unrest in the country as well as on attacks between religious groups, the military and the government. There were reports of extreme acts of violence that account for the high number of LLAs as a result of trauma.

2.5.2. Chronic diseases of lifestyle

Noncommunicable diseases, also known as chronic diseases, tend to be of long duration and are the result of a combination of genetic, physiological, environmental and behaviours factors. The main types of noncommunicable diseases are cardiovascular diseases, cancers, chronic respiratory diseases and diabetes (WHO, 2017).

Moxey et al. (2011) conducted a study on the global variability in the incidence of lower extremity amputation and found that the role of diabetes and its complications are one of the most important causes of LLA globally. However, they also highlighted that the extent of the burden of LLA worldwide cannot be accurately quantified due to a lack of standardised reporting measures. Both Beaglehole et al. (2008) and the

World Health Organization, (WHO, 2016) note that the burden of chronic diseases is high in low and middle-income countries and that it is predicted to increase with the ageing of population and urbanisation.

According to the World Health Organization (2016), the global prevalence of diabetes among adults over 18 years of age rose from 4.7% in 1980 to 8.5% in 2014 and that its prevalence has been rising more rapidly in middle- and low-income countries. The WHO (2016) also notes that diabetes is a major cause of blindness, kidney failure, heart attacks, stroke and LLA. In 2015, an estimated 1.6 million deaths were directly caused by diabetes. The WHO (2016) projects that diabetes will be the seventh leading cause of death in 2030 (WHO, 2016).

Hirsch, et al., (2001, p. 1317) describe peripheral arterial disease (PAD) as “the manifestation of systemic atherosclerosis that is common and associated with increased risk of death”. The common risk factors for PAD they identified were a history of smoking, diabetes (regardless of type), hyperlipidaemia and hypertension. (Dolan, et al., 2002) found that patients with PAD and diabetes had poorer lower extremity function than those that had PAD alone. They also highlight that the link between PAD and diabetes is frequently associated with increased prevalence of neuropathy and foot ulceration, which are closely linked with gangrene and LLA.

It is therefore crucial to understand the current prevalence of PAD and its associated risk factors. However, Hirsch, et al., (2001) note that while there is a high prevalence of PAD, it is often undiagnosed at primary healthcare level and/or undertreated in risk-factor modification and this is an area for concern in the management and early detection of patients who are at risk for LLA. Beaglehole et al. (2008) also confirm that the delivery of care in primary healthcare settings in low- and middle-income areas is compromised and that this state of affairs will therefore play a significant role in the detection and management of chronic diseases.

The International Diabetes Federation (IDF) estimated that there were 20 million persons living with diabetes in Africa in 2014 and this excludes 62% of undiagnosed patients (Dunbar, Hellenberg, & Levitt, 2015). With such a high percentage of patients undiagnosed or accounted for at local institutions, it can be assumed that these statistics would increase with an increase in people being screened for DM.

In South Africa, DM accounts for 58 deaths a day and it is the fifth highest cause of natural deaths (Pillay, Lutge, & Aldous, 2016). These authors state that DM is increasing at an alarming rate and especially in developing countries. In developing countries, foot ulcers and amputations are very common. Often poverty, lack of sanitation and hygiene, and barefoot walking interact to compound the impact of diabetic foot damage (Godlwana, Nadasan, & Puckree, Global Trends in Incidence of Lower Limb Amputation: A Review of the Literature, 2008).

South Africa is a developing country. The district report for the OR Tambo region in the Eastern Cape reveals that most of its population live in substandard conditions often associated with “rural” living. It has been reported that most of the population in the OR Tambo District do not have access to clean water or satisfactory sanitation and with the majority living below the poverty line it can be assumed that adequate footwear might not be accessible, therefore suggesting that the population of OR Tambo could be at risk for LLA related to diabetic complications such as foot ulcerations. A study by Manyema et al. (2015) noted the prevalence of diabetes in adults in South Africa. This study found that the prevalence nearly doubled from 5.5% to 9% between 2000 and 2009. Considering that the figures of the prevalence of Type 2 DM in South Africa nearly doubled over the given years, it can be assumed that diabetes-related amputation may also have increased accordingly.

2.5.3. *Differences between urban and rural living*

The rate of unemployment of the population in the OR Tambo District is 70.76%. The average per capita income in this district is R8 564.57 per annum, which falls well below that of the Eastern Cape. In addition, the district reflects the highest dependence on social welfare grants. This indicates that poverty is both deep and pervasive: the overwhelming majority (82.17%) of residents live in poverty and the district accounts for almost one third (32.99%) of the Eastern Cape poverty gap compared to its 26.20% share of the total provincial population (McCann, n.d).

These figures illustrate the low socio-economic status of the district, with poor determinants of health. This information, coupled with the literature of Moxey, et al., (2011) and Regenbogen, Gawande, Lipsitz, Greenberg, & Jha, (2009), suggests that the incidence of LLA in this population group could be high due to the risk factors identified; therefore, intervention on a multisectoral level should be investigated.

Rural residents are more likely to delay accessing care due to financial barriers than their urban counterparts. Travel times to doctors are generally longer for rural residents than for their urban counterparts. Overall, rural residents report higher levels of chronic conditions but they do not visit the doctor more frequently than do urban residents. The rural environment presents extraordinary threats to health, with sparse healthcare options in rural communities exacerbating difficulties. Rural residents with disabilities encounter substantial barriers to obtaining primary care. Healthcare providers face challenges in rural areas and this can create barriers to care (Vergunst et al., 2015).

In South Africa there is no standardised definition of rurality, and government bodies, research institutions and other stakeholders use a range of criteria to define the concept ‘rural’ – or do not use ‘rural’ as a variable at all. There have been some attempts to develop definitions, including the use of population densities, sizes of towns, characteristics of the infrastructure, or predominance of agriculture. In its report on urbanisation and migration, Statistics South Africa estimated that 43.7% of South Africa’s population was rural (Gaede & Versteeg, 2011). The authors used 1996 and 2001 census data and defined ‘rural’ based on several indicators, including whether an area fell under a traditional authority, whether it was located outside of the metros and whether it lacked ‘urban characteristics’ such as availability of amenities and infrastructure (Gaede & Versteeg, 2011).

A study by Schoeman, et al., (2010) looked at primary healthcare facilities in four rural districts of the Eastern Cape and KwaZulu-Natal and found challenges with basic infrastructure such as water, electricity or telephone connections (Table 2.1)

Table 2.1 Adapted from Schoeman, et al., (2010, p. 23): Access to basic amenities in the Eastern Cape (EC) and KwaZulu-Natal (KZN)

| | EC (n=20) | KZN (n=20) |
|-------------------------------------|-----------|------------|
| Availability of safe drinking water | 20% | 25% |
| Availability of electricity | 45% | 85% |
| Availability of flush toilets | 40% | 75% |
| Operational telephones | 20% | 5% |

(Source: (Schoeman, et al., 2010)

According to the study by Schoeman, et al., (2010) only 20% of the population within the Eastern Cape had access to safe drinking water at the time, and only 45% had access to electricity. This is a clear indication that the basic living conditions within the study setting could be defined as rural, according to Gaede and Versteeg (2011). The lack of adequate infrastructure has a negative impact on the quality of services, since basic functions such as calling an ambulance have the potential to become major service delivery challenges.

2.6. Impact of lower limb loss on an individual (general)

According to a study conducted in the Netherlands in 2011 on the factors that affect the quality of life in persons living with an LLA, factors that significantly affect the quality of life in lower limb amputees include the employment status, the use of their assistive device, use of a prosthesis, comorbidities, phantom limb pain and residual stump pain (Sinha, van den Heuvel, & Arokiasamy, 2011). Many of these factors affect persons living with an LLA as there are few employment opportunities in rural areas, no access to a prosthesis and the terrain in this environment makes it exceptionally difficult to mobilise using different assistive devices such as wheelchairs.

Godlwana and Stewart (2013) conducted a pre-op and post-op study of persons undergoing LLA in Johannesburg, South Africa, that explored the perceptions of their quality of life and function. They found a reduction in overall functional status three months post amputation and no difference in quality of life. The reduction in function could be due to a lack of rehabilitative input: a study by Zidarov, Swaine, and Gauthier-Gagnon (2009a) found that a good functional outcome is directly proportional to the amount of rehabilitation received and Godlwana & Stewart, (2013) noted that patients were unable to attend regular rehabilitation. However, the reason for the lack of change in quality of life among the patients could be viewed from a more holistic level. The factors that constitute quality of life (e.g. socio-economic status, employment status and health) should be reviewed before as well as after the procedure of amputation. The lack of change of overall quality of life could be due to the various categories that make up quality of life, such as economic status, employment and health remaining unchanged or even deteriorating. It is important to be aware of this aspect because amputations should not be viewed as functional

impairments only. As Zidarov and others explain, LLA has important functional, psychological, and social influences that can influence the quality of life of the person with amputation (Zidarov et al., 2009a; Eiser, Darlington, Stride, & Grimer, 2001).

Zidarov et al., (2009b) conducted further studies in an attempt to understand how the life habits of someone who had an LLA change after intervention at a prosthetic level. It was found that social roles appear to be more disturbed than those associated with activities of daily living which can extend to participation in the community when viewed on the ICF. The reason for a lack of improvement within the social roles could be that the psychological factor which encompasses aspects like self-esteem, courage and confidence might not be appropriately addressed during the rehabilitative process.

2.7. Process of rehabilitation post lower limb amputation

Optimal rehabilitation of the amputee should begin pre-amputation and should be provided by a specialised treatment team (Esquenazi & Meier, 1996). Communication between the patient, their family and/or caregivers and the rehabilitation team is crucial to develop a treatment plan that suits the lifestyle of the patient. The patient as well as the family should be informed on what to expect after surgery as well as during rehabilitation. At this point, the patient should understand both the short- and the long-term expectations of intended surgery.

The phases of limb amputation rehabilitation have been divided into nine phases of evaluation and interventions. Each of these phases contains specific evaluation items, treatment goals and objectives, presented in Table 2.2 below.

| PHASE | HALLMARKS |
|--------------------------------------|---|
| 1. Preoperative | Assess patient status, patient education, surgical level discussion, postoperative prosthetic plans |
| 2. Amputation surgery/reconstruction | Length, myoplastic closure, soft tissue coverage, nerve handling, rigid dressing |
| 3. Acute post-surgical | Wound healing, pain control, proximal body motion, emotional support |

| | |
|--|--|
| 4. Pre-prosthetic | Shaping, shrinking, increase muscle strength, restore patient locus of control |
| 5. Prosthetic prescription and fabrication | Team consensus on prosthetic prescription, fabrication of prosthesis, modification of components |
| 6. Prosthetic training | Increase prosthetic wearing and functional utilisation |
| 7. Community integration | Resumption of roles in family, community, and recreational activities Assure emotional equilibrium and healthy coping strategies. |
| 8. Vocational rehabilitation | Vocational evaluation, educational training, and job modifications |
| 9. Follow-up | Lifelong prosthetic use, functional and medical assessment as well as emotional support |

Table 2.2: Phases of rehabilitation post LLA according to Esquenazi and Meier (1996)

2.8 Prosthetic service delivery in South Africa

According to Esquenazi and Meier (1996), those with an LLA feel they can only resume their previous lives, roles, activities, and socialisation once they are ambulant. Thus, returning to bipedal ambulation is usually the stated goal of those with an LLA. Bipedal ambulation is achieved through prosthetic intervention and rehabilitation. The lower limb amputee's outlook brightens considerably when he or she is no longer confined to a bed. However, prosthetic and rehabilitation services are poor in South Africa and often patients do not reach this stage of rehabilitation (Ennion & Johannesson, 2017).

Ennion and Johannesson (2017) interviewed physiotherapists and occupational therapists in South Africa regarding challenges to rehabilitative and prosthetic services. The therapists identified lack of support from the government health system, poor socio-economic status of patients and cultural challenges as the main challenges prohibiting effective service delivery. A lack of basic equipment, staff shortages and long waiting times are some of the issues relating to lack of support by the

government identified by the therapists. Patients can wait up to three years to be fitted with a prosthesis (Ennion & Johannesson, 2017). Visagie and Swartz (2016) confirm that the provision of assistive devices in South Africa is challenged by issues which include referral, assessment, prescription, training and follow-up. As a result, these expensive resources are unused. This is both an inconvenience for the patient and a huge financial loss for the state. It is crucial to understand what assistive devices persons with LLA are using, their perceptions of the device, challenges pertaining to effective use of the device and, finally, the perception of prosthetic service delivery. This will allow for an accurate baseline, specific to a setting and community, which allows for relevant and suitable interventions to be created.

Ennion and Rhoda (2016) highlight barriers to effective rehabilitation services such as inaccessibility of health care services, lack of trained rehabilitation staff, inappropriate preparation of healthcare workers for a rural setting, a lack of resources and a lack of research and evidence, to name a few. It is evident that while rehabilitation predicts patient outcome, there are many barriers preventing this service in South Africa and especially in a rural setting.

Visagie and Swartz (2016) confirm that the shortfall in the efficacy of rehabilitation services in South Africa is challenged by a shortage in resources and service providers, insufficient budget and transport systems, insufficient length of stay in acute hospitals, communication difficulties (language barriers and intersectoral collaboration) and challenges with referral to secondary and tertiary institutions.

It is as a result of these inadequacies that patients do not achieve maximal independence, participation and integration back into society and will rely on rehabilitation services to reach previous levels of function. While research has found that the standard of rehabilitation and prosthetic services are poor (Visagie & Swartz, 2016; Ennion & Rhoda, 2016; Ennion & Johannesson, 2017), information pertaining to the needs of the user will help to improve the process. A bridge between challenges highlighted by medical professionals and those highlighted by persons with disabilities will allow for a holistic and sustainable approach to solving this issue.

Zidarov et al., (2009b) found that ADLs are significantly improved with correct and adequate rehabilitative input, thereby confirming the positive impact and importance that having a prosthesis and correct training can have on overall functional outcome.

Considering the increasing numbers of LLA in South Africa, these findings are particularly important and supported the objectives of this study. However, the study by Zidarov et al. (2009b) was conducted in Montreal, Canada and does not reflect the situation in South Africa. Regardless, it serves as a reminder of the end goal and the importance of striving to improve current intervention and processes.

2.9. Challenges with prosthetic service delivery in a rural setting in South Africa

Because of national differences in the characteristics that distinguish urban from rural areas, the distinction between urban and rural population is not amenable to a single definition that would be applicable to all countries, thereby making it difficult to define 'urban' and 'rural' globally (United Nations Statistics Division, 2017). The United Nations itself recognizes the difficulty of defining urban and rural (World Health Organisation, 2009)

Rural areas are usually defined as “what is not urban” according to the United Nations, (2004) and therefore inconsistencies in the definition of what is urban lead to inconsistencies in characterising what is rural. However, when comparing factors such as access to services (e.g. health care and education) between areas that are within a great radius from the cities, discrepancies become apparent. The trend is such that the further one migrates from a city centre, the bigger the challenge of service delivery and access to health care and education; also, employment opportunities decrease and therefore incomes are lower. All these factors are more indicative of rural living than urban living (World Health Organisation, 2009).

The OR Tambo District is underdeveloped. About 64.5% of households do not have access to piped water and 41.2% do not have access to improved sanitation (McCann, n.d). An improved sanitation facility is defined as one that hygienically separates human excreta from human contact (United Nations International Children's Emergency Fund, 2015). Instead, people have access to unimproved sanitation, for example the bucket system, a pit latrine without slab or a shared latrine.

This poor access to clean potable water and improved sanitation services makes the district prone to outbreaks of waterborne diseases like cholera. People rely mainly on rivers and communal taps for their water (Ziblim, 2013, p. 10). In terms of housing,

91% of the population live in informal houses. Informal housing can be defined as unplanned settlements and areas where housing is not in compliance with current planning and building regulations that denote “a group of individuals living under the same roof, [and lacking] one or more of the following conditions: (1) Access to improved water; (2) Access to improved sanitation...” UN Habitat, (2006/7) (as cited in Ziblim, 2013, p. 10).

This suggests that the setting of this research falls within a rural context as this district faces intense challenges in accessing basic services, levels of poverty are rife and there is a decreased employment and education status.

The district profile review of the OR Tambo District Municipality by McCann, (n.d) documents the demographics of the district and notes 99.49% are black, 0.15% are white, 0.29% are coloured and 0.07% are Asian. OR Tambo has a very youthful population, with over half (53.65%) of all residents aged below 20 years, which indicates a growing population. This is a cause for concern in view of the rise of chronic diseases in the rural areas and the identified correlation of LLA, chronic diseases of lifestyle and ethnicity (Regenbogen et al., 2009).

A survey by Statistics South Africa, (2008) highlighted that within the Eastern Cape, OR Tambo District, 4.08% of the population had medical insurance. This means that 95.92% relied on the government's healthcare services. Health services were provided by two provincial tertiary hospitals, one regional hospital, 12 district hospitals, 11 community health centres (CHCs), 49 clinics, 52 health posts and 15 mobile clinics. The provincial hospitals operated in the city of Mthatha, and the peripheries relied on clinics and CHCs as the primary access to health care (Republic of South Africa: Department of Health, 2015).

Primary health care is different to acute care and requires a greater level of organisation as it needs to be sustained, generally over a patient's lifespan. Patients are often in many ways their own primary carers and their needs and preferences need to be incorporated into the management plans. Primary health care has several advantages: the relative proximity of providers to the patients' homes reduces travel costs, and community care workers' knowledge of individual patients and their families and local communities. While these advantages make for a theoretically good

system, they might not always be realised. Often they are offset by deficiencies in training, supervision, drug supply and overall morale of healthcare workers. (Beaglehole et al., 2008).

While the challenges of providing effective rehabilitation services are widespread, they manifest in persons with disabilities and therefore, it is the responsibility of therapists to research and understand the shortfalls that prevent an efficient healthcare service. It needs to be understood with particular reference to South Africa. Visagie and Swartz (2016) conducted research into the experiences that people living in rural South Africa have with rehabilitation services. The setting was a semi-arid, isolated town in the Northern Cape province. The town had a low population density, poor infrastructure, high levels of poverty and inequities between social groups, and most people relied on livestock subsistence farming. The nearest healthcare facility was a CHC which was managed by nurses and had facilities for five overnight patients at a time. Weekly outreach services were provided by a medical doctor, speech therapist, occupational therapist, and physiotherapist. A secondary hospital was located about 200 km away with tertiary and specialist centres approximately 1 000 km away.

Visage and Swartz (2016) analysed the interviews with two families, each of which were caring for a person with a disability in a low-income area of South Africa. Both persons with disabilities who were involved in the case study developed higher levels of disability that would normally have been associated with their impairments and it had a negative effect on activity and participation.

It was understood that this situation was aggravated by personal and environmental barriers and that the lack of rehabilitation services meant that there was no attempt to modify impairments and the environment to compensate for loss of function and therefore ensure some degree of community integration. This information is alarming because the setting and cases described are not unique and are representative of many communities across South Africa. This is a clear indication that the health sector in South Africa is unable to provide required standards of primary healthcare services.

Environmental barriers such as rehabilitation services and systems, termination of home-based care, communication between service providers, CBR, time challenges and one-on-one treatment are found to be restricting efficient rehabilitation (Visagie

& Swartz, 2016; M’kumbuzi & Myezwa, 2016). However, M’kumbuzi and Myezwa (2016) point out that the collective scope and understanding of CBR among CBR practitioners is unknown in sub-Saharan Africa.

This is understood to be the result of an evolving global approach to CBR, input and involvement from a variety of governmental and non-government stakeholders and their associated miscommunication as well as the implementation of CBR in different political, social and cultural contexts. This is in line with the issues identified by Visagie and Swartz (2016) to challenge the delivery of rehabilitation services to South Africans. The effects of such an impotent system is evident from the cases identified within the study by Visagie and Swartz (2016).

The proposed framework for rehabilitation as described by Mji, et al., (2013) makes it clear that while there is evidence of guiding documents, their success relies on the availability of high-quality rehabilitation services and resources.

2.10. Conclusion

The global population is growing because of the longer life expectancy of humans. The increase in population coupled with the rise of chronic diseases of lifestyle – notably DM – sees an increase in the number of LLAs performed globally. Urbanisation influences these statistics as it encroaches into rural areas of developing countries. The gap between rich and poor remains. Those living in rural areas have difficulty in accessing healthcare services and the healthcare services that are in reach are unable to provide accordingly. Patients that have undergone LLA face psychological, emotional and physical challenges. Rehabilitation services in South Africa are unable to provide for the growing need. This ultimately results in an increase in the needs of persons with disabilities who depend on others for their well-being and are unable to contribute to society. Research has shown that provision of prosthetic services results in increased quality of life, independence and return to previous participation within society. If the gap in the need and provision for prosthetic services can be improved in South Africa, more persons with disabilities can return to their previous level of functioning, enjoy quality of life and feel empowered to contribute to society once more.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter provides an overview of the study design and methods used to collect data in order to meet the study objectives. Data were collected in two phases (A and B). The specific techniques and the advantages and disadvantages of the chosen methods as well of the rationale for choosing these specific methods are discussed under the specific phases. The process of data analysis is described in detail, and the steps taken to ensure the trustworthiness of the data are presented.

3.2 Overall study design

A mixed methods approach was employed to meet the objectives set out in this study, as illustrated in Figure 3.1.

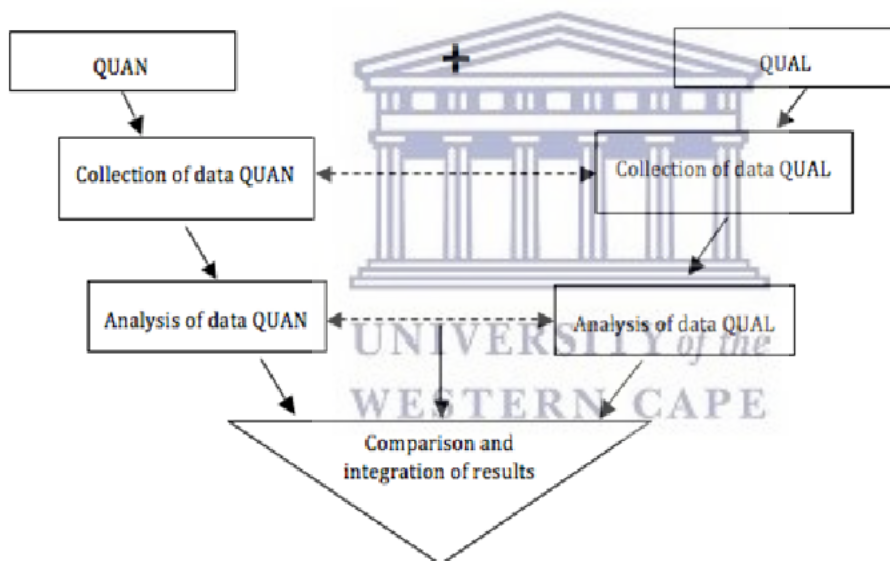


Figure 3.1: Mixed methods approach (Source: Creswell, 2003)

In the quantitative phase (Phase A) a retrospective archival study approach was used to collect data relating to the number of persons in the OR Tambo District who had lost their limbs and the causes thereof. The retrospective archival study was chosen to establish the need or demand for a CBR approach as there are no recorded figures relating to numbers of LLAs performed for this district.

The qualitative phase (Phase B) was followed to explore the rehabilitative needs of subjects under study in more depth. Here, a direct participant observation approach

was used with a case series study design. Within this design and approach to Phase B, three different techniques were chosen to record the data on the rehabilitation and assistive device needs of persons with a lower limb amputation. These three techniques included a self-developed, in-depth interview (Appendix 6), photo elicitation and video-based fieldwork. Photo elicitation can be considered a visual method as well as a technique to collect data, and it is described in detail in Phase B.

The rationale for this approach was that the quantitative data and subsequent analysis thereof would provide a general understanding of the research problem, and would establish the extent of the need for community-based rehabilitation. ~~It was believed that~~ The qualitative data and analysis would refine and provide a more in-depth understanding of the specific rehabilitation needs of the patients with lower limb amputations from their personal perspectives to inform the development of a potential CBR intervention (Rossman & Wilson, 1985; Tashakkori & Teddlie, 1998).

The strengths and weaknesses of this mixed-methods design have been widely discussed in the literature (Creswell, Goodchild, & Turner, 1996; Creswell, 2003, 2005; Green & Caracelli, 1997; Moghaddam, Walker, & Harre, 2003). Its advantages include straightforwardness and opportunities for the exploration of the quantitative results in more detail. This design can be especially useful when unexpected results arise from a quantitative study (Morse, 1991), which in this study was likely as there has been no research done to date in this regard. The limitations of this design are lengthy time and feasibility of resources to collect and analyse both types of data.

A case series is a study that tracks subjects with a known exposure, such as LLA in this case, in an exploration over time through detailed, in-depth data collection involving multiple sources of information that are rich in context (Merriam, 1998). The sources, in this case, were self-developed in-depth interviews, photo elicitation and video-based fieldwork.

3.3 Study setting

The study was conducted in the OR Tambo District in the Eastern Cape in South Africa. In 2016, the OR Tambo District had a total population of 630 088. It is considered a rural district due to poor access and delivery of basic services (Statistics South Africa Community Survey, 2016). Of this total population, 43.5% are

considered poor, and 78.7% rely on government grants and subsidies as their main income (Statistics South Africa Community Survey, 2016).

Health services are delivered by one tertiary hospital, two regional hospitals, 12 district hospitals; 11 CHCs, and 49 clinics (Nodikida, personal communication, 19 April 2018).

Data for Phase A were collected at the NMAH in Mthatha, the capital city of the former Transkei area of the Eastern Cape. Transkei is classified as rural because access to services is a major challenge. Basic services are a major problem. Although many new clinics have been built in the rural areas since 1994, large differences remain in the number of facilities per population, utilisation rates and staffing levels. According to Gaede and Versteeg (2011), this reflects under-provisioning in rural areas. The new facilities in rural areas often cannot be adequately utilised due to a lack of human resources.

The NMAH is one of the three main hospitals that service the entire district. It has operated as a tertiary hospital since it opened in 2004. However, in 2011 the Minister of Health formally published and announced a policy for management of public hospitals and the following year announced that NMAH was to become a central hospital offering quaternary services such as kidney transplants, oncology and a burns unit (Nodikida, 2018). However, the NMAH has the least number of beds, namely 512, which is far below the stipulated 1 200 on the policy of categorisation of hospitals. The hospital still operates at the level of a regional or tertiary service not yet offering the desired package of a central hospital (Nodikida, 2018).

Most of the major limb amputations are performed at the NMAH because it is the only fully functioning tertiary hospital in the district. Mthatha General Hospital is supposed to function as an independent regional hospital; instead it runs as an extension wing of the NMAH. This is said to be due to a lack of leadership, infrastructure, resources, specialist skills and management (Nodikida, 2018).

While facilities with capacity to cater as tertiary level institutions exist further south in the deeper and more remote areas such as Lusikisiki, they are unable to retain specialists, and patients are referred to the NMAH for specialised procedures such as LLA. The NMAH is therefore the only hospital in the district that has the expertise, resources and process of care to manage patients needing LLA (Nodikida, personal

communication, 19 April 2018). Patients that should be treated at regional hospitals are referred to the NMAH, which places further strain on the institution as it tries to uphold the work of most of the district hospitals and various health institutions.

Gaede and Versteeg (2011) support the above information in their report which states that rural hospitals and clinics form part of a larger referral system, which is not always based on rational planning but rather on historical factors such as location and, perhaps more importantly, availability of services. The availability of specialist services at regional hospitals may be very variable. If regional services are poor or unavailable, a patient from a rural hospital must be referred to tertiary services, usually even further removed geographically, ultimately placing further strain on tertiary level institutions such as the NMAH.

Phase B was set in the more coastal villages of the OR Tambo District, situated on the peripheries of the city Mthatha. Two participants were located in a remote village in the Nyandeni District called Qandu (north-west of Port St Johns). Another participant was from a small village called Swazini, located an hour north-east of Port St Johns, and the fourth participant was located in Coffee Bay (south of Port St Johns).

3.4 Phase A: Period profile/prevalence of lower limb amputation

3.4.1 Study design

A quantitative approach and a retrospective archival survey were used to determine the number of LLAs and the most common causes thereof. Period prevalence is the percentage of a population that are cases at any time within a stated period. This also includes new cases (Moulton, 2018).

3.4.2 Population and sampling strategy, and sample size

All available medical records of persons who received a major LLA at the NMAH from September 2015 to September 2017 were included in the study. This was the only period of two consecutive years that had all theatre records available. All previous records had either been lost or were incomplete. Of the 256 folder numbers of patients who received an amputation in this period (according to the theatre

records), only 17 medical folders were available to be retrieved from the records department.

3.4.3 Data collection procedure

Ethical clearance was obtained from the Biomedical Research Ethics Committee of the University of the Western Cape (Appendix 1: BM17/5/8).

Permission to conduct the study was obtained from the Eastern Cape Department of Health (Appendix 2: EC2017RP16_740). Permission was obtained from the chief executive officer of the NMAH to begin collecting data from the medical archives (Appendix 3). Medical folder numbers for persons who lost a limb were obtained from the theatre records by the researcher. Medical folder numbers, date of surgery, patients' age, gender, level of amputation and the type of surgery (i.e. revision or guillotine) as well as any other notes documented in the theatre records were documented on a data extraction sheet (Appendix 4). The list of medical folder numbers of identified patients who had undergone LLA surgery were then taken to the records room to retrieve the relevant folders. The researcher was not allowed to search for folders and the records clerk retrieved them. According to the clerk many folders were missing, or not available for unexplained reasons.

3.4.4 Data collection instruments

A data extraction sheet (Appendix 5) that was developed for this purpose in the research supervisor's previous study was used to extract the relevant data from the medical records. Data included demographic details such as patient's name, gender, age, level and side of amputation, type of amputation, initial symptoms and cause of LLA, co-morbidities and whether the patient received in patient physiotherapy.

3.5. Phase B: Exploring experiences and rehabilitation needs of persons living with a lower limb amputation in a rural setting

3.5.1 Methodological framework for the study: Direct participant observation

Observation, particularly participant observation, has been used in a variety of disciplines as a tool for collecting data about people, processes and cultures in

qualitative research (Kawulich, 2005). Marshal and Rossman (1989, p. 79) (as cited in Kawulich, 2005, p. 1) define observation as “the systematic description of events, behaviours and artefacts in the social setting chosen for the study”. Participant observation is believed to increase the validity of the study, as observations may help the researcher gain a better understanding of the context and phenomenon under study (DeWalt & Dewalt, 2002). The current research was guided by a combination of two processes of observation: focused observation and selective observation. In the focused observation process, the observation is supported by interviews in which the participants’ insight guides the researcher's decision about what to observe (Angrosino & Mays de Perez, 2000). Selective observation would guide the process by encouraging the researcher to focus on different activities to help delineate the differences in those activities. In this study, the themes that arose from the interviews guided the researcher to focus on the activities or areas of concern specific to each participant. These activities were then photographed and filmed to observe them closely and to collect visual data to add dimension for discussion and further interpretation of the selected topic under observation.

Selective observation was particularly relevant in highlighting the differences in execution of activities of daily living between someone living with a prosthesis and someone without. In this phase of participant observation, cases were purposively selected and observed.

3.5.2 Study design

A case study utilises a qualitative approach and begins with the identification of a specific case which can be an individual, a small group, a partnership, or an organisation which is viewed as a concrete entity (Creswell, 2013). Typically, a case study is used to focus on real-life cases that are in progress so that it can gather accurate information not lost by time. The key factor is to define a case that can be bounded or described within specific parameters (Creswell, 2013). In this study, the parameters that defined the selected cases were persons with a unilateral lower limb amputation who live in a rural setting in the OR Tambo District of the Eastern Cape.

A case study approach was most suitable to this setting and the overall aim of the study, which was to understand the experiences of persons living with an LLA in a deep rural setting. Creswell (2003) explains that case studies are a strategy of inquiry

in which the researcher explores one or more individuals in depth. Cases are bounded by time and activity, and researchers collect detailed information using a variety of data collection procedures over a period of time (Stake, 1995). Therefore, for the purpose of this study, which was to showcase the experiences of someone living with an LLA in a rural setting, a case study using visual feedback and interviews were most suited. Spending time with selected participants experiencing the same disability within the same environment allowed for a more detailed and well-rounded understanding of the challenges experienced as well as the overall relationship the environment plays in the dynamic. Hence the decision was made to use a case series (more than one case study) to portray the findings.

Two methods of data collection were used: First, qualitative in-depth interviews were conducted, and then followed by direct participant observation. In order to capture the observations most accurately, photo elicitation (Lenette & Boddy, 2013) and video-based fieldwork (Jewitt, 2012) were deemed most suitable.

Interest has grown in conducting qualitative research that focuses on the visual images themselves to explore participants' experiences and meaning making (Frith, Riley, Archer, & Gleeson, 2005). The use of images is not a new vehicle to collect data and is rooted in disciplines such as anthropology and sociology (Harper, 2002).

One advantage of visual methods is that not all participants are able to express themselves verbally. Similarly, not all experiences are best expressed through words (e.g. pain) and some people prefer visual expression (Guillemin, 2004).

In this scenario, the participants spoke isiXhosa as their home language and had little understanding of English. Therefore, the method of photo elicitation was very suitable as it allowed for moments to be captured in a way that might not have been easily articulated by the participants themselves. The participants were also able to recognise characteristics or scenarios that they might not have known to speak of within the interview environment.

The purpose of video-based fieldwork is to provide objective visual data of people in their natural environment (Jewitt, 2012). This technique was chosen as it provides the most objective contextual information to portray the daily challenges of persons with an LLA. It also allows for moments not necessarily elicited through interviews or stills photography to be expressed, such as nuances in family dynamics, expressions,

or execution of activities or actions performed by the participant (Rouse, 2013). In this environment it allowed for a more lived experience of the environment in which the participant is immersed. The additional aspect of audio complements the visual experience as the viewer is submerged into the portrayed reality of a certain moment or experience. The researcher triangulated the video footage in accordance with the main themes that arose from the interviews and photo elicitation section. These main focus areas were retrieved from the raw footage and compiled into a short sequence in line with (Berg, 2004), report on data analysis of action research.

3.5.3 Sampling strategy and sample size

A collective case study or case series was used to showcase different perspectives of the same issue (Creswell, 2013). A stratified purposeful sampling strategy (Creswell, 2013) was used in order to facilitate comparisons between the two levels of amputations. Stratified purposive sampling was used to deliberately select two persons with a trans-tibial amputation and two persons with a trans-femoral amputation. The intended total sample size for this study was four participants with an LLA. However, one participant was not at home despite committing to participate in advance. Therefore, the study had two participants with a trans-femoral amputation and one participant with a trans-tibial amputation. The total population size was achieved with the fourth participant being a prosthetic user. A prosthetic user was purposively sampled to showcase a comparison in function to those without a prosthetic limb.

3.5.4 Inclusion criteria

Individuals were included in the study if they had received a major LLA (either trans-tibial or trans-femoral) and were above 18 years of age.

3.5.5 Data collection instruments

A semi-structured, self-developed in-depth interview guide (Appendix 6), photographs and video footage were used to document the activities of daily living of the participants within their home environment, and to establish their rehabilitation needs.

The in-depth interview schedule was self-developed and based on the CBR matrix (WHO, 2010) (Appendix 7). The interview included questions relating to the Health

and Social pillars of the CBR matrix specifically. The questions ranged from the cause and process of amputation to perceptions of function and access to communities and integration. The questions were open-ended, and probing questions were asked for patients to elaborate on what they said. Photographs were captured by the researcher using a Nikon d3100 and a 50 mm Nikon lens while the video was recorded by a videographer using a Nikon d850 with a Tamron 24 mm–70 mm lens.

3.5.6 Data collection procedure

After ethical clearance and permission to conduct the study were received (Appendix1: BM17/5/8), data collection commenced. A translator/research assistant who was from the OR Tambo region and fluent in both the local language isiXhosa and English was employed and accompanied the researcher. The 17 patients who had undergone an LLA between September 2015 and September 2017 were contacted telephonically in order to be recruited as cases for the second phase of the study. Of these 17 potential participants, 10 contact numbers did not exist or were engaged, one patient was deceased, two patients had moved provinces, two were unwilling to be involved, and two were unwell. In order to continue with the case study, a local district hospital in the Gomolo area of the Port St Johns District was approached to assist with recruitment of participants. The therapist working at Isilimela Hospital then identified six potential participants with a unilateral LLA. The research assistant (fluent in isiXhosa) contacted the participants telephonically, and explained the purpose and intentions of the study to collect visual data. Four were willing to participate.

The ethical considerations were explained, and permission from the participant to be audio- and video-recorded as well as photographed was explicitly obtained. Participants who were interested in participating were recruited and briefed six months in advance and then one month, one week and finally the day prior to the time of data collection. Patients were called to be reminded about the study and asked whether they would still like to participate. All four participants confirmed their availability. The research team consisted of the primary researcher, the research assistant and a videographer. Data were collected over a period of one week, and the research team spent a minimum of nine hours with each participant. The researcher and team spent the day from 07:00 to 16:00 with each participant in their residence

together with their families and documented and observed general activities of daily living.

On arrival at each participant's residence, the translator again explained the background and information sheets to the participant, and written informed consent was obtained for all methods of data collection. Participants gave written consent for the use of audio-recordings as well as photographic and videographic material for research purposes. First, the research assistant conducted the semi-structured interview in isiXhosa and translated it into English for the researcher to ask probing questions. In-depth interviews, guided by the relevant categories of the CBR matrix - rehabilitation and assistive devices were audio-recorded with each participant. The participant then replied in his or her home language. Audio-recordings were later translated and transcribed for analysis. The entire interview lasted approximately 20 minutes.

The researcher took photographs of the everyday activities of the participants for one day. The participants were then shown all the photographs and were instructed to select the three photographs that most accurately represented their circumstances and challenges. The participants were then encouraged to describe the reasoning for their three choices of the photographs that they felt best portrayed their rehabilitation needs or situation. These discussions were audio-recorded (Boddy, 2013) and later translated and transcribed. Interviews were also used during the discussion process to help contextualise the footage before composing a presentation or short video.

The researcher advised a videographer to follow her as the participants went through their daily activities. Video recording was similar in process to that of the photo elicitation and footage was recorded of all daily activities seen on the day.

3.6 Data analysis

3.6.1 Phase A: Archival survey of medical records

Data collected in Phase A were coded and captured on a Microsoft Excel spreadsheet in preparation for analysis. Demographic details and data relating to causes of amputation were analysed descriptively by means and frequencies in Microsoft Excel and presented as graphs and tables. This first source of data was intended to describe the number of amputations performed in order to define the need for a community-

based rehabilitation approach.

3.6.2 Phase B: Interviews, photo elicitation, video-based fieldwork

In-depth interviews were transcribed verbatim, translated and placed in summary charts following Creswell, (2009) process of thematic analysis (Figure 3.2). The data were sorted into piles that shared the same broader theme, and thereafter a summary that captured the essence of each broader category was written, thereby creating descriptive accounts of the participants (Berg, 2004)

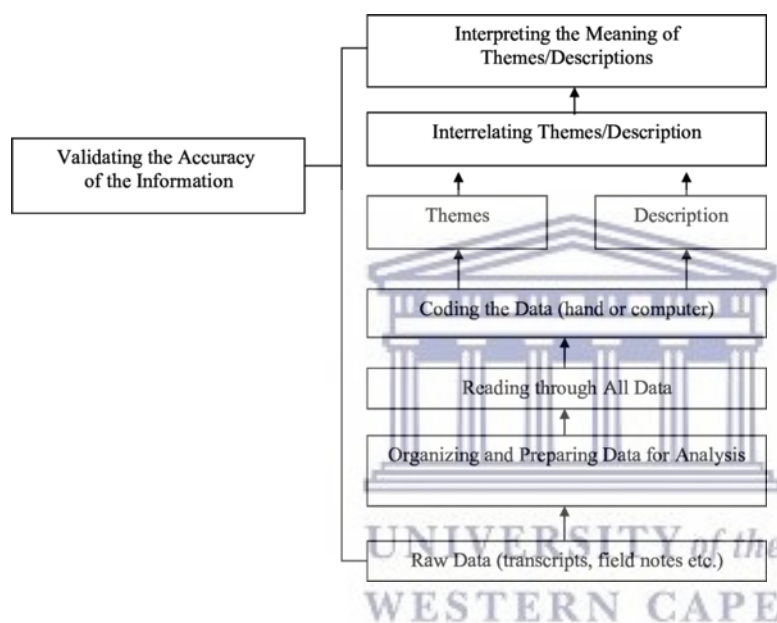


Figure 3. 2: Data analysis in qualitative research (Source: Creswell, 2009)

After the images and footage had been taken, a process of selection and contextualisation took place in line with (Berg, 2004), report on data analysis of action research. In the first step, Selecting, the participants were given the opportunity to identify which three images most accurately reflected their needs, issues or concerns. In the second step, Contextualising, the participants offered verbal accounts about their choices, which were then audio-recorded and transcribed verbatim. Through this iterative process it was ensured that the participant was part of the process of data analysis.

The first step that was taken with footage retrieved from the video-based fieldwork was to become familiar with the content. The researcher played the footage over. This is known as inductive selection where the researcher becomes familiar with the

content. This is where the raw footage was repeatedly viewed with broad questions in mind. Vaguely keeping the themes that had risen from the photo elicitation and interview phases in mind. In the next step, deductive selection, the researcher had a clearer theory. Common themes were combined by creating a suitable video dataset and systematically sampling from it to examine specific research questions.

The final stage of video-based fieldwork is narrative evolving. Here the researcher used the perceptions gained by the participants in the photo elicitation stage as well as from the interviews to guide the narrative of the final video data set (Jewitt, 2012). The footage and narration were compiled into a final video data set by a skilled video editor who was completely directed by the researcher.

Finally, the findings from all three these instruments (photo elicitation, video-based fieldwork and semi-structured interviews) were triangulated via methodological triangulation to provide a holistic and patient-centred view of participants' physical challenges and rehabilitation needs. Triangulation is defined as the use of more than one source of data to answer the research question (Creswell & Miller, 2000). Methodological triangulation involves using more than one kind of method to study a phenomenon. It has been found to be beneficial in providing confirmation of findings, more comprehensive data, increased validity, and enhanced understanding (Bekhet & Zauszniewski, 2012). According to Denzin (1978, p. 28) the logic of triangulation is based on the premise that "no single method ever adequately solves the problem of rival causal factors. Because each method reveals different aspects of empirical reality, multiple methods of observations must be employed."

The data from the three instruments (interview, photo elicitation and video-based fieldwork) were combined and compared over a single category to develop a comprehensive view of the finding.

3.7 Validity and trustworthiness of data

The data extraction sheet was assessed for face and content validity in a previous study in a different rural area. Credibility of the qualitative data analysis was ensured by the fact that the participants assisted with the analysis of the photographs in the photo elicitation (Lenette & Boddy, 2013). Video footage was sent back to participants for member checking after the narration was complete, which ensured that their views and lifestyle were portrayed accurately (Creswell & Plano Clark, 2007). The study is

transferable to other rural settings in South Africa as the researcher documented the process meticulously in order to make it easier to duplicate. The study supervisors conducted a data audit of all the raw data and performed an independent analysis of the qualitative data to ensure the confirmability of the study findings (Creswell & Plano Clark, 2007).

The study findings are not generalisable to all persons with LLA due to the small sample size. However, it provides some insight into the similarities and differences in challenges experienced by persons with different levels of amputation and function in a rural setting.

3.8 Ethics statement

Permission to conduct this research was obtained from the Ethics Committee of the University of the Western Cape, the Eastern Cape Provincial Department of Health, and the Clinical Manager and Chief Executive Officer of the NMAH in order to conduct the study in this district.

Written informed consent was obtained in isiXhosa from all participants. This included consent for audio-recording, photography and video-recording. Each participant was issued with an information sheet written in isiXhosa explaining the above. All participants were made aware of the aims and objectives of the study, as well as the outcome. Any community member who was not one of the four case studies but whose face is captured on footage and visible, also signed a release/consent form to use their image for research purposes. The release/consent form was described to them in isiXhosa to ensure transparency. The findings of the study have been shared in a report that will be made available to the NMAH, as well as the Provincial Department of Health. The video footage might still be used in conference presentations in order to share the real-life experiences and needs of these patients. With regard to the case study, research objectives were articulated verbally and in writing for clarity. The participants were informed of all data collection devices and activities. Verbatim transcriptions and written information sheets and reports were made available to the participants. The participants' rights, interests and wishes were considered first when choices were made regarding reporting the data, and the final decision regarding participant anonymity rested with each participant.

3.9 Conclusion

This chapter discussed the methods followed in collecting and analysing data related to this study. A mixed methods approach was used to determine the prevalence of LLA as well as the perceptions of someone living with a LLA within the study setting. Phase A comprised of a retrospective archival study to ascertain the number of LLA performed within the OR Tambo District and data was captured using Microsoft excel for analysis. Phase B explored the perceptions of three participants living with a LLA and one participant who was a prosthetic user. A case series design using in-depth interviews, photo-elicitation and video-based fieldwork as instruments of data collection. The data was then analysed using a process of thematic analysis and triangulated in table form.



CHAPTER FOUR: RESULTS

Introduction

This chapter presents the results of the study. Phase A presents the findings for the quantitative section of the study that explored the period prevalence of LLA at the main hospital of the district. Thereafter, the findings of Phase B are presented according to each instrument of data collection (interview followed by photo elicitation and finally video-based fieldwork). Lastly, the results from the three instruments of Phase B are triangulated in a summary table to provide an overview of the results.

PHASE A

4.1. Overview

This first source of data was intended to describe the number of amputations performed in order to define the need for a community-based rehabilitation approach. Within a two-year period, 256 LLAs were performed at the NMAH. On average, between 10 and 11 amputations were performed per month. General demographic statistics were retrieved from the theatre records where available and represented using tables and charts. Of the 256 theatre records and medical folder numbers that were identified, only 17 medical folders were made available from the records department. Relevant information pertaining to in-patient therapy, medical history and cause of amputation is also provided in this chapter. However, it should be noted that the quality of documentation of medical records was poor and information pertaining to medical history and management of patients was often missing.

THEATRE RECORDS:

The majority (61.3%; N = 256) of LLAs performed at the NMAH over the two-year period were on male patients.

The majority of patients who sustained an LLA at the NMAH over the two-year period were between 41 and 80 years of age (see Figure 4.1.1).

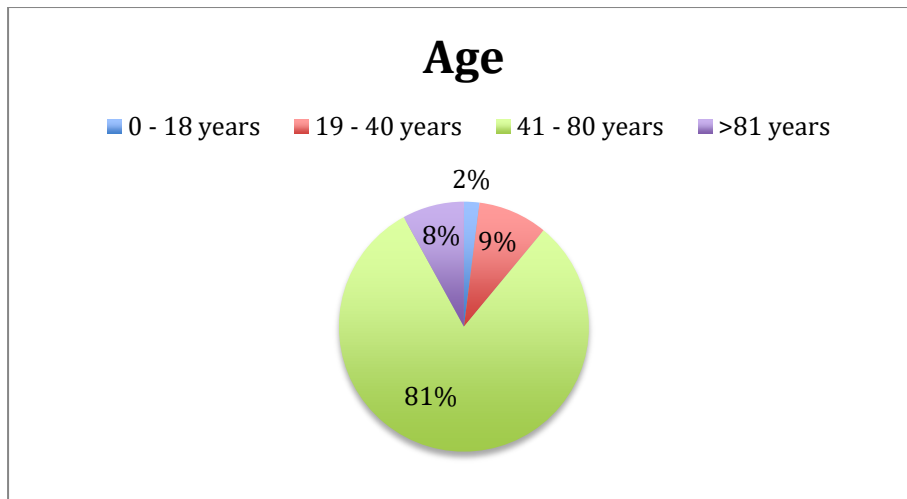


Figure 4.1.1: Age at time of amputation of patients who underwent a LLA from NMAH theatre records

The majority (59%; N = 256) of the patients sustained a trans-tibial amputation with 35% undergoing a trans-femoral amputation (see Figure 4.1.2).

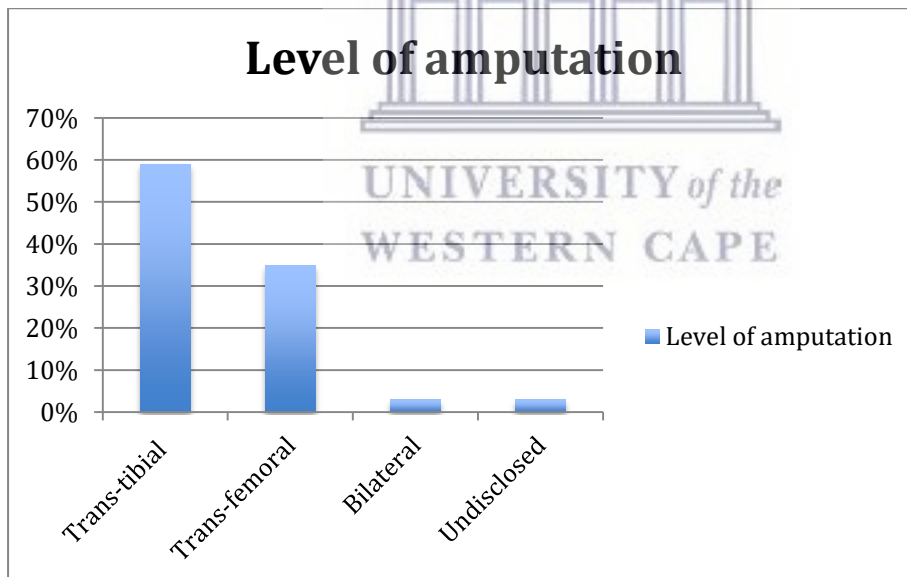


Figure 4.1.2: Level of LLA from theatre records

The most common cause resulting in LLA documented in the theatre records at the NMAH was related to diabetic complications and sepsis. Most of the records (75%; N = 256) lacked information or notes and no cause was documented. Altogether 23% (N = 256) were noted to be due to complications related to DM.

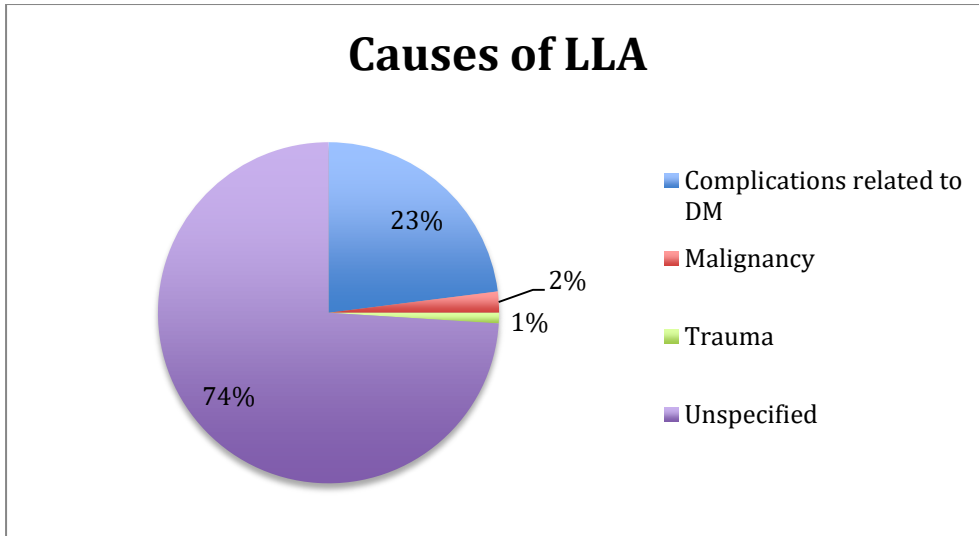


Figure 4.1.3: Causes of LLA from NMAH theatre records

MEDICAL RECORDS:

Out of 256 theatre records, only 17 medical folders could be retrieved from the records department at NMAH. The information retrieved from the medical folders was intended to expand on information relating to the process of care and other relevant information relating to LLA. However, due to the low number of folders retrieved and poor note taking within those retrieved, findings were limited. Regardless, the information is depicted below (Figure 4.1.4 and Table 4.1.1).

70% (n = 17) had no record of receiving in-patient rehabilitation.

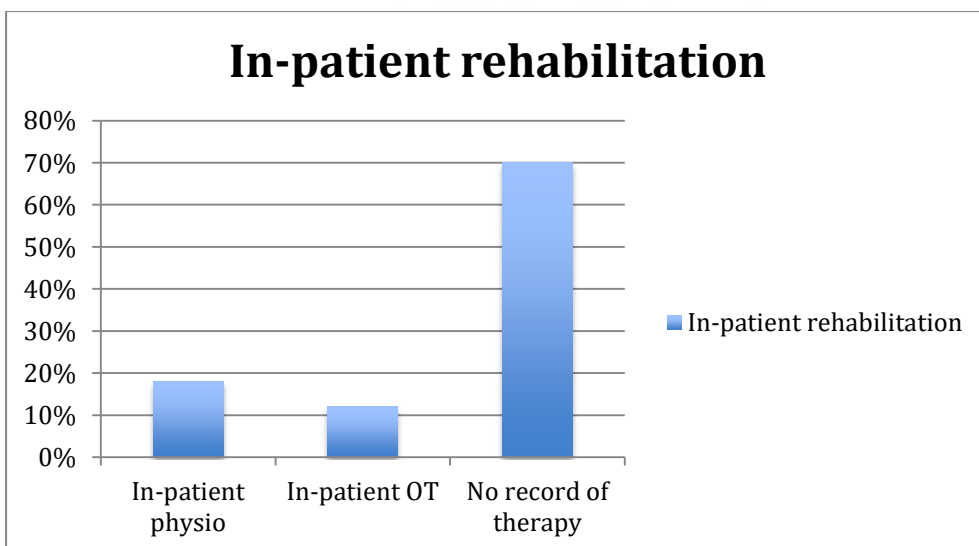


Figure 4.1.4: In-patient rehabilitation from medical records at NMAH

The comorbidities that were most commonly associated with LLA were the combination of DM and Hypertension (n = 41%)

| RELEVANT MED Hx | Percentage |
|---------------------|------------|
| DM | 6% |
| DM and Hypertension | 41% |
| Hypertension | 12% |
| Other | 24% |
| None | 17% |

Table 4.1: Comorbidities associated with LLA from medical records at NMAH



PHASE B:

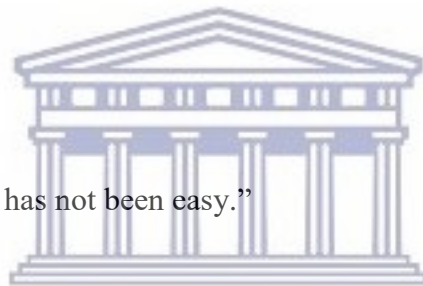
4.2. Overview

This section introduces each of the three case studies in detail. The results of the photo elicitation for each of the main case studies follow the interview findings for each participant. Thereafter, the interview findings for a single case of a person with a prosthesis are presented in order to explore the functional outcomes of living with a prosthesis as opposed to those who do not. Photo elicitation was not used for the prosthetic user as this participant was used to compare the impact that prosthesis makes. A link to the video-based feedback section is provided with a password for reference. A table is presented at the end that triangulates all the findings from each of the instruments (see Table 4.2).

4.3. Participant 1

4.3.1 Interview

“I am struggling, it has not been easy.”



P1 is a 63-year-old woman. She is known to be hypertensive and is a poorly controlled diabetic. In 2015, she suffered a left trans-tibial amputation as a result of a diabetic foot ulcer. The ulcer progressed, and her left foot became gangrenous and necrotic, resulting in the amputation.

“I developed a foot wound ... a diabetes wound”

“Then I was told that the foot would be amputated and at that point the foot was already rotten. In 2015 the amputation was done then I had this problem of not having a leg.”

Prior to the amputation, the participant was independent in her daily living activities and caring for her family. She was not formally employed but provided for her family by working in their garden and doing subsistence farming. At the time of the amputation, the participant did not receive any counselling regarding her limb loss, and she felt as if she had not had a say in the decision-making process.

“I did not agree to have my leg amputated.”

After the amputation, the patient did not receive any rehabilitation or counselling, but was just told by the doctor to “continue as before”. On discharge she had to overcome the challenges of adjusting to having only one leg by herself. Trying to adapt to her living environment with only one leg proved particularly difficult due to physical barriers such as landscape, terrain and inaccessibility. The participant explained that she had to teach herself how to adapt to her surroundings. She was no longer able to tend to the garden, which added strain on the family’s financial resources.

“I had no idea what I would do, it was difficult.”

“... but I tried to train myself.”

Due to the steep gradient within her property, the participant had to rely on someone for assistance when leaving the bedroom in order to avoid falling. The kitchen is situated at the bottom of the garden on their property and the participant explained that if she does not have help, she needs to crawl on her hands and knees up or down the steep slope if she wants to go to the kitchen. This is particularly challenging when the weather is bad. Muddy or slippery conditions confine the participant to her bedroom, further isolating her from her family and daily routine.

“I stay in my bedroom and I cannot even go outside when it rains.”

“... if it is raining like right now, I cannot go cook in the kitchen. Our kitchen is far, I am struggling.”

After her amputation, she had to rely on her children and husband to take over the tasks that she used to be responsible for, placing strain on the family dynamic. Her husband had to assist with cooking, which is not acceptable in this cultural context. She mentions how the family have taken strain with the shift in dynamics and how members have had to take on additional chores and assist her by bringing water to her when she needs to wash. Her children have also struggled to accept their mother's lack of independence.

“I stay with my husband and he cooks for me; it is not right.”

“... some family members have still not accepted it.”

However, the participant reported trying to stay positive, and showing her family that she can still contribute to the household by being able to sweep the floor on her hands and knees in the kitchen and wash the dishes.

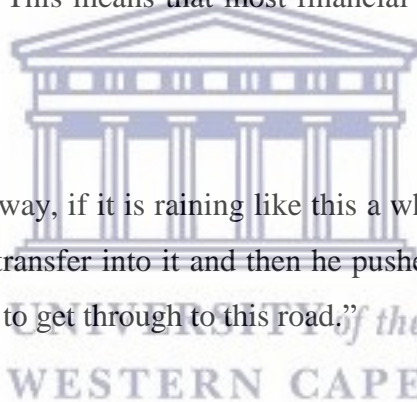
After her amputation, the participant was unable to attend community meetings or visit friends as she had previously done, due to her challenges with mobility. She mentioned that she had previously often visited neighbours and worked in the gardens every day. Now she was bound to her house. She rarely receives visitors, as she lives at the top of a steep hill and, according to her, people do not enjoy walking the distance to visit her. The only time the participant leaves the house is for special occasions or to visit the hospital to manage her medication. The participant is still struggling to control her diabetes, and sometimes has to visit the hospital as often as three times a month.

“Even in the community, if there is a problem being discussed then I cannot attend.”

“It is painful to not be able to do anything and I hear about everything while sitting at home.”

“I get happy when someone arrives, even if I do not know them.”

Due to her mobility challenge as well as the environmental challenges, travelling to the hospital is expensive. The participant must hire private transport because she is unable to sit in the taxis as they are not suitable for persons with disabilities. The private vehicles charge R400 for each trip; which means that often, R1 200 is spent on her health condition per month. Her family rely on government grants as income since no one is employed. This means that most financial resources are spent on her health condition:



“... the stop is far away, if it is raining like this a wheelbarrow is used and my husband helps me transfer into it and then he pushes it until the stop because vehicles are unable to get through to this road.”

“I go to the city once a month perhaps; however, to the hospital I go up to three times some months because I keep failing. My diabetes acts up and my blood sugar levels increases, the pressure increases and I fail.”

“It is R400 when I have taken a special to their hospital.”

The participant feels that a prosthetic leg would assist her in her mobility challenges. She feels that it would fix all her problems and allow for more independence. She would be able to join her family and partake in community events. She also wishes to be taught a skill that requires her to use her hands, in order to earn some income.

“I really wish to receive a leg so that I can be with my family. Then I would be able to walk independently and get to be there.”

“Perhaps by showing us things that we can make by hand...”



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4.3.2. Photo elicitation

P1 chose three images that related to her function. She wanted to portray that despite her disability she is trying to maintain some level of independence in executing her usual activities. However, despite her attempts to maintain independence, she still relies on her husband and children to assist her and this has a negative impact on her dignity and self-esteem.



1a. "This picture you can see I am struggling to get into the house."



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2b. "I am trying to help the family."



3c. "I am relying on someone who helps me with everything I need."

4.4. Participant 2

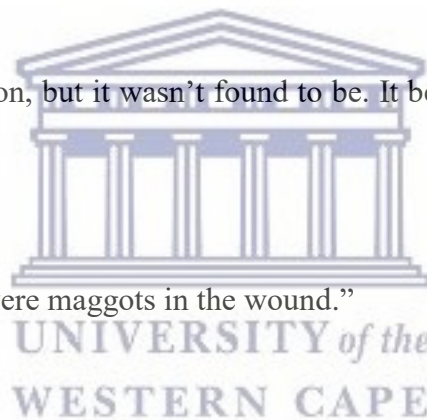
4.4.1. Interview

“No, I am seen as just ... a person who they stay with at home. I am not seen in the same way as before where I would speak and be heard.”

P2 is 59-year-old male. He underwent a right sided trans-femoral amputation in 2014. The amputation was the result of a sore on his foot which developed over time into a necrotic wound. P2 was diagnosed with diabetes just after seeking medical attention for the wound. The participant underwent four revision surgeries but the infection could not be controlled, necessitating a trans-femoral amputation. He is currently on Metformin and insulin injections.

“I thought it was a bunion, but it wasn’t found to be. It became a wound when it appeared.”

“I found out that there were maggots in the wound.”



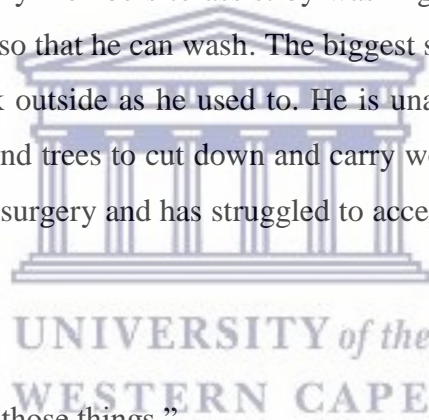
Prior to the amputation he could bring in an income that would help support his family and school-going children. His job was to collect and carry wood which he would then sell. He was used to an active lifestyle and would care for his herd of cows and maintain his yard, garden and kraal (an enclosure for sheep and cattle). His responsibilities would include letting his cows out in the morning and sending them out to pasture. In the evening he would have to walk for long distances to bring the herd back home. During the day he would work in the vegetable garden or do maintenance on the kraal or be out chopping wood.

“I stopped working because of not having this leg.”

“There are many things which I was able to do before. I could garden independently, I could use my rake independently in my garden using my foot. Now I am unable to do those things.”

“I would chop down tree branches, and carry them near the road. I would do this so that I can get money selling the wood in order for us to eat at home.”

After the amputation he has been unable to carry out these activities and there is no income in the family other than his disability grant and the grants for his children under the age of 18. P2 has adapted to living with an LLA since the time of his amputation. He is able to dress himself, eat, wash and use the toilet independently. However, he still relies on family members to assist by washing his clothes, cooking food and bringing water to him so that he can wash. The biggest struggle for him since his LLA is that he cannot work outside as he used to. He is unable to work with his cows, fix the kraal or walk to find trees to cut down and carry wood home. P2 lived a very active lifestyle prior to his surgery and has struggled to accept his current level of function.



“Now I am unable to do those things.”

“For something to happen now, I have to first beg people, whereas before I would simply do things myself.”

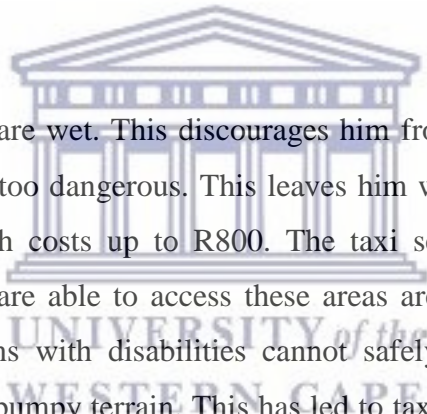
Not being able to provide for his family as he used to leads to feelings of disempowerment. His children no longer come to him for their needs as they used to. He feels disrespected within the home. He used to be in charge of his cows and the kraal and the garden. Now he relies on his sons to help. The tension comes about when he asks for help and no one helps. He feels he must shout and scream before anyone will help, whereas before, he could do his usual routine independently. This leads to tension between him and his sons and pushes him to take risks that might be unsafe,

with a high risk of falling when attempting to do tasks independently. P2 feels depressed and unworthy. He feels as if he does not fit in with his family and that no one understands his situation.

“It does not make me feel good, it makes me feel bad a great deal.”

“It hurts me. It hurts me because when the children needed anything for school and money was needed, then the children were always looking to me.”

“Now they (are) looking to their mother now but their mother also doesn't have money, she's unemployed.”



P2 falls easily when the roads are wet. This discourages him from venturing outside during the rainy season as it is too dangerous. This leaves him with no choice but to arrange private transport, which costs up to R800. The taxi service in his area is unsafe. The only vehicles that are able to access these areas are pickup trucks with wooden benches inside. Persons with disabilities cannot safely stay seated as the vehicle makes its way over the bumpy terrain. This has led to taxis passing him by on the road when he is looking for transport. P2 says that the people in the back ask the driver to pass him because he has only one leg.

“Living in the rural areas, we struggle because the places we have to travel are in a bad shape.”

“... we slip and fall constantly.”

“This causes us to seek vehicles which can assist us to get where we need to go.”

P2 has to plan his trips to the clinic carefully. He will have to wake up early in the morning and (if it is not raining) he will take a long and slow walk to the clinic and return late that afternoon. A trip to the clinic to collect medication takes an entire day. If it is raining he cannot get there and might not get his medication, which would mean he would have to schedule a trip to the local hospital, which is much further away. Spending money on transport just to access the clinic or hospital for medication negatively affects his family. Money that could be spent on his family's needs has to be spent on his health. This too places strain on the family dynamic.

P2 enjoys attending community events and social gatherings; however, to attend events further away, he will need to hire a vehicle. If there are no funds for this, it means he will have to stay home. P2 notes that the community has not treated him differently since the amputation – only that a taxi might pass him by because he has had an amputation.

“In order for me to be able to attend events which are further away, there has to be a car.”

“No, I couldn't accuse people for treating me badly because they treat me very well.”

“Sometimes I'll see taxis pass me by because people ask the driver to do so since they ask where will they sit. That hurts me, that a taxi may not stop because of the way I am, because I have this one leg.”

He yearns for his independence and has searched far and wide for a solution. P2 has tried every avenue possible to find a prosthetic leg, only to be met with excuses and

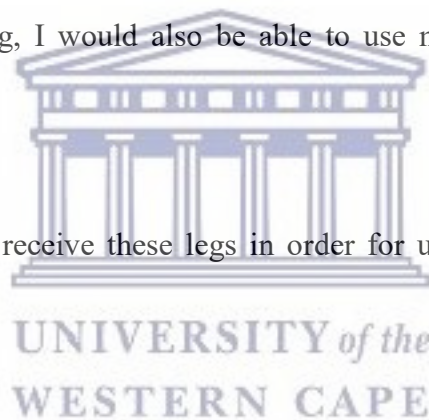
waiting lists. It has been five years since his amputation and he has not received any feedback from healthcare providers regarding prosthetic rehabilitation.

P2 wishes for improved healthcare services and transparency in the process. He wants better communication from the healthcare service and does not want to be met with empty promises. He wants a prosthetic leg as he feels this will give him independence. He would then be able to work in his garden again and walk independently.

“I would like to ask for is that any services which may help us could be done faster.”

“If I could receive a leg, I would also be able to use my spade and do my gardening.”

“It is my wish that we receive these legs in order for us to be able to walk independently.”



4.4.2. Photo elicitation

From the three images that were selected by P2, it is clear that his biggest need is to be independent in his activities of daily living once again. Being able to manage his animals and garden make him feel fulfilled. Now that he is unable to manage these duties as before, he feels unworthy and this has a negative impact on his psychological well-being.



1a. "This picture shows how I stand with a crutch without a leg as I can't do it any other way."



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2b. "This picture shows how I take my cows to the veld which I shouldn't be doing but don't have a choice."



3c. "This picture shows how hard the life is that I am living."

4.5. Participant 3

4.5.1. Interview

“My daughter was born with this disability. While she depends on me, I am also a burden.”

P3 is a 60-year-old female with hypertension, osteoarthritis and DM. She noticed a sore under her toes and went directly to the local hospital where she underwent a trans-metatarsal amputation. Subsequently the infection spread and this led to the trans-femoral amputation in 2015.

“A wound developed underneath. I had a huge wound.”

As far as she could recall, the participant did not receive physiotherapy. She mentioned that she could do nothing for herself. She was wheeled around in a wheelbarrow or would shuffle on her buttocks until she managed to get to the local hospital in 2016 and was given a wheelchair. The participant was unable to use crutches due to her right lower limb deformity secondary to a motor vehicle accident in 1998 and was unable to weight bear through the right lower limb. She was unable to use crutches safely and was not evaluated or issued with an appropriate assistive device prior to discharge. She left the hospital with no assistive device. P3 had no post-operative stump care and a stitch remains in the distal end of the poorly shaped stump.

Post-operatively, P3 recalls that she was and is still not able to go to the toilet. A bucket must be brought to her inside her house because the toilet is situated outside and up a slight incline. She is unable to access it. Since her amputation she has been unable to execute her usual activities such as gardening and fetching wood. P3 has become house-bound. Furthermore, she has a 34-year-old daughter who was born with an intellectual impairment. Her daughter is completely dependent on her for all activities of daily living.

“My daughter was born with this disability. Now she is unable to even wash herself, she is a child.”

“I have to do everything for her”

Since being discharged from hospital, she can now cook for her family as they bring the utensils and ingredients to her. The same is true for washing clothes and dishes. P3 can cook, wash dishes and laundry and dress herself and grandchildren as long as there is always someone around to help move or bring items closer or away.

“I am now dependent; whenever I need to go somewhere people are needed to assist me.”

“I can scrub the floors at home.”

“I get on the wheelchair then I am able to wash and cook.”

She is no longer independent and feels trapped and isolated from her community. P3 wishes that the roads were in a better condition so that she can be pushed in the wheelchair to attend church. Her family come to her on a Sunday as she is unable to leave the property easily.

“What bothers me is being unable to do things which I could do independently before.”

“I cannot get out of here. I shuffle on my behind.”

Being isolated and restricted to the house exacerbates P3’s feelings of depression and restricts and limits her autonomy. She has become passive to the restrictions her disability has placed on her. Whilst she does not appreciate her situation, she realises there is no point in fighting it. It is emotionally taxing and she feels disempowered by having to rely on others.

She would desperately like to go out to church and get out of the house. She can only leave the house for emergencies and when this happens she is carried into a wheelbarrow and pushed to a private vehicle. These trips cost her R600 of her minimal grant money.

“I only go for an urgent problem.”

“I have a wheelbarrow brought out and the chair is taken to a hired car which transports me to the city for that problem.”

“It costs R600.”

The participant had to learn to adapt to living with her left lower limb amputated and to care for herself as well as for her family and disabled daughter. She did all of this without an assistive device. The participant feels she is burdened by her daughter’s disability while she herself is a burden. She has had no rehabilitative input for herself, her daughter or the situation. P3 has tried hard to adjust to her situation and mentions that she struggles to process and deal with the reality of the situation.

“I accept it then I have times of not accepting.”

P3 feels that an artificial leg would help to increase her independence and hopes for the day she might receive one. She also hopes for the road to be fixed which will make travelling easier and she could push her own wheelchair or access transport services more easily. This would allow her more opportunity to integrate and join in on community activities or do her own shopping.



4.5.2 Photo elicitation

Despite being housebound, P3 makes an effort to contribute to the household and care for her family. She chose these images as they best depict how she is responsible for her family – yet she is burdened by her disability.



1a. “The first pic reveals that I am not just sitting, I am performing something. I am doing the washing.”



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2b. “You can see that my family eat under my name because I am cooking for them.”



3c. “Here you can see that I use a bucket for urinating and number two.”

4.6. Participant 4

4.6.1. Interview

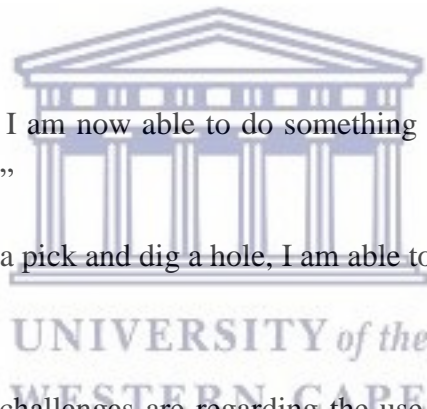
“... some of the things I could not do, I am now able to do.”

P4 is a 42-year-old male who underwent a trans-femoral amputation in 2003, following a soccer injury. He received a prosthesis in 2016 through a private sponsor organised by the rehabilitation team at the local hospital.

P4 indicated that having a prosthetic leg has allowed him to execute activities such as digging that he could not do before he received the prosthesis.

“... with the second leg I am now able to do something which I could not do when it was just one leg.”

“... when I need to hold a pick and dig a hole, I am able to dig now.”



When asked what some of the challenges are regarding the use of his prosthesis, P4 noted that chafe of the prosthesis on his stump limited him from optimal use. He mentioned that he has developed pressure sores secondary to chafe.

“... it chafes a lot when I'm wearing it for a long period of time.”

“... when I am walking uphill it gives me a hard time.”

“Chafing is the biggest problem.”

“I sometimes find that there is a pressure sore there on the part that chafed.”

P4 felt that more sponge to soften the lining of the socket might improve this problem.

“... perhaps a sponge-like material to help make it soft and comfortable inside the leg.

“Maybe it would be better.”

P4 was not included in the photo elicitation because he was ~~merely~~ included as a reference that compares the impact of a prosthesis on the functioning of an individual who lives with an LLA in a rural area of the Eastern Cape.



4.7. Video-based fieldwork

During each patient visit, the researcher spent an entire day with the participant. The videographer followed them, and captured footage as they performed their normal activities of daily living. A video-documentary was then compiled from the footage that was captured during the day, based on the similarities between the three cases. This footage was used to visually represent the activities of everyday life and challenges or rehabilitation needs. It was finally used for triangulation with the findings from the photo elicitation, and interviews.

Please view the video-based fieldwork at the link below:

- <https://vimeo.com/276403898>

The password to access the Vimeo link is: Nyamezela

4.8. Triangulation of findings

The main themes identified were: psychological/personal challenges, activity limitation, environmental factors as well as access and community participation restrictions (see Table 4.2).

Table 4.2: Triangulation of interviews, photo elicitation and video-based fieldwork

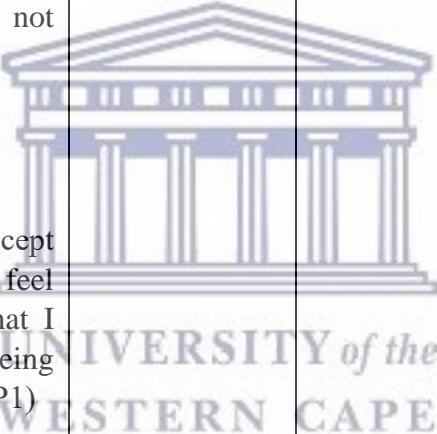
| Theme | Categories | Supporting quotes | Photographic evidence (Refer Appendix 8) | Reference to time in video documentary (see https://vimeo.com/276403898 ; Password: Nyamezela) | Resulting need |
|--|---|---|---|--|---|
| Psychological/ personal challenges | Difficulty accepting amputation | “... some family members have still not accepted it” (P1) | e) v) | 01:08 – 01:13 | Psychological counselling |
| | “I accept it then I have times of not accepting” (P3) | d)ii) | | | |
| | Sense of disempowerment | “It does not make me feel good, it makes me feel bad a great deal.” (P2) | l) t) | | Rehabilitative input to train or restructure environment that could encourage independence, advocacy and communication, |
| | | “Here you can see that I use a bucket for urinating and number two.” (P3) | e)i) | | |

| | | | | | |
|--|------------------|--|---|---|---|
| | | <p>“No, I am seen as just ... a person who they stay with at home. I am not seen in the same way as before where I would speak and be heard.” (P2)</p> <p>“... I do not feel good when the tasks that I should be doing are being done by my husband.” (P1)</p> | <p>y)</p> | <p>05:10 – 05:23</p> | <p>and community mobilisation to change people’s perceptions.</p> <p>Self-help group to support and learn from one another. This may serve as a platform for support and decision making.</p> |
| | Burden on family | <p>“My daughter was born with this disability. She depends on me for everything while she depends on me, I am also a burden.” (P3)</p> <p>“The family is affected negatively by that because the money could be used for buying food. There is nothing that anyone can do to stop it because I am going for health reasons. My family is hurt by that.” (P2)</p> | <p>a)</p> <p>c)</p> <p>j)</p> <p>w)i)</p> <p>a)i)</p> <p>c)i)</p> <p>d)i)</p> <p>g)i)</p> <p>i)i)</p> <p>k)i)</p> <p>l)i)</p> <p>t)i)</p> <p>z)</p> | <p>0:46 – 0:48</p> <p>01:19 – 01:28</p> <p>01:35 – 01:43</p> <p>01:59 – 02:11</p> | <p>Need for family counselling and planning pre-op to see how the dynamic of family could be affected by amputation and then to intervene appropriately.</p> <p>For example, if the patient was the breadwinner how can a new income be generated within the family, or if the patient has a child with disability can a community member or community care worker be assigned to the family to help?</p> <p>Needs appropriate employment</p> |

| | | | | | |
|---------------------|----------------------|---|--|---|--|
| | | | | | opportunities. |
| | Motivation | <p>“I tell them no there is still hope because I am still alive. I am able to hold the broom and sweep ...” (P1)</p> <p>“I can scrub the floors at home when I'm given the water I can clean the floor all over the house, that's what I am able to do here at home.” (P3)</p> | f) g) | 05:24 – 05:39 | |
| Activity limitation | Confinement to house | <p>“My wish is to be able to get a way to be able to get out the house.” (P3)</p> <p>“Living in the rural areas, we struggle because the places we have to travel are in a bad shape. We slip and fall constantly.” (P2)</p> <p>“I cannot go cook in the kitchen. Our kitchen is far, I am struggling. I stay in my</p> | u)i) j)i) d)i) r) s) a) | <p>02:15 – 02:28</p> <p>0:06 – 0:22</p> <p>05:52 – 06:02</p> <p>10:09 – 10:11</p> | <p>Need for improved quality of pathways (concrete) as well as rehabilitative input which includes prosthetic intervention.</p> <p>Patients need training on how best to structure components for activities of daily living. A prosthesis may help them to be more independent within usual activities of daily living as they might not have to rely on family members to bring water or cutlery to them, etc. They could possibly carry out these</p> |

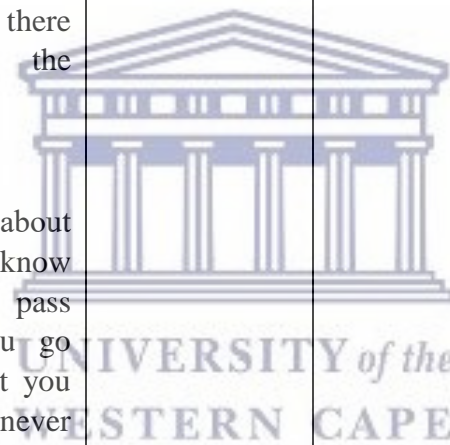
| | | | | | |
|--|--|--|--|--|--|
| | | <p>bedroom and I cannot even go outside when it rains.” (P1)</p> <p>“I stay in my bedroom and I cannot even go outside when it rains.” (P1)</p> | <p>u)i)</p> | <p>09:54 – 09:57</p> | <p>activities independently.</p> |
| | <p>Lack of comprehensive rehabilitation services and follow-up</p> | <p>“It was difficult! I could not even wake up and make the bed.” (P1)</p> <p>“This picture shows how I stand with a crutch without a leg as I can’t do it any other way.” (P2)</p> <p>“Even if I move on my knees at home, but to keep trying. It was just darkness, but I tried to train myself.” (P1)</p> <p>“We are always told about waiting lists that we know nothing about. Years pass</p> | <p>e) f) g)</p> <p>t)</p> <p>a)</p> <p>w) x)</p> | <p>01:34 – 01:42 09:47 – 10:00</p> | <p>Pre-operative and post-operative rehabilitation: transfers and activities of daily living training.</p> <p>Need for appropriate assistive technology.</p> <p>Rehabilitation services need to have better outreach services and sustainable staff programmes.</p> <p>Prosthetic rehabilitation needs to be implemented with specific focus on the environment.</p> |

| | | | | | |
|--|----------------------|---|---|--|--|
| | | <p>by but whenever you go there you get told that you will be called but that never happens, we're just waiting now.” (P2)</p> <p>“For a long time now I have been asking but I have not been answered.” (P3)</p> | | | |
| | Lack of independence | <p>“For something to happen now, I have to first beg people, whereas before I would simply do things myself.” (P2)</p> <p>“When I have to do something, perhaps there is no one or I just have these children and this young lady around, then that bothers me, it is not fun at all... because what I thought I could do, I end up being unable.” (P3)</p> | <p>l)</p> <p>o)</p> <p>f)i)</p> <p>a)i)</p> <p>b)i)</p> | <p>04:01 – 04:13</p> <p>04:46 – 05: 07</p> | <p>Rehabilitation and prosthetic intervention and long-term training</p> |

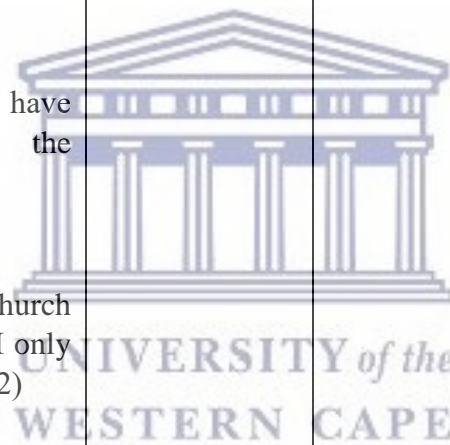
| | | | | | |
|--|------------------------|---|---|--|--|
| | | <p>“I really wish to receive a leg so that I can be with my family. Then I would be able to walk independently and get to be there.” (P1)</p> | <p>u)i) l)i)</p> | | |
| | <p>Role adjustment</p> | <p>“I stay with my husband and he cooks for me, it is not right.” (P1)</p> <p>“That I really cannot accept fully, because I do not feel good when the tasks that I should be doing are being done by my husband.” (P1)</p> <p>“My daughter was born with this disability. Now she is unable to even wash herself, she is like a child. I have to do everything for her. She depends on me for everything.” (P3)</p> |  | <p>01:37 – 01:41 01:59 – 02:15 04:06 – 04:15</p> | |

| | | | | | |
|-----------------------|---|---|-----------------------|--|---|
| | | <p>“It hurts me ... It hurts me because when the children needed anything for school and money was needed, then the children were always looking to me.” (P2)</p> | | | |
| Environmental factors | Lack of access to medical information and rehabilitation services | <p>“I was diagnosed with diabetes. The leg got injured then, then I continued with diabetes treatment. Then as time went by, this foot became swollen and then a wound developed underneath. I had a huge wound.” (P3)</p> <p>“I go to the city once a month perhaps however to the hospital I go up to three times some months because I keep failing. My diabetes acts up and my blood sugar levels increase, the pressure increases and I fail then a 'Special' is called and a car is hired that takes me to the hospital. I even go three times.” (P1)</p> | <p>b)ii) m)i)</p> | <p>03:35 – 03:39 03:45 – 03:50 06:01 – 06:22</p> | <p>Community members can be trained as community care givers who can then be trained to do diabetes screening and monitoring.</p> |

| | | | | | |
|--|---|--|------|--|--|
| | | <p>“At first, something appeared there on my big toe. I thought it was a bunion, but it wasn’t found to be. It became a wound. When it appeared, I went to the hospital because of that wound. When I arrived there, I found out that there were maggots in the wound.” (P2)</p> <p>“We are always told about waiting lists that we know nothing about. Years pass by but whenever you go there you get told that you will be called but that never happens, we’re just waiting now.” (P2)</p> | l)i) | | |
| | Poor infrastructure and access to transport | <p>“I only go for an urgent problem I have a wheelbarrow brought out and the chair is taken to a hired car which transports me.” (P3)</p> | | | <p>Need for improved and suitable access pathways from house to road where transport can pick up the patients.</p> <p>Prosthetic intervention may also</p> |



| | | | | | |
|---|-------------------|---|--------------------------------------|--|--|
| | | <p>“Sometimes I'll see taxis pass me by because people ask the driver to do so since they ask where will they sit. That hurts me, that a taxi may not stop because of the way I am, because I have this one leg.” (P2)</p> <p>“It is R400 when I have taken a special to the hospital.” (P1)</p> <p>“I am able to go to church services, even though I only go to those nearby.” (P2)</p> | <p>r) d)i) h)i) u)i)</p> | <p>06:29 – 06:31 05:52 – 06:01</p> | <p>be a solution for some people.</p> <p>Appropriate surfaces/paths on which to propel wheelchairs</p> |
| Access and community participation restrictions | Community support | <p>“No, I couldn't accuse people for treating me badly because they treat me very well.” (P2)</p> <p>“The community and at services they sound very sympathetic towards me and</p> | | | |



| | | | | | |
|--|------------------------------------|---|---------------------------------|---------------|---|
| | | treat me very well, even better than before.” (P1) | | | |
| | Financial challenges | <p>“The family does not pay for my travels, I use my grant money.” (P1)</p> <p>“I would chop down tree branches, and carry them near the road. I would do this so that I can get money selling the wood in order for us to eat at home.” (P2)</p> <p>“I stopped working because of not having this leg.” (P2)</p> | <p>v)</p> <p>w)</p> <p>a)i)</p> | 05:51 – 06:00 | Occupational rehabilitation and skills development suitable to environment and individual |
| | Restricted community participation | “Even in the community, if there is a problem being discussed then I cannot attend.” (P1) | <p>d)i)</p> <p>w)</p> | | |

| | | | | | |
|--|--|---|--|--|--|
| | | “In order for me to be able to attend events which are further away, there has to be a car.” (P2) | | | |
|--|--|---|--|--|--|

4.9. Conclusion:

This chapter revealed the incidence of LLA within the OR Tambo District of the Eastern Cape as well as the related common causes and comorbidities. Thereafter, the personal experiences of those living with an LLA in the rural areas of the OR Tambo District were revealed via three different instruments, namely in-depth interviews, photo elicitation and video-based fieldwork. The findings of these three instruments were triangulated and tabulated into common themes and these themes were further expanded into categories. The main themes discussed in accordance to the ICF and were Psychological/personal challenges, activity limitations, environmental factors and community participation/participation restrictions. Thereafter the main findings were tabulated into categories under the relevant headings and were found to be difficulty accepting amputation, sense of disempowerment, burden on family, motivation, confinement to house, lack of comprehensive rehabilitation services and follow-up, lack of independence, role adjustment, limited access to medical information and rehabilitation services, poor infrastructure and access to transport, community support, financial challenges and restricted community participation.

CHAPTER 5: DISCUSSION

5.1. Overview

In this chapter the results from this study are discussed and the findings are compared with those in the current literature. Recommendations to overcome the relevant challenges and needs identified are also offered.

5.2. Discussion of quantitative findings

5.2.1. Number of lower limb amputations

From 2 October 2015 to 12 September 2017, 256 major LLAs were performed at the NMAH in the Eastern Cape. Of all the theatre records, this was the only consecutive two-year period with records available. On average, 11 LLAs were performed per month during this period. This is almost five times more than the average of two amputations performed per month recorded at Jos University Teaching Hospital in Nigeria over a period of five years (Kidmas, Nwadiaro, & Igun, 2004) which could be indicative of the change in lifestyle habits of South Africans that encourages chronic diseases resulting in LLA. The high incidence of LLA in the OR Tambo District in South Africa is disconcerting and the causes of these amputations should be considered in order to inform preventative measures. In the current study, it was found that the majority of amputations were caused by late diagnosis of diabetes and a lack of awareness of its complications. These findings were also supported by the qualitative data collected from the participants in the case series:

P3: “I thought it was a bunion, but it wasn’t found to be. It became a wound when it appeared.”

P2: “I found out that there were maggots in the wound.”

Similarly, in the study by Kidmas et al., (2004) the authors highlight that most amputations in developing countries could be avoided as they generally result from late

presentation, faulty beliefs regarding management or late diagnosis of the underlying condition.

Accessing clinics can be a challenge for people living in rural areas and especially so for those who are already physically impaired or generally unwell (Pillay, Lutge & Aldous, 2016). This can influence late diagnosis of chronic diseases of lifestyle as well as poor compliance to treatment. Access to rehabilitation services is challenged due to resource issues and patients' inability to reach the clinic for management.

Other than employing measures to prevent LLA, the high incidence of amputations also requires more post-operative rehabilitation services. It is, however, well documented that there is an acute lack of professional rehabilitation staff employed in rural areas globally as well as in South Africa (Visagie & Swartz, 2016).

Amputation rates decrease with a decline in defaulter rates and therefore, strategies to decrease defaulter rates will help minimise the burden of DM and its complications (such as LLA) on the patient as well as the economy. There is thus an urgent need for education and training at community level for both patients and staff (Pillay et al., 2016). The large number of LLA indicates the need for improved management and prevention of chronic diseases of lifestyle. Similarly, there is a need for improved rehabilitation services that follow a community-based approach to rehabilitation. This will encourage improved reintegration of those who have sustained an LLA back into society.

5.2.2. Lack of in-patient rehabilitation

Sustaining an LLA is a major physical, emotional and psychological trauma that requires multidisciplinary rehabilitation (Ennion & Rhoda, 2016). In the current study, 82.3% of the population represented in the medical folders had no record of receiving in-patient physiotherapy. The participants in the case study also reported a lack of in-patient rehabilitation:

P1: "I had no idea what I would do, it was difficult."

P3: “I am now dependent; whenever I need to go somewhere people are needed to assist me.”

P1: “... but I tried to train myself”

Multidisciplinary and interdisciplinary rehabilitation has been proven to be more successful than therapy provided by individual therapists in a number of different populations, regardless of the population studied (Visagie & Swartz, 2016). The large number of LLAs performed in this area necessitate more rehabilitation staff. However, in most developing countries, there is a significant shortage of rehabilitation staff in order to facilitate multidisciplinary rehabilitation (Ennion & Rhoda, 2016).

Within the Eastern Cape there are 0.49 physiotherapists for every 10 000 people, compared to the Free State, which has 1.1 physiotherapists for every 10 000 people (DoH, 2012). Nationally, rural areas are further understaffed, with 0.79 physiotherapists for 10 000 of the rural population compared to 2.5 for 10 000 of the urban population (DoH, 2012). This acute lack of physiotherapists to meet the rehabilitation needs of persons with an LLA in this rural setting necessitates the training of mid-level healthcare or rehabilitation workers and a community-based approach to rehabilitation.

South Africans in remote rural areas experience particular challenges regarding access to rehabilitation (Visagie & Swartz, 2016). As a result, many South Africans do not attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life after limb loss (Visagie & Swartz, 2016). This could result in permanent disability thereby placing further strain on family members, communities and the greater society (Kidmas et al., 2004).

5.3. Discussion of qualitative findings

5.3.1. Psychological and personal challenges

Sustaining an LLA is a massive life-changing event for an individual (Zidarov, Swaine & Gauthier-Gagnon, 2009). Participants in this case study reported difficulty in accepting their amputation and feelings of disempowerment in the sense that their lack of independence made them a burden to their families. Godlwana and Stewart (2013) also found that participants had general feelings of disempowerment and depression, which

affected their well-being. These feelings were linked to poor functional independence during their integration back into the community (Godlwana & Stewart, 2013). Psychological well-being is an important aspect of health and many persons with LLA experience anxiety and depression after limb loss (Godlwana & Stewart, 2013). Therefore, the management of both the psychological and physical status of the patient should be considered in rehabilitation. Self-help groups in communities could provide a haven for support within an immediate setting, which could lighten the burden on institutions. However, professional psychological counselling should also be incorporated both pre-operatively and post-operatively to both prepare the patient for the event as well as to manage the patient post-operatively.

Despite the general feelings of depression, the participants all seemed motivated and yearned to return to previous levels of independence. Over and above the psychological and physical rehabilitation of the individual, there is a need for family counselling and planning that addresses what the family can expect as a whole as well as what they can expect the individual to experience. This will allow better understanding within the family. Discussions regarding the function of the family pre-operatively by a family planner or counsellor could prepare the family for change in a constructive way by providing the family with possible solutions to overcome the change in dynamic within the household. Self-help groups comprising persons with LLA can support, share coping strategies and learn from one another. These groups could also provide platforms for discussion with regard to policy and planning for community-based rehabilitation intervention strategies.

5.3.2. Activity limitations

In this study, participants indicated that they experienced multiple limitations in their activities of daily living, after losing their lower limb. It appeared that this may be due to the lack of post-operative rehabilitative input which meant participants had to learn ways to reintegrate their lives without professional help. As a result of activity limitations, participants experienced decreased levels of independence, which meant confinement to their homes. Participants were now reliant on their family members for various activities of daily living. In one case, the husband had to take over the duties of his wife and this role adjustment posed a challenge to the family dynamic.

From the findings of the quantitative records review as well as the case studies, it is clear that there is a need for post-operative rehabilitation, in order to improve the patients' level of independence after LLA. Persons with disabilities have challenges in accessing rehabilitation and assistive technology services and has a negative impact on their quality of life and participation in society (Zidarov et al., 2009b; Godlwana & Stewart, 2013). Challenges to accessing health care include limited rehabilitation staff, harsh terrain and far distances from services, a lack of access to transport or the lack of confidence in the service provided by the healthcare institutions (Ennion & Rhoda, 2016; Godlwana et al., 2008; Goins et al., 2005).

Rehabilitation and prosthetic fitting could potentially assist those living with an LLA to be more independent within their activities of daily living as they might not have to rely on family members as heavily as they would without a prosthesis. Pre-operative and post-operative rehabilitation such as training of either a family member, community care worker and/or the person with the LLA on how to perform transfers safely and activities of daily living training could improve reintegration into the home after discharge from hospital. Longer term follow-up rehabilitation and home visits that can assist with improving function within the home could also potentially improve patients' function and independence in their activities of daily living. Therefore, there is a need for both intensive in-patient and out-patient rehabilitation services. Rehabilitation services need to have better outreach services and sustainable staff programmes to ensure continuity and correct follow-up. Prosthetic rehabilitation needs to be implemented with specific focus on the environment, which calls for appropriate assistive technology input with focus on correct stump shaping and socket fabrication to prevent chafe issues highlighted by P4.

5.3.3. Environmental factors

Environmental factors such as poor infrastructure and transport services were said to be the most important factors that limited access to healthcare and rehabilitative services in this study. Healthcare and rehabilitative services are especially important to those living with a disability. Yet, persons with disabilities are more likely to experience barriers to access to these services than the general populace. Vergunst et al. (2015), who explored barriers to accessing health care in the rural areas of the Eastern Cape, South Africa, found this to be especially true for those living in rural areas. Geographical barriers, with special reference to transport, terrain and distance, were found to be the most significant

barriers to accessing health care which is also in line with international literature (Tomlinson et al., 2009). Similarly, the findings in this study agreed with the literature as participants voiced the challenges of accessing health care services. This had a negative effect on the collection of chronic medication, seeking rehabilitation as well as prosthetic intervention.

While taxi services are the main mode of transport in the area, the service is infrequent. Accessing health centres via these services is often the only option as it is too far to walk or impossible to propel a wheelchair over the rugged terrain. Taxi services are generally unpleasant for someone travelling with a disability, since they are over-loaded and uncomfortable as they travel over the dusty, uneven, gravel roads. Furthermore, taxi drivers also complain of having to transport persons with disabilities their assistive devices take up extra space (Sinha et al., 2011). Patients in this study said they often seek private transport at exorbitant costs to avoid the attitudinal barriers experienced with this service.

There is a need for the decentralisation of healthcare services in this rural setting. The use of trained community care workers could facilitate this process on a primary health level. Screening for diabetes, foot care and general education on healthy eating and lifestyle could provide a solution to this challenge. Furthermore, if the current infrastructure of roads, pathways and public transport were improved and pathways from houses are made wheelchair friendly to accommodate easy access to public transport persons with disabilities would benefit greatly.

Unequal access to health care is in breach of section 27 of the South African Constitution. Community-based rehabilitation strategies could be a possible solution to the shortfalls of the current model of healthcare services in rural areas of South Africa. With such a high rate of LLA being performed annually, emphasis needs to be placed on improved access to rehabilitation services to ensure early independence of patients, which will reduce the burden on themselves as well as families and ultimately society.

5.3.4. Access and community participation

All participants that formed part of the case study expressed their concerns regarding decreased mobility within their homes as well as within the community. They mentioned that their lack of mobility had a negative effect on their ability to work within the household as before. It also made it difficult for them to care for their families, and they

found they could not engage in community events as before. One participant mentioned that he was no longer able to be part of community discussions regarding important issues as the distance was too great. Another participant commented that she had stopped attending social events in the community; the only way she can interact with her community is if people come to visit her or if she is at the clinic.

Mobility, or a lack thereof, in conjunction with the physical environment, is the biggest barrier to participation for persons living with disabilities (Cawood, Visagie, & Mji, 2016; Cunningham & Rhoda, 2014; Maleka, Stewart & Hale, 2012). Walking is an important human activity which enables us to be productive and participative members of a community (Ada et al., 2009). These findings emphasise the need to improve functional independence of the person with an LLA through physical rehabilitation and prosthetic intervention if applicable. Self-help groups that are more easily accessible would give the individual a sense of belonging and community. These groups could comprise persons with disabilities and could be run by members who could use the group as a church meeting for those who cannot attend formal gatherings, as well as a structured environment to support each other or to discuss topics relating to disability. Rehabilitation with a focus on the functional outcomes of the individual would mean the person would have an improved chance of returning to previous levels of function. An improved functional level would allow the person to return to previous occupation and community integration. This would minimise feelings of disempowerment and isolation.

The majority of this study's population were aged between 40 and 81 years of age, and potentially the economically productive breadwinners of their families. In the current study, it was found that these breadwinners were no longer able to provide financially for their families after undergoing the amputation.

In developing countries, where an adult male or female is often the breadwinner within a family, lower limb loss with inadequate or no rehabilitation can threaten the survival of the family (Kidmas et al., 2004; Ennion & Rhoda, 2016). Persons with disabilities are more likely to be unemployed with less economic participation than able-bodied persons (WHO, 2011). Persons with disabilities thus experience higher rates of poverty than non-disabled persons, further exacerbating the poverty cycle. With the rate of unemployment for OR Tambo District being 70.76% of its total population, the chances of employment are few. The chance of finding employment for persons with disabilities is even less that

an able-bodied counterpart. This means that, in an already challenging environment, those with disabilities are practically excluded from opportunities to maintain or seek employment.

These findings indicate the need for occupational and vocational rehabilitation and skills development that are suitable to the environment and individual. This training should be incorporated into a community-based rehabilitation programme that is specific to rural environments. Along with physical rehabilitation there is a need for suitable prosthetic intervention and training that could allow individuals to reintegrate to previous levels of occupation that may provide an income for their families once again.



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

6.1. Introduction

In this chapter conclusions are drawn from the findings of this study. Recommendations for future research are provided and limitations experienced within this study are highlighted.

6.2. Summary of the study

The purpose of this study was to explore the rehabilitation needs of persons living with a lower limb amputation (LLA) in the rural area of the OR Tambo District of the Eastern Cape, a province of South Africa. An additional aim was to determine the number of LLAs performed at the major operating hospital for the OR Tambo District, namely the Nelson Mandela Academic Hospital (NMAH). To satisfy the aims of this study, the common causes and comorbidities associated with LLA as well as the level of in-patient rehabilitation received post-operatively were identified. Together with this, the day-to-day experiences of four persons living with an LLA in a rural area were explored and documented using visual instruments and in-depth interviews.

Altogether 128 LLAs were performed in the OR Tambo District annually in the period September 2015 to September 2016. Men were more likely to undergo an LLA than females. The most common comorbidity associated with LLA was diabetes mellitus (DM). In this study, complications or late diagnosis of DM was found to be the leading cause of LLA. The average age group for an LLA was seen to be between 41 and 80 years of age. The trans-tibial amputation was the most commonly occurring level for surgery. For the majority of patients there was no record of receiving in-patient rehabilitation.

The lack of rehabilitation experienced by the participants in the case series had a negative impact on their function, and restricted their activities of daily living and participation in society. These challenges with executing activities of daily living resulted in a lack of independence. Additionally, participants experienced difficulty in re-integrating into their home environments due to these activity limitations and participation restrictions. Decreased levels of function meant patients were no longer able to provide an income to support their families, causing feelings of disempowerment. Furthermore, participants

expressed difficulty in accepting their situation and this had a negative impact on their psychological well-being. However, despite a generally poor outlook on themselves and their situation, participants were highly motivated and yearned for their independence. Environmental barriers such as transport, terrain and distance limited access to rehabilitation services as well as other healthcare services. Similarly, participants experienced challenges with community integration due to these environmental barriers.

6.3. Study limitations

Different challenges were experienced during the qualitative and quantitative phase of this study. In the quantitative phase, the retrospective archival study was limited by the number of folders that could be retrieved, which resulted in a small sample size. Illegible handwriting and missing folders made it impossible to retrieve accurate patient details for every recorded LLA.

The qualitative phase revealed a different set of challenges. External elements such as stormy weather patterns made it challenging to access participants' homes. Additionally, due to the adverse weather, electricity and cell phone reception was impaired, which made it difficult to contact participants for directions and final details of our visits. This meant that arrival times were slightly delayed (08:00 as opposed to the planned 07:30). Furthermore, the adverse weather conditions limited the already short length of stay with one participant. Due to the poor condition of the roads and the heavy rainfall, the research vehicle could only access P3's house at 09:00. However, all main activities of daily living were observed and discussed in the interview which accounted for the delayed arrival time. This meant that the time spent observing each participant was not the same. However, it did not have an effect on the reliability of the study findings because regardless of set arrival and departure times, the most common activities of daily living were observed and those that were not observed were discussed in the interview. The common themes that arose illustrate that the participants have common challenges and rehabilitation needs and the slight delay in arrival time would not have skewed these findings in any way.

Despite the small sample size, the themes that arose could still be generalised to the larger population of persons living with LLA within a rural environment of the OR Tambo District of the Eastern Cape because the nature of the pathology and the

associated socio-economic background as well as environmental factors would correlate directly.

6.4. Recommendations

With the increase in urbanisation comes an increase in chronic diseases of lifestyle, specifically DM in this case (Pillay et al., 2016). When chronic diseases of lifestyle, such as DM, are combined with limited access to healthcare services in rural areas, there are increased chances of complications of DM that could result in an LLA. Limited access to healthcare services also implies that there is limited access to rehabilitation services (Vergunst et al., 2017; Ennion & Rhoda, 2016). Without adequate rehabilitation the person with a disability is likely to have decreased function and increased levels of dependence, which can lead to feelings of disempowerment and a decreased quality of life (Godlwana & Stewart, 2013). Along with this increased dependence comes strain on the family unit: since most often the person with the LLA is the breadwinner, financial stress sets in due to decreased income. This exacerbates the disability poverty cycle and has a negative impact on the entire family.

Therefore, there is an urgent need for interventions that address the prevention and management of chronic diseases of lifestyle, with specific focus on DM, that cause LLA. These interventions should be targeted specifically within the rural context and with cultural sensitivity in order to ensure adherence to the programme. To reduce the rapid increase in the number of persons diagnosed with DM, patients should be educated regarding self-screening for lower limb foot complications and early signs of infection, measures to prevent foot injuries, healthy lifestyle strategies and regular hypertension and DM screening at local facilities.

Services should be decentralised to allow for better accessibility of rehabilitation services for persons with LLA. A community-based approach to rehabilitation should be used to facilitate programmes. Home visits should be initiated by rural healthcare providers and incorporated into these programmes. Barriers may be reduced by the involvement of relevant stakeholders such as the Department of Health and local municipalities.

Healthcare workers and physiotherapists should also provide more informed and holistic management to their patients to reduce some of the barriers in accessing services that were identified. Health professionals can do this by providing more in-depth patient

education and spending more time with those patients who are known to have increased difficulty in accessing treatment.

Physiotherapists can also motivate and educate patients on the effects rehabilitation has on minimising factors associated with an LLA, such as pain and lack of functionality. This will encourage patients to seek and utilise rehabilitation services more regularly, which, in turn would help motivate the government to increase the numbers of rehabilitation staff to these areas. Additionally, self-help and family group therapy sessions initially facilitated by therapists would help to educate and involve the family members in the rehabilitation process and advise them on how to assist the patient. It would also provide a space for groups to come together to share their personal experiences. Personal factors, such as self-motivation, were identified and serve as a facilitator and encouragement to improve access to services. Policy should be implemented for financial compensation to enable those persons to afford transportation to the rehabilitation centre to ensure attendance.

6.5. Conclusion

This study provides a visual representation and qualitative understanding of the experiences of those living with an LLA within the OR Tambo District of the Eastern Cape province of South Africa. These experiences have highlighted various rehabilitation needs that will assist in informing discussion on the policy and practices of health professionals working in rural areas.

The high prevalence of LLA within the OR Tambo District is cause for concern. DM was seen to be the leading cause of LLA in this study and the relationship of diabetes-related amputation is on the rise. This reiterates the need for mass education from school to community level regarding the risk and appropriate management of chronic diseases of lifestyle in order to minimise preventable disability in rural areas.

Poor functionality of those living with an LLA resulted in increased dependence and limitations in the performance of activities of daily living. Decreased function, together with increased dependence, has a negative impact on the patients' psychological well-being. Feelings of disempowerment were revealed as patients expressed difficulty in accepting their situations. Participants felt they lacked purpose as they were unable to provide and care for their families as before and this exacerbated the feelings of depression. Despite general feelings of depression, some participants were still positive

and motivated to regain their independence. Each of the participants implored the government to provide better quality of services and for transparency in the system as they felt they were waiting indefinitely for prosthetic intervention.

Environmental barriers limited both reintegration into the community and access to health services. These barriers included decreased functional independences of participants, financial challenges, poor quality of transport services, difficult terrain and far distances. Efforts need to be made to reduce these barriers in order to facilitate inclusion of patients into their communities as well as to ensure equitable access to services as highlighted in section 27 of the South African Constitution. Eradicating these environmental barriers will ensure improved quality of life of those living with an LLA. The policies developed in accordance with the Convention on the Rights of Persons with Disabilities need to be further implemented, to decrease existing barriers to access to general health care and rehabilitation and prosthetic services for persons with disabilities in the OR Tambo District.

Several recommendations to improve access and quality of services have emerged from this study. It is critical that the Department of Health and local municipalities, work together to strengthen available services and systems and ensure that affordable and appropriate services are available to persons with LLAs. Furthermore, data capturing of disability-related statistics needs to be drastically improved and overseen by the authorities in order to maintain compliance. This will ensure that disability services and programmes meet their goals and it will also provide a credible background for advocacy. Finally, there is an urgent need for growth of available rehabilitation staff within a rural context in order to provide quality service and cope with the needs of those with LLA. Throughout all of the above-mentioned, it is integral that persons with disabilities are central to discussions around decision making and policy in this regard.

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APPENDIX 1: ETHICS CLEARANCE CERTIFICATE

 **OFFICE OF THE DIRECTOR: RESEARCH
RESEARCH AND INNOVATION DIVISION**

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

29 June 2017

Ms S Manig
Physiotherapy
Faculty of Community and Health Sciences

Ethics Reference Number: BM17/5/8

Project Title: Understanding the rehabilitation needs of a person living with a lower limb amputation in rural areas of the OR Tambo District of the Eastern Cape, South Africa.

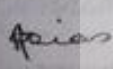
Approval Period: 09 June 2017 – 09 June 2018

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

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

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

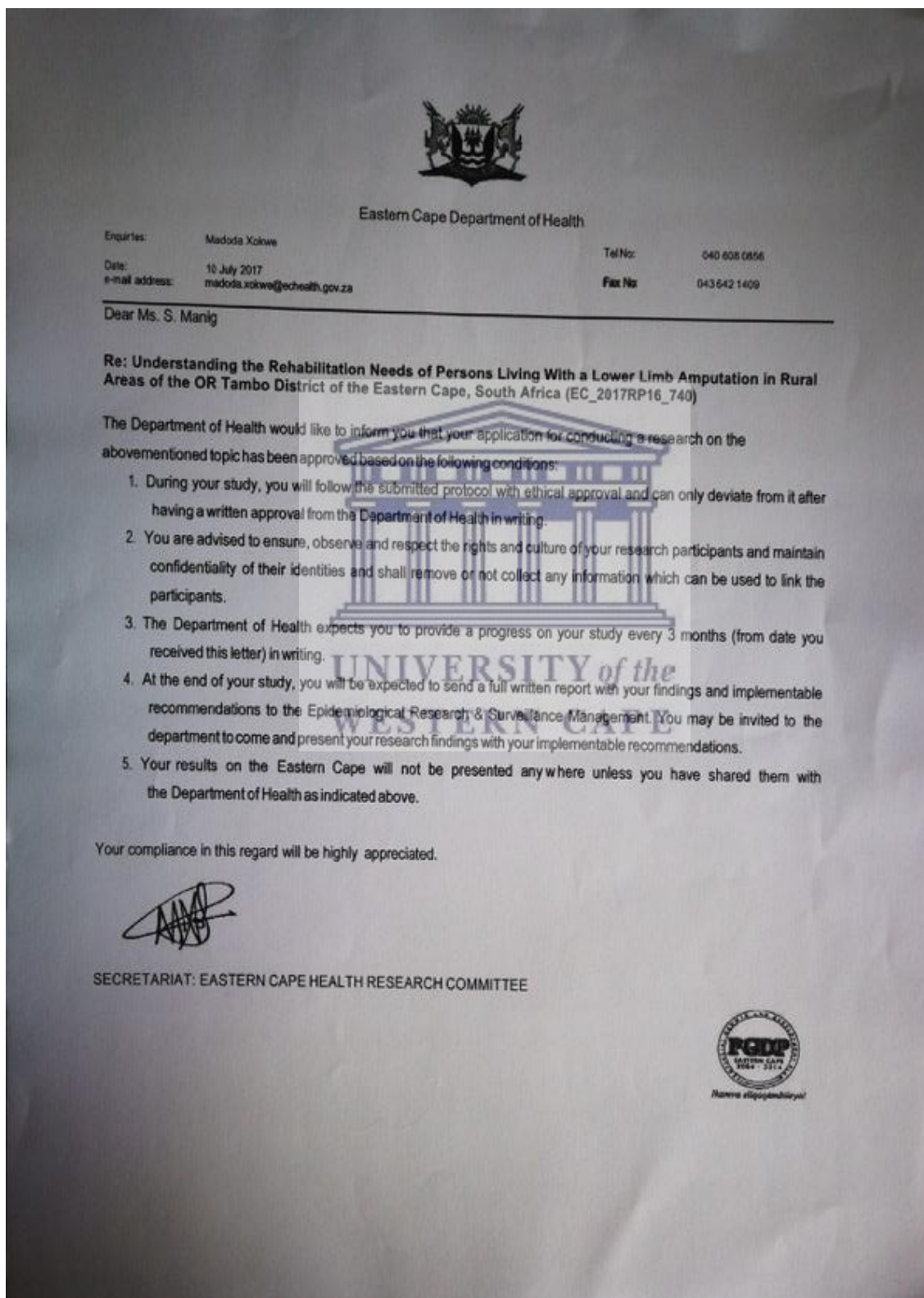
The Committee must be informed of any serious adverse event and/or termination of the study.


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

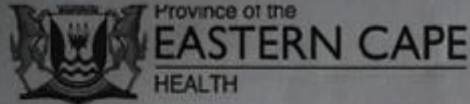
**UNIVERSITY of the
WESTERN CAPE**

PROVISIONAL REC NUMBER -130416-050

APPENDIX 2: PERMISSION FROM EASTERN CAPE DEPARTMENT OF HEALTH TO CONDUCT STUDY: EC2017RP16_740



APPENDIX 3: PERMISSION FROM CEO NMAH TO COLLECT DATA



Research Ethics Committee • Level 3 • Nelson Mandela Academic Hospital • Sissons Street -Fortgalie •
Private Bag X 5152 • MTHATHA • Eastern Cape • 5100 • REPUBLIC OF SOUTH AFRICA •
Tel.: +27 (0)47 502 4546 • Fax: +27 (0)47 502 4968

18 October 2017

Ms Sarah Manig
Department of Physiotherapy
University of Western Cape
Cape Town, RSA.

Re: Letter of Research Ethics Approval


Study Title:

**Understanding the Rehabilitation needs of persons living with a lower limb amputation
in rural areas of OR Tambo District of the Eastern Cape, South Africa.**

The above-mentioned study has been approved by the Research Ethics Committee.

Yours sincerely

**UNIVERSITY of the
WESTERN CAPE**


Prof. Nomawethu Tonjeni
Chair: Research Ethics Committee
Nelson Mandela Central Hospital
Mthatha

NELSON MANDELA ACADEMIC CENTRAL HOSPITAL
CHIEF MEDICAL SUPERINTENDENT
2017 -10- 18
Eastern Cape Government
Private Bag X 5152-Umtata 5100

APPENDIX 5: DATA EXTRACTION SHEET FOR MEDICAL RECORDS

Retrospective amputation Survey:

TO BE COMPLETED BY PHYSIOTHERAPIST ON 1ST CONTACT WITH PATIENT (according to hospital folder):

Hospital name:

Date of data collection:

Patient name:

Gender: M / F

Age / Date of birth:

Left or Right limb: _____

Contact:

Level of amputation: Trans-femoral (AKA) / Trans-tibial (BKA) Other: _____

Initial symptoms and **primary cause of amputation** according to hospital folder: (specify source if not noted in folder) _____

- | | | |
|---|--|------------------------------------|
| <input type="checkbox"/> Diabetic sepsis / ulcers / gangrene | <input type="checkbox"/> Peripheral vascular disease | <input type="checkbox"/> Cancer |
| <input type="checkbox"/> Congenital deformity of the lower limb | <input type="checkbox"/> Trauma | <input type="checkbox"/> Snakebite |
| <input type="checkbox"/> Other (please specify) | | |

Relevant medical history: (circle as many as is applicable)

(co-morbid diseases according to hospital folder eg. Hypertension)

- **Orthopaedic conditions:** (arthritis, osteoporosis, back or neck pain) other: _____
- **Cardiac or respiratory conditions:** (asthma, COPD, ARDS, emphysema, angina, hypertensive, CCF) other: _____
- **Neurological conditions:** (stroke, Multiple sclerosis, migraines, incontinence, peripheral neuropathy) other: _____
- **Mental health:** (depression, anxiety or panic disorders) other: _____
- **Diabetic:** Y / N **HIV/AIDS:** Y/N

Did this patient receive in-hospital physiotherapy? Y / N

APPENDIX 6: SEMI-STRUCTURED, IN-DEPTH INTERVIEW

CHARACTER INTERVIEW

Participants living with a lower limb amputation

- 1) Introduction (establish familiarity and trust)
 - 2) Can you tell me what happened to you and how you came to have your leg amputated?
** What was happening at that time – socially, emotionally, family**
 - 3) Did you have a choice in this decision to have your leg amputated? ** How did this make you feel?*
 - 4) What are you unable to do now that you could do before your leg was amputated?
 - 5) What does a normal day consist of for you? How is it different now that you have an amputated leg?
 - 6) How has your life changed since having your amputation? **How have you had to adapt and what has this meant/changed for you and your family*
 - 7) What were your hopes and dreams before having the amputation?
 - 8) How do you feel your community treats you? **Treated differently than before?*
 - 9) Do you/did you feel down or sad sometimes due to having had your leg amputated? How do you cope with this? What would you say makes you feel sad?
 - 10) Tell me how you think your life could be improved? **work, sense of purpose, linked to money, support, friends, something to do, improved function etc**
 - 11) Explain the process you go through to go to your nearest town if you need to go? What transport do you use? ** How many times a month do you need to do this?*
 - 12) Explain how you get to your nearest hospital if you should need to go? What needs to be taken care of?
 - 13) If you had two wishes, what would they be?
-

APPENDIX 7: CBR MATRIX

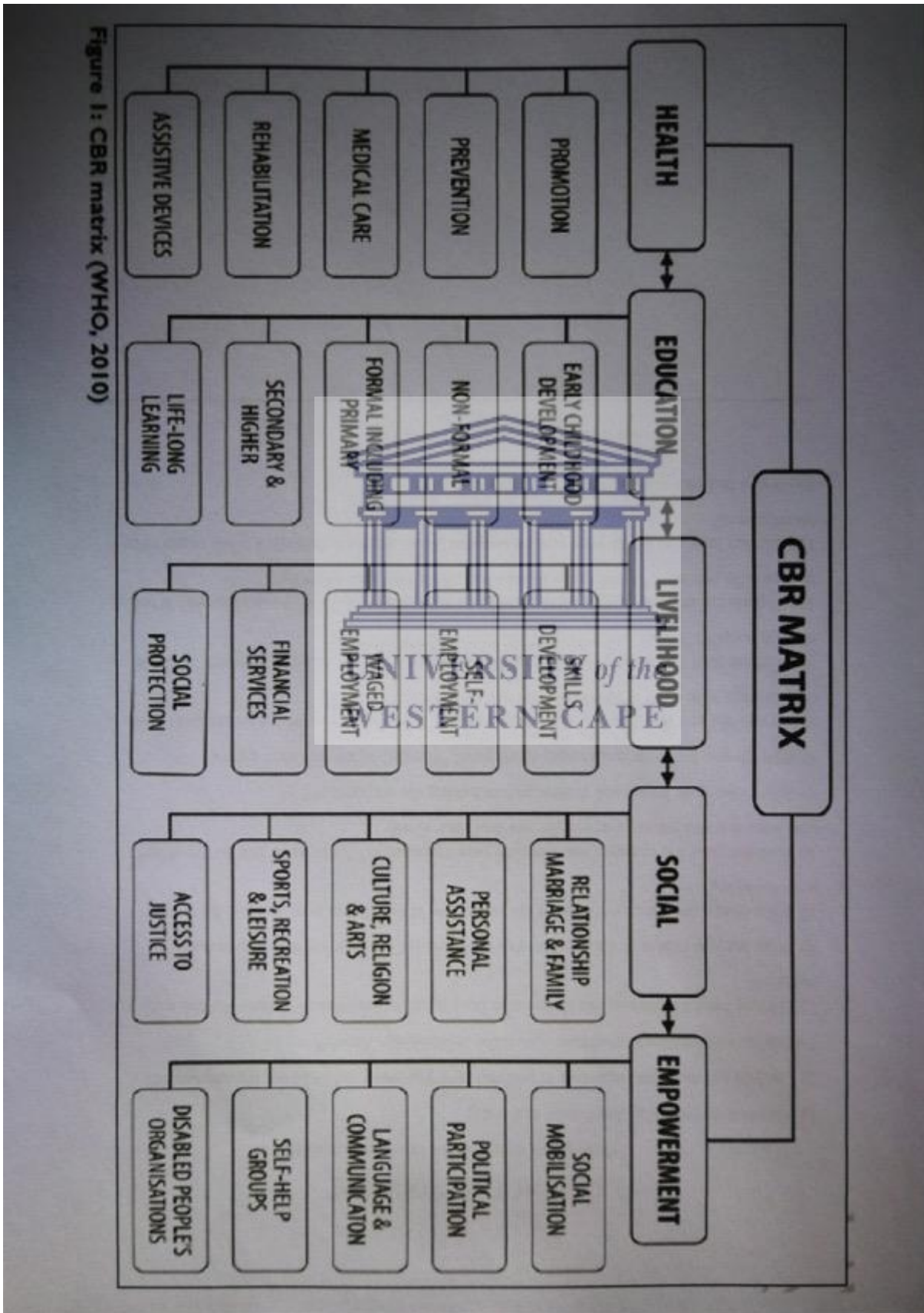


Figure 1: CBR matrix (WHO, 2010)

APPENDIX 8: PHOTO APPENDIX

a)



UNIVERSITY of the
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b)



c)

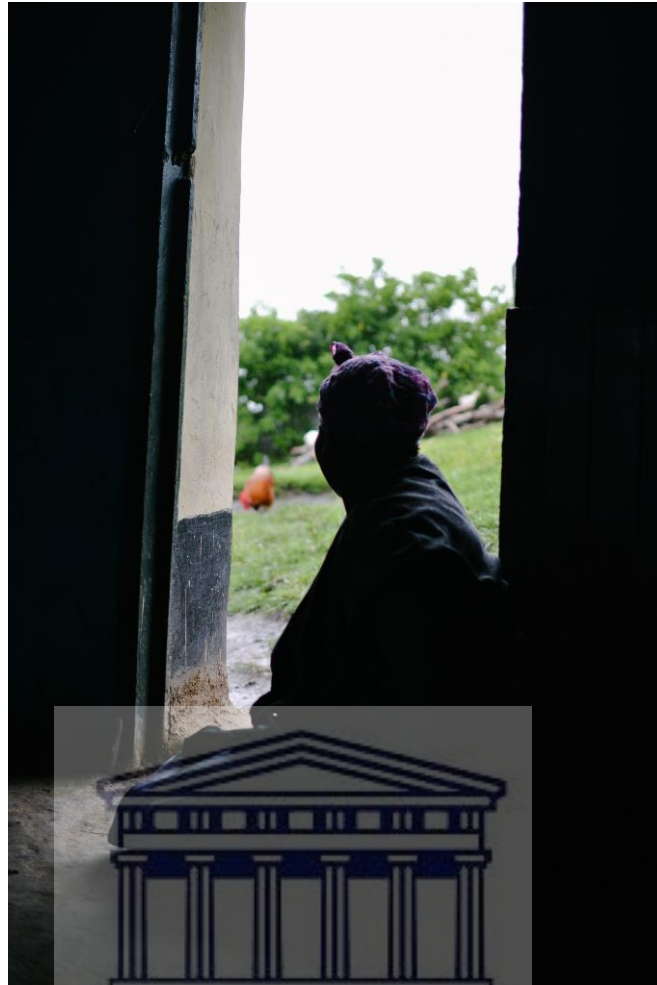


d)



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e)



f)



g)



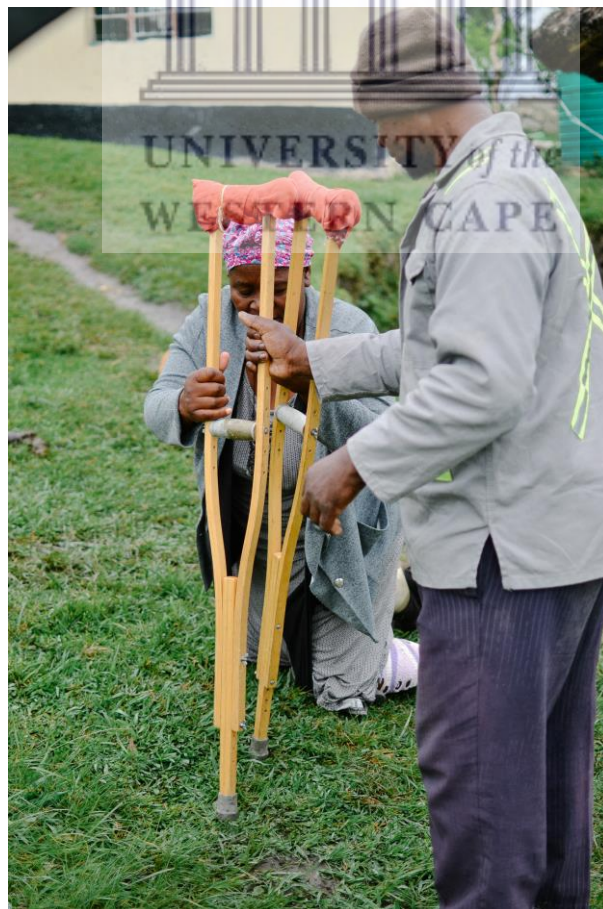
h)



i)



j)



k)



l)



m)



n)



UNIVERSITY of the
WESTERN CAPE

o)



p)



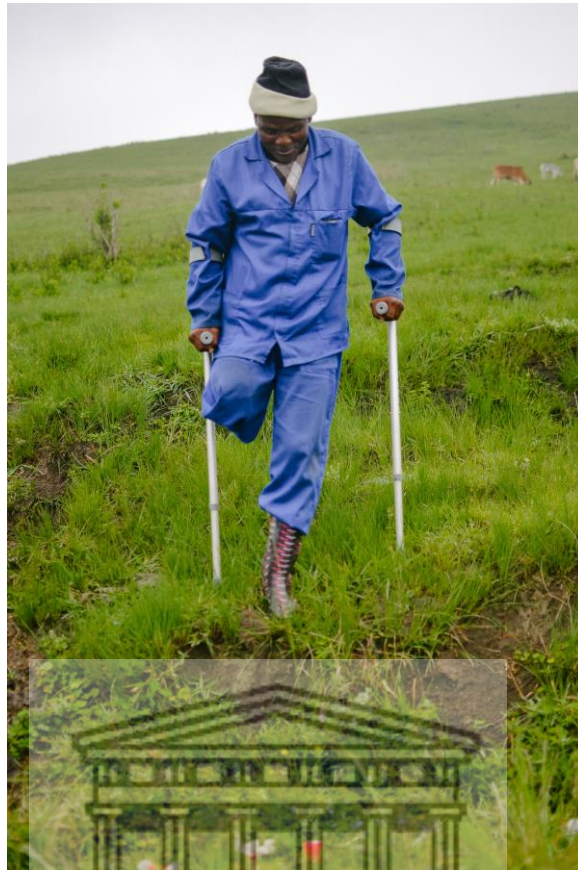
q)



r)



s)



t)



u)



UNIVERSITY of the
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v)



w)



UNIVERSITY of the
WESTERN CAPE

x)



y)



UNIVERSITY of the
WESTERN CAPE

z)



a)i)



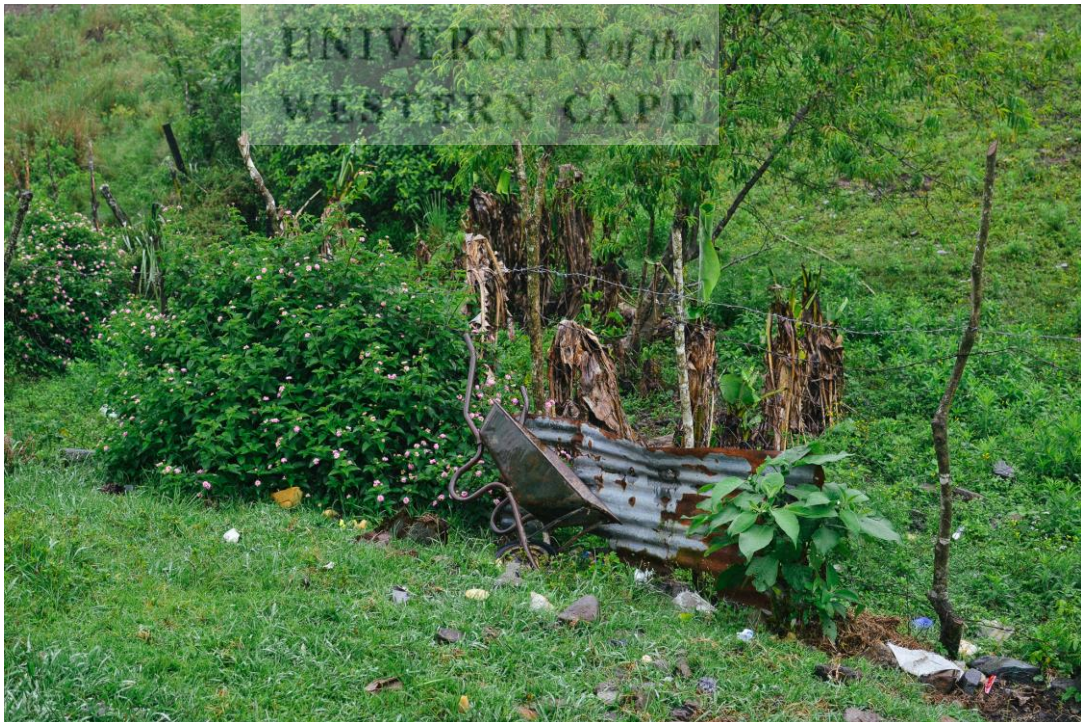
b)i)



c)i)



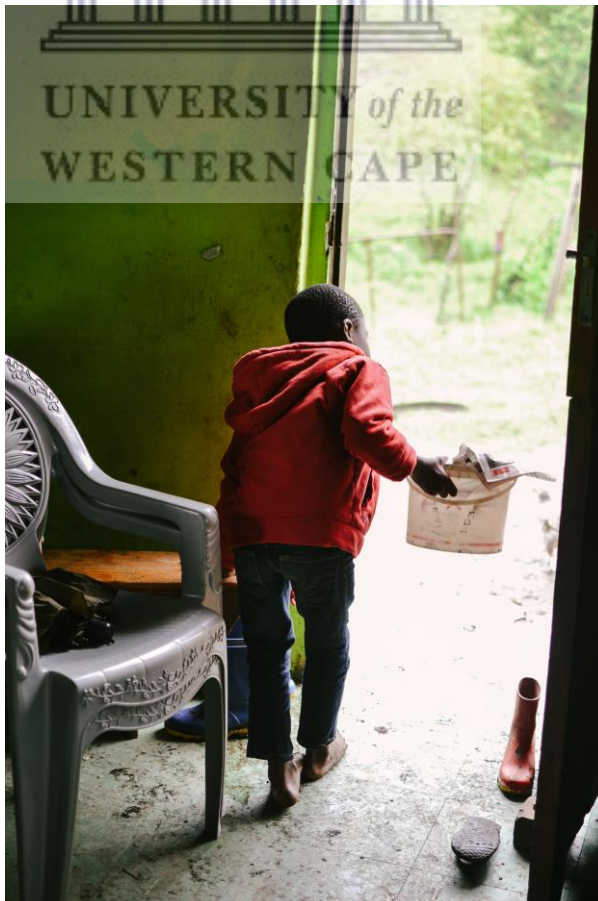
d)i)



e)i)



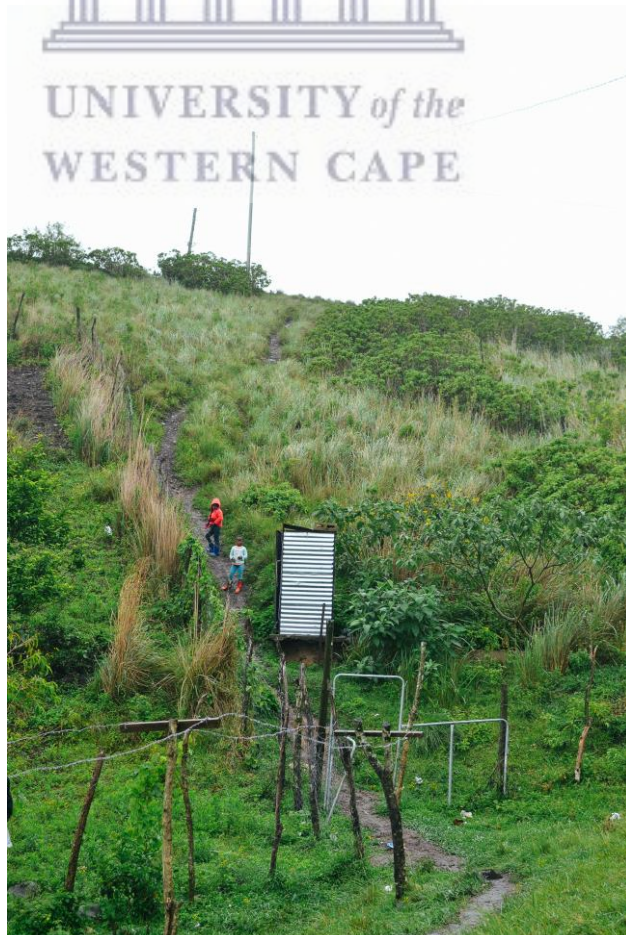
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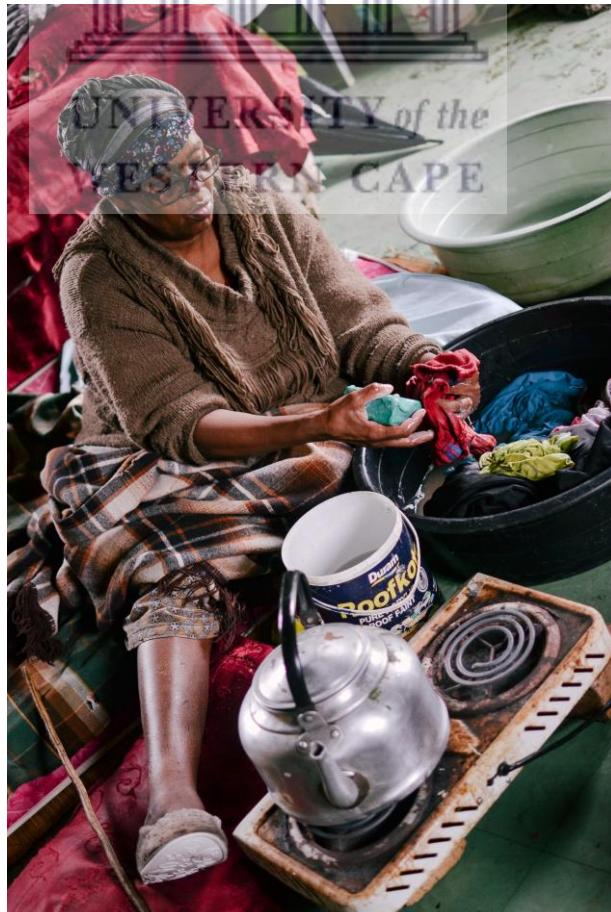
h)i)



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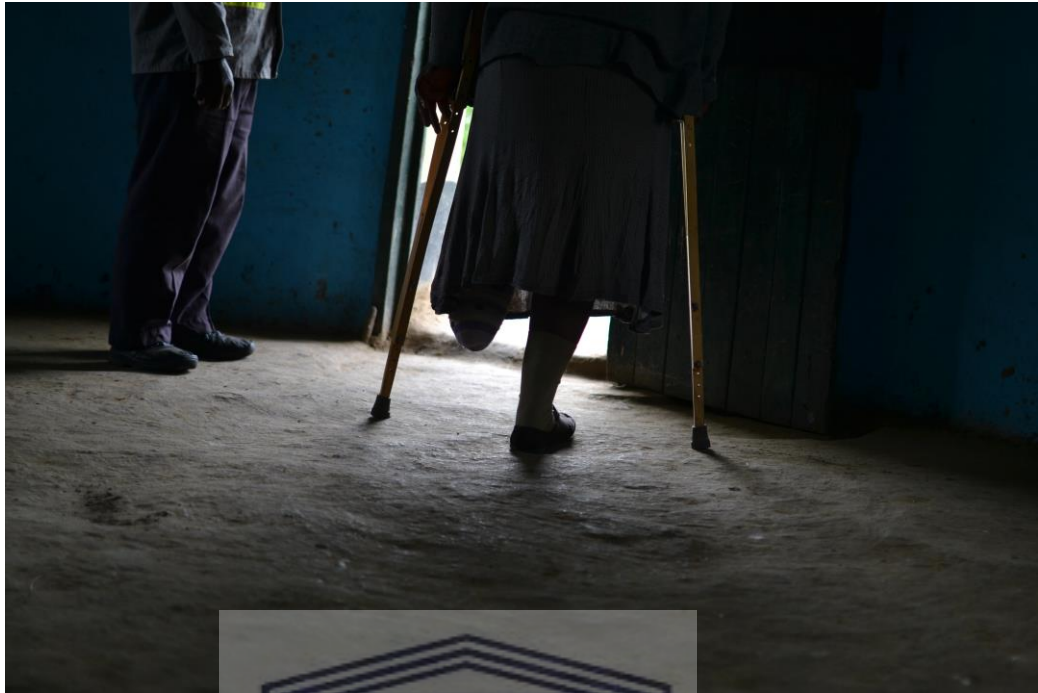
v)i)



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w)i)



x)i)



UNIVERSITY of the
WESTERN CAPE

y)i)



z)i)



a)ii)



b)ii)



c)ii)



d)ii)



e)ii)



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ANNEXURE 9: DECLARATION FROM EDITOR

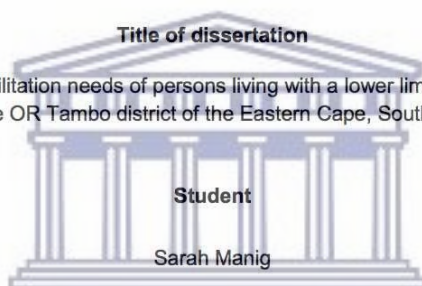
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DECLARATION

I hereby certify that the Master's dissertation mentioned below has been properly language edited. The 'track changes' function was used and the editor did not see the dissertation in its very final form after delivery to the author. The author was also responsible for the technical editing and correctness of the references.

Title of dissertation
Understanding the rehabilitation needs of persons living with a lower limb amputation in rural areas of the OR Tambo district of the Eastern Cape, South Africa



Student

Sarah Manig

UNIVERSITY of the
WESTERN CAPE

Belcher.

ELLA BELCHER
Somerset West
21 September 2018



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