The Impact of Lower Limb Amputation on Quality of Life: A study done in the Johannesburg Metropolitan area, South Africa

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Abstract

Background: The impact of non-traumatic lower limb amputation on participant's quality of life (QOL) is unknown. In an effort to provide better care for people with lower limb amputation, there is a need to first know the impact of this body changing operation on people's quality of life.

Aim of the study: To determine the impact of lower limb amputation on QOL in people in the Johannesburg metropolitan area during their reintegration to their society/community of origin.

Objectives:

1. To establish the pre-operative and post-operative:
    - QOL of participants (including the feelings, experiences and impact of lower limb amputation during the time when they have returned home and to the community).
    - The functional status of participants.
    - Household economic and social status of these participants.
2. To establish factors influencing QOL.

Methods: A longitudinal pre (amputation) test –post (amputation) test study utilized a combination of interviews to collect quantitative data and in-depth semi-structured interviews to gather qualitative data. Consecutive sampling was used to draw participants (n=73) for the interviews at the study sites pre-operatively. The three study sites were Chris Hani Baragwanath Hospital, Charlotte Maxeke Johannesburg General Hospital and Helen Joseph Hospital. Participants were then followed up three months later for post-operative interviews and key informants were selected for in-depth interviews (n=12).

Inclusion criteria: Participants were included if they were scheduled for first time unilateral (or bilateral amputation done at the same time) lower limb amputation. The participants were between the ages of 36-71 years.

Exclusion criteria: Participants who had an amputation as a result of traumatic or congenital birth defects were excluded from the study. Participants with co-morbidities that interfered with function pre-operatively were not included.

Procedures:

Ethics: Ethical clearance was obtained from the Committee for Research on Human Subjects at the University of the Witwatersrand and permission was obtained from the above hospitals. Participants gave consent before taking part in the study.

Instrumentation: A demographic questionnaire, the EQ-5D, the Modified Household Economic and Social Status Index (HESSI), the Barthel Index (BI) and semi-structured in-depth interviews were used.

Data collection: Participants were approached before the operation for their pre-operative interviews using the above questionnaires and then followed up post-operatively using the same questionnaires and some were selected to participate in semi-structured in-depth interviews three months later.

Pilot study: The demographics questionnaire and the modified HESSI were piloted to ensure validity and reliability.

Data analysis: Data were analyzed using the SPSS Version 17.0 and STATA 10.0. The significance of the study was set at p=0.05. All continuous data are presented as means, medians, standard deviations and confidence intervals (CI 95%). Categorical data are presented as frequencies. Pre and post operative differences were analyzed using Wilcoxon Signed-rank test. A median regression analysis (both the univariate and multivariate regression) was done to establish factors influencing QOL. Pre and post operative differences in the EQ-5D items and the BI items were analyzed using Chi square/Fischer's exact depending on the data. Data were pooled for presentation as statistical figures in tables. Both an intension to treat analysis and per protocol analysis were used.

A grounded theory approach was used to analyze the concepts, categories and themes that emerged in the qualitative data.

Results: Twenty-four participants (33%) had died by the time of follow up. At three months, n=9 (12%) had been lost to follow up and 40(55%) was successfully followed up. The preoperative median VAS was 60 (n=40). The postoperative median VAS was 70. The EQ-5D items on mobility and usual activities were reported as having deteriorated significantly postoperatively (p=0.04, p=0.001respectively) while pain/discomfort had improved (p=0.003). There was no improvement in QOL median VAS from the preoperative status to three months postoperatively

The preoperative median total BI score was (n=40). The postoperative median total BI score was 19. There was a reduction in function (median BI) from the preoperative status to three months postoperatively (p<0.001).

The ability to transfer was improved three months postoperatively (p=0.04). Participants were also found to have a decreased ability to negotiate stairs (p<0.001). Mobility was significantly reduced three months postoperatively (p=0.04).

During the postoperative stage (n=40), 38% of the participants were married. Most (53%) of the participants had no form of income. The highest percentage of participants in all instances (35%) had secondary education (grade10-11), while 25% had less than grade 5. Only one participant was homeless, 18% lived in shacks, 55% lived in homes that were not shared with other families.

People with LLA in the Johannesburg metropolitan area who had no problem with mobility preoperatively (EQ-5D mobility item), who were independent with mobility (BI mobility item) preoperatively, who were independent with transfer preoperatively (BI transfer item) had a higher postoperative quality of life (postoperative median EQ-5D- VAS) compared to people who were dependent or had problems with these functions preoperatively. Being females was a predictor of higher reported quality of life compared to being male.

Emerging themes from the qualitative data were psychological, social and religious themes. Suicidal thoughts, dependence, poor acceptance, public perception about body image, phantom limb related falls and hoping to get a prosthesis were reported. Some reported poor social involvement due to mobility problems, employment concerns, while families and friends were found to be supportive. Participants had faith in God.

Conclusion: Participants' QOL and function were generally scored high both preoperatively and postoperatively but there was a significant improvement in QOL and a significant reduction in function after three months although participants were generally still functionally independent. Good mobility preoperatively is a predictor of good QOL postoperatively compared to people with a poor preoperative mobility status

Generally, most participants had come to terms with the amputation and were managing well while some expressed that they were struggling with reintegration to their community of origin three months postoperatively with both functional and psychosocial challenges.

Declaration

I, Lonwabo Lungile Godlwana, declare that this dissertation is my own work. It is being submitted for the degree of Master of Science in Physiotherapy at the University of the Witwatersrand, Johannesburg. Due acknowledgement has been made in the text, where material from other authors has been used. This dissertation has not been submitted before for any degree or examination at this or any other University.

………………………………………. [Signature of Candidate]
………………………. Day of ……………………………….. [Month], 2009

Lonwabo Lungile Godlwana

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Most importantly, I thank the participants for taking part in this project.

Dedication

I wish to dedicate this work to my late mother (iNkosazana yamaMpondo), Mrs. Claribel Nonkululeko Godlwana and my late aunt (iNkosazana yamaMpondo), Mrs. Nomfundo Iris E. Twabu, (B.A. (Hons) Fort Hare, M.A. Stell).

Publications related to this thesis

1. *Godlwana L, Nadasan T, Puckree T, 2008: Global trends in incidence of lower limb amputation: A review of the literature. South African Journal of Physiotherapy; 64 (1); 8-11*

Presentations

School of Therapeutic Sciences Research Day, University of the Witwatersrand, August 12th, 2009:

Experiences during reintegration to community three months after a major lower limb amputation.

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List of acronyms and abbreviations

ADL	Activities of daily living
AKA	Above knee amputation
BI	Barthel Index
BKA	Below knee amputation
CHBH	Chris Hani Bargwanath Hospital
CI	Confidence Interval
CM JH	Charlotte Maxeke Johannesburg Hospital
COAD	Chronic obstructive airway disease
DVD	Digital video display (DVD) player
EQ-5D	Health Questionnaire
HESSI	Household Economic and Social Status Index
HJH	Helen Joseph Hospital
ICC	Intraclass correlation coefficient
ICF	International Classification of Functioning
ICIDH	International Classification Impairment, Disability and Handicap
IHD	Ischaemic heart disease
LEA	Lower Extremity Amputation
LLA	Lower limb amputation
MI	Myocardial infarction
NS	No significance
PVD	Peripheral vascular disease

QOL	Quality of life
SF-36	36- Item Short Form Health Survey
SPSS	Statistical Package for Social Science
Soweto	South western townships
SRM	Standardized response mean
VAS	Visual analogue scale
WHO	World Health Organisation

Chapter 1

1.1 Introduction

Lower limb amputation (LLA) is performed for a variety of reasons that range from disease to trauma (Wong, 2005; Spichler et al, 2001; The Global Lower Extremity Study, 2000; Van Houtum et al, 1996; Engstrom & Van de Ven, 1999). Lower limb amputation (LLA) results in a wide range of outcomes. Amputation generally results in poor physical function, physical role performance, social function, vitality, general health, and more pain compared to population norms (Eiser et al, 2001). Everyday competence tends to decrease with age for both males and females following lower limb amputation but males usually have better physical function than females (Eiser et al, 2001). People who have the following features also tend not to be able to live independently in their homes after the amputation: over the age of 70, a high anatomical level, dementia or those who had a homebound ambulatory status preoperatively (Taylor et al, 2005).

Amputation may impact negatively on mobility, emotion, sleep, pain and social function. People with a lower limb amputation experience problems with activities of daily living including household chores, hobbies and social relationships (Pell et al, 1993). Some people with a lower limb amputation can be mobile around their home while others may require a walking aid or use a wheelchair. Amputation may result in an inability to leave home (home bound) even with the assistance of the family thus impacting negatively on involvement in social activities. Even those who are able to leave home tend to use wheelchairs and only a few use walking aids (Pell et al, 1993).

However, some people with a lower limb amputation remain independent despite infrequent use of their prostheses and outdoor ambulation (Nehler et al, 2003). Despite all the challenges faced by people following lower limb amputation some remain independent in activities of daily living and use their prostheses (Mac Neill et al, 2008). The preoperative status of people with lower limb amputation can also determine the functional outcome of the amputee postoperatively. Nonambulatory status preoperatively, having an above-knee amputation, being home bound preoperatively, dementia, being over 60 years of age, having end-stage renal failure and having a coronary artery disease may be associated with not wearing a prosthesis. People over the age of 70 and those with a bilateral lower limb amputation might not walk after the amputation (Taylor et al, 2005). Other physical problems associated with amputation include phantom sensations and phantom pain (Mosaku et al, 2009).

Mobility and daily living are important elements of Health-Related Quality of Life (HRQOL). Therefore declining mobility may have a greater negative impact on HRQOL than any other distinct disease state (Groessl et al, (2007). Therapeutic effects cannot be compared based only on functional recovery resulting from the use of a prosthetic device but should also be based on the fulfillment of a new and highly important criterion parameter, namely “quality of life (QOL)” (Poljak-Guberina et al 2005).

Another significant aspect of amputee health is that of psychological well-being. People with lower limb amputation experience anxiety and depression following amputation of the lower extremity. These psychological reactions correlate significantly with age and marital status, and there is no correlation with level of amputation, mode of ambulation and indication for amputation (Mosaku et al, 2009).

People with diabetes with a lower limb amputation tend to undergo a second amputation compared to those who do not have diabetes who have a lower limb amputation. Moreover, people with diabetes with a lower limb amputation are more likely to undergo amputation to the contralateral leg compared to people who do not have diabetes (Papazafiropoulou et al, 2009). People who stop smoking are unlikely to undergo a major amputation whereas those who continue to smoke may undergo a major amputation (Ohta et al, 2004).

Another problem in people with a lower limb amputation involves length of stay in hospital. Length of stay in hospital is similar in both people with diabetes and those without diabetes who have a non-traumatic LLA, however, people with diabetes have been seen to stay longer than their non-diabetic counterparts when the anatomical level of amputation is the same (Calle-Pascual at al, 1997). This is due to nosocomial infection and general infection control issues and may have an impact of functional recovery (Burger & Marincek, 2007).

Lower limb amputation is also associated with morbidity and mortality (Nehler et al, 2003). The survival rate varies across countries but mortality rate is generally high (Papazafiropoulou et al, 2009, Wong, 2005, de Godoy et al, 2005, Resnick et al 2004, Nehler et al, 2003, Spichler et al, 2001). Old age and higher anatomical level of amputation are associated with poor survival and the mortality rate is higher in both people with diabetes and people who do not have diabetes (Papazafiropoulou et al, 2009).

In South Africa, there is limited information on this subject. There are no existing publications on QOL in people who have had a lower limb amputation, although there have been studies on people with lower limb amputation.

1.2 Problem statement

The literature shows that people with lower limb amputation face many challenges post operatively despite healthcare provision efforts in various parts of the world. These challenges range from physical to emotional and psycho-social matters and they affect the quality of life of people with lower limb amputation. These challenges impact on return and integration to the society of origin. The physical, psychological and social well-being of people with lower limb amputation has not been studied in the Johannesburg metropolitan area. The impact of lower limb amputation and life satisfaction following a lower limb amputation has not been determined. Thus this study investigates the impact of LLA on QOL in people with a lower limb amputation during their reintegration to the society/community of origin, in the Johannesburg metropolitan area.

1.3 Research question

What is the impact of non-traumatic lower limb amputation on participants' quality of life (QOL), who live in the Johannesburg metropolitan area during their reintegration to the society/community of origin?

1.4 Aim of the study

To determine the impact of lower limb amputation on QOL in participants from the Johannesburg metropolitan area, during their reintegration to the society/community of origin.

1.5 Objectives:

1. To establish the pre-operative and post-operative:
    - QOL of these participants (including the feelings, experiences and impact of lower limb amputation during the time when they have returned home and to the community).
    - Functional status of these participants.
    - Household economic and social status of these participants.
2. To establish the factors influencing QOL.

1.6 Significance

The results of this study may be important in identifying areas of potential improvement in the management of people with LLA. This study may give the opportunity to identify gaps in rehabilitation after LLA and address them in a participant centered manner for people with LLA. The study may help identify if there are any aspects that need to be modified in the management of people with LLA.

Chapter 2: Literature Review

2.1 Introduction

The review specifically aimed at capturing information on the psycho-social, functional and physical impact and the quality of life of people with a lower limb amputation (LLA). In this chapter, LLA has been defined including the various anatomical levels of amputation, its causes and the mortality rate following this operation. The review further covers the reintegration of people into their society of origin postoperatively, the International Classification of Functioning (ICF) and its applicability to LLA, the Barthel Index (BI), the Household Economic and Social Status Index (HESSI) and Heath Questionnaire (EQ-5D).

2.2 Literature search strategy

The literature used in this study was found through internet web pages such as EBSCO HOST electronic journal service, Elsevier Science Direct, PubMed, Sabinet and Google. Different keyword combinations (amputation, amputee, incidence, prevalence, epidemiology, quality of life, impact, physical impact, psychological impact, socio-economic impact, outcomes, prosthesis, ICF) were utilized to search and gather the literature for this study. The National Research Foundation was contacted to assist in locating local literature but these are not published studies and therefore have not been peer reviewed but they are the only available South African literature and may be relevant for the population being studied.

2.3 Definition of lower limb amputation

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

1. Toe-ectomy- removal of a single or multiple toes at the level of the metatarsal phalangeal joints.
2. Transmetatarsal- amputation through the shafts of the metatarsals.
3. Mid-tarsal (Chopart/ Lisfranc) - amputation through the tarsal bones.
4. Through-ankle (Symes) - the ankle is disarticulated and everything from the talus cut down.
5. Below-knee- a lower limb amputation 11-12 cm distal to the knee.
6. Through knee- the knee joint is disarticulated leaving the person to weight bear on the condyles.
7. Gritti-Stokes (femoral condyles)-with good healing qualities but unlikely to have a prosthesis
8. Mid-thigh (Above knee- amputation) - through the femur, ideal length of 12 cm above the knee.
9. Hip disarticulation- the femur is disarticulated from the acetabulum usually after trauma or malignancies, not for peripheral vascular disease
10. Hemipelvectomy (Hind quarter) - removing the lower limb and half of the pelvis. The hemipelvectomy is usually performed in malignancy.

(Engstrom & Van de Ven, 1999, Thomson et al, 1991)

2.4 Aetiology & Epidemiology of LLA

Diabetic complications such as neuropathic foot and ischaemic foot, peripheral vascular disease (PVD), trauma, infection, malignancy and congenital lower limb defects result in LLA, at varying rates (Wong, 2005; Spichler et al, 2001; The

Global Lower Extremity Amputation (LEA) Study Group, 2000; Van Houtum et al, 1996; Engstrom & Van de Ven, 1999). Burns, rhabdomyolysis, sepsis and cellulitis may result in lower limb amputation (Eskelinen et al, 2004). Risk factors for lower limb amputation include hypertension, coronary arterial disease, tobacco use and end stage renal failure (Abou-Zamzam et al, 2003). The Global LEA study, (2000) found that trauma in males accounts for less than 10% of major lower limb amputation. People with high systolic blood pressure (135-221), high diastolic blood pressure (86-117), high pulse pressure (53-125), severe retinopathy, high pack-years smoked (greater than or equal to 15) have a high incidence of lower limb amputation (Moss at al, 1999).

Non-traumatic LLA is associated with more than 80% of people over the age of 65 and retired, 5% unemployed and 2% working (Calle-Pascual at al, 1997). Low income and being single (whether divorced, widowed, and never married) and having a history of foot ulcers are associated with a high incidence of LLA in people with diabetes and those with cardiovascular diseases (Godlwana et al 2008; Resnick at al, 2004; Hennis at al, 2004). However, the reported marital status was on studies done in the Caribbean on people of African descent. Diabetes is the leading cause of LLA and trauma accounts for a minority of cases. In some parts of Africa where there is violence and wars, trauma is the leading cause of LLA (Godlwana et al, 2008).

There is an association between the incidence of LLA and race (Feinglass et al, 2005; Dillingham et al, 2002). These studies reported that black people are twice as likely to have a LLA as a result of PVD than other races. This could be related to their lifestyles e.g. smoking and drinking habits and a fatty diet. Racial differences in the incidence of lower limb amputation are consistent regardless of the presence of diabetes (Dillingham et al, 2002). White people have a higher incidence of LLA compared to Asians (Gujral et al, 1993). This may be as a result of different lifestyles and dietary habits that different races indulge in, or a possible genetic predisposition.

The incidence of LLA is similar in females and males in some regions and higher in females compared to males in other regions although the overall incidence is higher in males than females. The Global Lower Extremity Study however only involved Japan, Taiwan, Spain, Italy, North America and England as individual study sites, which then means that in some sites the incidence was higher in females. The highest rates for both men and women are in North America and the lowest in Japan. The incidence rate in Spain is substantially lower than that in England (The Global Lower Extremity Study, 2000).

In South Africa, only studies by Kamel, (2000), Henry, (1993) and Kubheka, (1993) were found. These are completed theses but unpublished work. Thus they have not been peer reviewed and the level of evidence and scientific standard could potentially be found wanting. But these studies are relevant as they are South African and there are no other publications in this subject in South Africa.

In South Africa the mean age at first amputation is 60 years (Henry, 1993). In this survey, white males underwent their first LLA ten years later than their coloured counterparts and white females have a lower risk of being amputated earlier, on average fifteen years later than their coloured counterparts. This could be related to their lifestyles e.g. smoking and drinking habits and a fatty diet, a possible genetic predisposition and even a difference in their socio-economic status. In this study the mean age of amputation due to malignancy, trauma, and Buerger’s disease was relatively young at 33, 37, 38 years respectively, compared to those who have been amputated due to diabetes and PVD. Therefore vascular causes were generally a later age phenomenon (Henry, 1993). However there is no recent information on the current incidence of lower limb amputation in South Africa. Traumatic LLA occurs at a young age (mean age of 33 years old) (Kubheka, 1993).

In the Western Cape, South Africa, the leading causes of LLA are vascular (83%), trauma (12%), malignancy (3%), infection (2%) and congenital limb defects constituted 0.2% (Henry, 1993). In this study, females were consistently outnumbered by males for all causes of LLA in each of the categories while the number of coloured participants exceeded that of white participants and there were no reasons given for this difference. When comparing the groups, the ratio of coloureds to whites with LLA due to trauma was 5:1 and that of females to males was 3:1. The difference between coloured and white males with peripheral vascular disease was minimal. The percentage of white males and coloured females who underwent LLA was similar (19%). For people amputated due to infection and malignancy, the primary causes were meningococcal septicaemia and osteogenic sarcinoma. Hypertension, chronic obstructive airway diseases (COAD), hemiplegia, ischaemic heart disease (IHD) and myocardial infarctions (MI) were the most prevalent co-morbidities in this study. These are largely diseases of lifestyle and may well be seen in older people. This study population had a mean age of 60 years old.

People who are single have a higher incidence of lower limb amputation than married people (Kubheka, 1993). However this study involved only traumatic amputation generally of young age (although adult) and therefore it is difficult to generalize for the rest of the population with a lower limb amputation. People who are amputated at an early age are more likely to walk, be independent in activities of daily living and end up using their prostheses. The study revealed that the sample also identified failure of rehabilitation personnel to identify limitations in home infrastructure. In this study, stump infection was reported to delay rehabilitation. Other physical problems associated with amputation are sores on the stump, joint stiffness, mobility problems and severe stump pain including phantom pain. Although many people are accepted by their families, some are rejected mainly because they are in some way blamed for their condition. Most people with a traumatic LLA in this study were unemployed.

People with traumatic lower limb amputations have no psycho-social preparation for LLA as they are amputated on the day of admission (Kubheka, 1993). This may have been due to the fact that a person may be coming into the hospital for an emergency amputation following an injury, and therefore does not have the opportunity for counselling. However this study only looked at traumatic LLA and this may not be the case with people that have had an amputation as a result of a nontraumatic event.

People tend to depend on disability grants and small businesses (Kubheka, 1993). This may be because they could not see themselves going back to work or possibly they were aware that if they were injured, they are eligible for a grant especially if the nature of their work is manual rather than sedentary.

2.5 Survival and mortality following LLA

The Table 2.1 below illustrates the mortality rate of people following a lower limb amputation from the period one week after the operation to six years later.

Table 2.1 Survival and mortality following LLA

Follow up period	Reported predictor/cause of death	Mortality rate	Author
Within 30-day to six months	Older age	14.7% of participants with diabetes and 21.3% of participants without diabetes	Papazafiropoulou et al, (2009).
	Not stated	14%	Pernot et al, (2000).
One week, 30-days	Not stated	12%, and 29% respectively	Eskelinnen et al (2004).
	Acute MI, pneumonia, septicaemia, cerebrovascular accident, cancer, gastrointestinal bleeding	15%	Leung& Wong, (2004)
	High level of amputation	9.2%,	Wong, (2005).
	Not stated	10.4%.	Nehler et al, (2003).
	Renal insufficiency	renal insufficiency accounts for a third of all deaths following LLA and half of the deaths	O'Hare et al (2004).
	Older age	One third dies within six months regardless of gender and age.	Back-Pettersson& Bjorkelund, (2005).
1-2year		36%, in people with diabetes and 28%, in those without diabetes	Papazafiropoulou et al, 2009).
	Not stated	52%	Eskelinnen et al, (2004).
	Older age	44%	De Godoy et al, (2005).
		22%	Nehler et al, (2003).
2years	Older age, poor self-care	20%	Otiniano et al, (2003).
		6%	De Godoy et al, (2005).
		37%	Leung& Wong, (2004)
3-4year		47% in people with diabetes and 44%, in those without diabetes	Papazafiropoulou et al, (2009).
		10%	De Godoy et al, (2005).
		45%	Nehler et al, (2003).
4years		4%	De Godoy et al, (2005).
		55%	Leung& Wong, (2004)
5-6 year		48% in people with diabetes and 46% in those without diabetes	Papazafiropoulou et al, (2009).
		4% dies at 5 and 6 years respectively.	De Godoy et al, (2005).

Footnote: The information reported above refers to the entire study that has been referenced, i.e. if a predictor/cause of death is reported at a give time interval for the follow up period, this by no means imply that its for that timeline only.

As seen in Table 2.1 above, a number of people with a disease related lower limb amputation die between the first and fourth year postoperatively. The table further shows that a substantial number of these people die within six months postoperatively, indicating that the operation most probably just delayed death by a few months.

2.6 Psychological and emotional impact of LLA

2.6.1 Overview of the general psycho-emotional impact

Lower limb amputation can be a devastating experience for a person. Psychological support is critical to successful rehabilitation (Wegner et al, 2009; Bosmans et al, 2007; Desmond & MacLachlan, 2006; Engstrom & Van de Ven, 1999). People with a traumatic lower limb amputation have inadequate psycho-social preparation for LLA. This is attributed to the fact that these people often get amputated as early as the day of admission (Kubheka, 1993). People with diabetes with a lower limb amputation and people with a diabetic foot ulcer have significantly poorer psychological adjustments to their situation compared to a control group consisting of people with diabetes but with no history of foot ulcers according to Carrington et al, (1996). Family support as well as professional intervention forms the basis for facing life without the limb. People with a lower limb amputation need to be allowed to grieve the loss of the limb (Engstrom & Van de Ven, 1999).

Mobility impaired people report most distress with psychological well-being issues especially satisfaction with life. Aspects linked with the greatest distress in mobility impaired people include overall satisfaction with life. Males indicate greater distress than females on overall satisfaction with life (Misajon et al, 2006). This could be related to the role men perceive they have to play for example, being a breadwinner and having to provide for their family.

2.6.2 Pain

Preoperative pain

Hanley et al, (2007) reported an average preoperative pain intensity of 5.39 on a scale of 0 to 10. Constant pain was reported in 56% of the cases while intermittent pain was reported in 40% of the cases. In their study, the median preoperative pain duration was 18 months and only 10 people had preoperative pain of less than one month.

Postoperative pain

The incidence of residual limb pain is greatest at four to five days postoperatively and this is mainly associated with the operation and the healing process. However, residual limb pain declines by 30% in 56% of the people by two years after the operation and increases by 30% in 22% of the people with a lower limb amputation by two years (Hanley et al, 2007). Phantom limb pain may decrease by 30% for 35% of the people with a lower limb amputation and increase by 30% in 24% of the people by two year after the amputation (Hanley et al, 2007).

The influence of amputation and phantom pain on social well-being is different for each person. Discomforts such as phantom pain following a lower limb amputation may affect the social well-being of some participants, hampering them in achieving status, affection and behavioral confirmation (Bosmans et al, 2007). Phantom pain may vary in intensity, some people find it unbearable while others find it not so bad to be referred to, as unbearable. Some people rate their subjective well-being as high although they have severe phantom pain while others rate their subjective well-being as low although they hardly have any pain (Bosmans et al, 2007).

Predictors of acute pain

Greater preoperative pain predicts greater acute postoperative residual limb pain. Greater preoperative pain predicts greater acute postoperative phantom limb pain. Age is not a significant predictor of acute pain although older people have more pain (Hanley et al, 2007).

Predictors of chronic pain

Early phantom limb pain is a predictor of phantom limb pain at six, 12 and 24 months, such that greater acute phantom limb pain is associated with greater phantom limb pain at six and 12 months. Preoperative pain intensity is the best predictor of phantom limb pain at 24 months and early residual limb pain is not a significant predictor of phantom limb pain postoperatively (Hanley et al, 2007).

Residual limb pain at six and 12 months is strongly predicted by acute residual limb pain at four to five days postoperatively (Hanley et al, 2007). Thus, greater acute residual limb pain intensity and duration is associated with greater long term residual limb pain.

2.6.3 Acceptance and body image

People with LLA may have psychological difficulties in coming to terms with the stump. Some people may not look at the stump for some time and may deny to themselves that amputation has been performed whereas others may accept the new condition gradually. People may be withdrawn, feeling that coping in their new chapter of life will be overwhelming. It has been reported that if the therapeutic staff handles the stump normally, the person adapts sooner (Engstrom & Van de Ven, 1999). Although people may be of different nationalities, their thoughts, feelings and concerns could be similar regardless of their cultural background (Kamel, 2000).

People may share the same views on self-image. “This thing is going to change my life”. The effect on relationship with self is impacted upon. This may include not feeling confident about the new body image (Kamel, 2000). People may feel that their body image has been distorted and some will never fully acknowledge and accept the new situation (Zidarov et al, 2009; Kamel, 2000; Engstrom & Van de Ven, 1999). Changes in body image also results in high anxiety and to a lesser extent with depression and also dissatisfaction with body image is associated with emotional distress (Fisher & Hanspal, 1998a). Females have a higher body image disturbance than males and people with an above knee amputation report poorer body image perception than those who have a below knee amputation (Zidarov et al, 2009). Psychological problems may sometimes result in physical deterioration not because the person cannot walk but because they choose not to do so. People may present with a negative attitude towards treatment after the amputation (Desmond & MacLachlan, 2006; Fisher & Hanspal, 1998a; Engstrom & Van de Ven, 1999). Body image is a significant predictor of quality of life, as it is positively correlated (Eiser et al, 2001).

2.6.4 Feeling of worthlessness

People may be in shock following an amputation and may need specialized therapeutic intervention. They may feel dependent and hopeless (Kamel, 2000; Engstrom & Van de Ven, 1999). People with a lower limb amputation report a feeling of worthlessness and not being valued in their society (Amosun et al, 2005). However, in some instances, people with a lower limb amputation experience higher subjective well-being during rehabilitation and they express that their life is different but not any way less worthwhile. People with a lower limb amputation may report higher subjective well-being in spite of suffering severe phantom pain whereas those people with hardly any pain may rate their subjective well being as low (Bosmans et al, 2007). The study by Amosun et al, (2005) however is different in that it involved people with a traumatic lower limb amputation as a result of war injuries, from a third world country, Rwanda and therefore their needs and expectations may have been different. Some people may tend to give up and felt that it is better to die (Kamel, 2000).

Some people feel that they may withdraw from social interaction as they are pessimistic, worried, desperate, anxious, and sad while others are happy and convinced that it was better to go for the operation (Kamel, 2000). However, there are those who cope with amputation on their own and only require guidance and support. In some instances regression, helplessness, anger and denial are evident (Kamel, 2000).

2.6.5 Depression

Depression has been reported in people with lower limb amputation (Desmond & MacLachlan, 2006; Schoppen et al, 2003; Livneh et al, 1999; Engstrom & Van de Ven, 1999). Nineteen percent and 11% of people with a LLA might be depressed at two weeks and six weeks respectively after amputation (Schoppen et al, 2003). In some cases, about 35% of people are depressed following an LLA and of these, almost half are female (48%). However, the study by Schoppen et al, (2003) was strong in that their sample had controls. The frequency of depression is independent of the cause of amputation (Kashani et al, 1983). However, greater use of problem solving and social support seeking strategies are associated with lower levels of depression and extensive use of avoidance is associated with higher levels of reported depression (Desmond & MacLachlan, 2006). For example, those people who did not have social support were more likely to de depressed and those who tended to avoid facing their new situation were also more likely to be depressed.

Marital status does not influence the frequency of depression (Kashani et al, 1983). High frequency of depression among people with lower limb amputation is also associated with decreased social interaction, lowered self-esteem due to distortion of body image, increased dependency and lack of social support. Duration since amputation and a person’s age are associated with depression, that is, the younger the person is and shorter the duration since amputation are associated with higher levels of depression (Livneh et al, 1999).

2.6.6 Psychological adjustments

Individuals who employ more avoidance behaviour as a coping strategy are reported to have lower levels of adjustment to amputation, and disease related amputation is associated with lower levels of general adjustment. Age, level of amputation and time elapsed since amputation show a significant relationship with adjustment limitation (Desmond & MacLachlan, 2006). Younger people with an above knee lower limb amputation with less time elapsed since amputation have less favourable levels of adjustments to the limitation. This may be because this group of people is still looking forward to a career and suddenly they do not see their ambitions unfolding. People who have had an amputation as a result of a disease generally adjust poorly to the amputation (Desmond & MacLachlan, 2006). Active problem solving influences psychological adaptation with people reporting higher levels of adjustment and acceptance of disability and acknowledgement, with lower levels of depression and internalized anger. Higher levels of active problem solving coping lead to higher levels of adjustment (Livneh et al, 1999).

2.6.7 Anxiety

Amputation duration and the person's age are significant predictors of anxiety, the more recent the occurrence of the amputation and the younger the person the more pronounced is the reported experience of anxiety (Desmond & MacLachlan, 2006; Livneh et al, 1999). Time elapsed since amputation is a significant predictor of anxiety, the more recent the occurrence of amputation the more pronounced is the reported experience of anxiety. Higher levels of avoidance behaviour are associated with higher scores of anxiety and high levels of acceptance is associated with lower levels of anxiety (Desmond & MacLachlan, 2006). People with amputation who have better problem solving skills are more at ease in dealing with their amputation. However, in a study by Fisher & Hanspal, (1998b), it was reported that time elapsed since amputation was not strongly associated with distress so anxiety and depression do not seem to vary consistently over time. This means that people seem to show any of these symptoms regardless of the time elapsed since amputation. In the above study, anxiety was reported more often than depression.

Poor cognitive function among people with LLA results in high levels of anxiety (Livneh et al, 1999). There is no significant difference in anxiety scores in people with diabetic foot ulcers, people with diabetes with a lower limb amputation and people with diabetes with none of these (Carrington et al, 1996).

2.6.8 Substance abuse

People with a lower limb amputation may abuse substances as a coping mechanism. Depressed people with a lower limb amputation have a higher prevalence of alcohol abuse than people with a lower limb amputation who are not depressed (Kashani et al, 1983). However an amputation is unlikely to result in a totally new psychological state in a person but may heighten some of the more neurotic, obsessive, histrionic, or depressive qualities which were present in the persons' psychological make up prior to amputation (Amosun et al, 2005; Engstrom & Van de Ven, 1999).

People with a lower limb amputation express that they would not like to take drugs but have to and more so due to the amputation. “I wouldn't like to take drugs, smoke or even drink alcohol, but my friend, if you were in my place you would find yourself doing all this too” (Amosun et al, 2005). Other people with a lower limb amputation report a sense of satisfaction and content following their use of drugs, “by the way I feel some relaxation when I smoke”. It is, however, reported that it was clear that some people got involved in drugs before the amputation, however the presence of the disability appeared to have exacerbated the behaviour (Amosun et al, 2005).

2.6.9 Satisfaction with prosthesis

A person's satisfaction with the prosthesis also depends on their psychological status. People who do not use prostheses or wear them for short periods, do so, due to reasons of a psychological nature. They may not be using the device because they are not confident or do not feel that it plays any role in their lives (Poljak-Guberina et al, 2005). People who are dissatisfied with a prosthesis of objectively good quality have psychological problems. These people tend to have higher scores when evaluated for depression and anxiety (Poljak-Guberina et al, 2005). This implies that if a person is dissatisfied with a prosthesis, although its of good quality, this is usually related to the fact that they are in a state of anxiety and depression.

The geographical/regional affiliation and origin of people is not related to the degree of satisfaction with their prostheses (Poljak-Guberina et al, 2005). However, their study was conducted in Croatia (Europe), and is therefore very different from the African and South African context in terms of home environment and infrastructure. In their study it was reported that people's satisfaction with a prosthesis depended also on the degree of dependency in activities of daily living, general heath condition, psychological status and social circumstances. Young people were generally less satisfied with their prostheses and this could be due to a higher need for involvement in other activities and realizing personal goals than in older people (Poljak-Guberina et al, 2005).

The degree of satisfaction with the prosthesis is associated with the person's attitude towards prosthetic devices (Amosun et al, 2005, Poljak-Guberina et al, 2005). The type of ambulatory device appears to significantly influence participation in physical exercises ($p<0.001$), but the condition of the device is not as significant ($p<0.05$) (Amosun et al, 2005). This implies that, those people who tend to exercise do so even if the assistive device, for example crutches or a prosthesis, was of poor condition as there was no difference in involvement between those with a very poor ambulatory device and those with a good and functional device. However, those with a definitive prostheses exercise more e.g. compared to those still in a wheelchair or using axillary crutches.

The greatest barrier to participation in physical exercise is a lack of knowledge of where to exercise (Amosun et al, 2005). The lack of knowledge as a barrier to participation in physical exercise in their study is consistent with the findings by Kim et al, (2004), reporting that people with adequate health literacy exercised more than those with lower literacy, taking into account that in the study by Amosun et al, (2005), participants were using different assistive devices. Their study did not explain what they meant by the various descriptions of the assistive devices, for example, these were described as good and functional, repairable condition, very poor condition and others (Amosun et al, 2005). Therefore it is not clear how these descriptions would have affected the results as there is no specified criteria in their study to define these conditions. What was clear, however, was that the condition of the assistive device did not predict involvement in physical activity.

In a follow-up done after one-year in a Dutch study by Pernot et al, (2000), it was found that more than 60% of the people were able to walk with their prostheses. Findings by Kubheka, (1993) revealed that marital status of the person was not related to the degree of satisfaction with their prosthesis as none of the single people were dissatisfied with the prosthesis and there were only a few people who were dissatisfied in the categories of married and separated. People’s satisfaction with their prostheses depends on their general health, the degree of social circumstances e.g. lack of social support upon return to the community and the possibility of realizing personal goals and their motivation (Kubheka, 1993).

2.6.10 Religious beliefs

LLA may also have an impact on one's spiritual being and one's relationship with God. "Why me, why now?", "God is not fair", these were some of the expressions as some respondents felt like they were being punished by God. LLA results in many concerns for the person (Kamel, 2000). However, in a study by Zidarov et al, (2009) people with LLA consistently reported low scores of spirituality in a three months follow up study their study measured spirituality preoperatively, at discharge and three months later. The former study did not have a follow up and people were measured only preoperatively.

2.6.11 Perceived social worries

Kamel, (2000) revealed that respondents were also worried about their position in the society in which they lived. "How will people take me?" Concerns about inferiority, lack of pride and rejection, resentment and neglect by the family came up frequently. Fear of losing their spouse, and spouse response was crucial in deciding about the operation. Concerns about sex and getting married, losing respect of their children were expressed. One respondent revealed that his family would be more accepting once the foot no longer had an offensive odour (Kamel, 2000).

2.7 The functional and physical impact of LLA

Lower limb amputation results in pain, immobility, changes in perception of body image, and social function (Resnick at al, 2004; Engstrom & Van de Ven, 1999). Many factors come into play when considering return to activities of daily living. The anatomical level of amputation also predicts how much mobility will be possible especially considering safe function (Burger & Marincek, 2007; Taylor et al, 2005; Engstrom & Van de Ven, 1999). Mobility impaired people report the least distress in self care compared to mobility, usual activity, pain/ discomfort and anxiety/depression (Misajon et al, 2006). The study by Misajon et al, (2006) was conducted in mobility impaired people and is comparable with lower limb amputation studies as amputation impacts on mobility. However the ability to perform daily activities such as going to the toilet, (un)dressing and washing decrease comfort so much that they have to be relearnt as soon as possible (Bosmans et al, 2007). Age and preoperative physical condition amongst other concerns may dictate the functional outcome following LLA (Burger & Marincek, 2007; Nehler et al, 2003; Engstrom & Van de Ven, 1999).

Modifications in rehabilitation and prosthetic design may be necessary in these cases (Engstrom & Van de Ven, 1999). As a result, a rehabilitation programme for the elderly prioritizes minimal and relevant exercises especially targeting balance and transfers, stump exercises and improving quality of life. A much more aggressive and progressive programme is utilised when it comes to younger LLAs whose rehabilitation may focus on dynamic and optimal functional ability (Engstrom & Van de Ven, 1999).

People who have been amputated at an early age are more likely to walk, and be independent in activities of daily living and use their prostheses (Kubheka, 1993). Age at amputation is especially important for the person’s general functioning, the younger the person the more functional they are (Schoppen et al, 2003). Standing balance two weeks postoperatively is found to be a significant predictor of all functional parameters for example, if a person has a poor balance, they have a reduced chance of walking. In this study, it is stated that, the role of the unaffected leg is very important for the functioning with or without a prosthesis. The functional prognosis is less positive if the person is unable to stand on the unaffected limb without support. The presence or absence of complications may also shape the return to function. In the case of diabetes, poor vision or even blindness may restrict functional outcome (Zidarov et al, 2009; Engstrom & Van de Ven, 1999).

Reintegration to society

At one year after operation, 70% of people live independently at home, 19% live in a nursing home or home for the elderly and less than 6% stay in a rehabilitation centre. People experience many restrictions in their daily functioning and activities of daily living in the home setting (Schoppen et al, 2003). Other findings in their study were that, cardiopulmonary disease and level of amputation were not predictors of functional outcome but low association of cardiopulmonary disease with outcome may have been a coincidence and the fact that the level of amputation did not affect outcome was accounted for as being due to the skewed distribution of the variables (mainly people with below knee amputations in their study).

Elderly people with LLA have a low level of functioning one year post operatively and an important part of functional outcome could be predicted two weeks after the amputation by age at amputation, balance on the unaffected leg and cognitive function (Schoppen et al, 2003). In their study, older people had poor balance on the unaffected leg and therefore could not stand on one leg without support. For example, in their study six participants who could stand on one leg without support for more than ten seconds at two week after the amputation were using a functional prosthesis compared to ten participants who could not stand unsupported at two weeks after the amputation and did not achieve functional use of their prosthesis at one year after the amputation. However, their study did not indicate the clinical significance of their findings. Physical well-being is more important directly after the amputation (Bosmans et al, 2007). In this instance, a good state of physical well-being helps people during their reintegration to society. If a person is in pain, their physical well-being will be diminished and this results in poor recovery. The presence of co-morbidities e.g. a stroke, also contributes to the prognosis of the person (Bosmans et al, 2007).

People with a lower limb amputation end up with decreased speed, decreased range of motion of the hip and knee, poor vertical ground reaction force, increased amplitude and periods of muscle activation, short single support on stance leg (amputated leg), small stance, instability in stance and decreased proprioception (Vickers et al, 2008). This may thus result in functional limitation.

Stump complications may include: open areas, sinuses, bone infections, exostoses, dermatitis, oedema with suspected underlying pathology, soft tissue lesions, necrosis, neuroma, contractures and a phantom limb (Engstrom & Van de Ven, 1999). Stump complications may also compromise physical well-being and thus have a negative impact on function.

People with a lower limb amputation frequently report loss of walking, loss of biking and driving a car as concerns (Bosmans et al, 2007). Mobility problems and difficulty with public transport are also expressed (Kamel, 2000). These expressions of concern have a negative impact on functional independence. Following such expressions, the persons' function limitation can therefore restrict the social component of their life and result in a negative impact psychologically. A person may be reluctant to joint in leisure activities with their friends or family because of their difficulties in moving around.

2.8 Socio-economic impact of LLA

2.8.1 Home

Studies show that most lower limb amputations are performed in the elderly (Groessl et al, 2007; Hennis at al, 2004, Schoppen et al, 2003, Calle-Pascual at al, 1997). This group of people is usually made up of retired citizens. Following a lower limb amputation, the person may have to be discharged to a home for the elderly in an effort to improve living conditions. Socially, this group will need more support for re-adaptation to society. People with amputation may need their houses adapted (Bosmans et al, 2007). Higher levels of seeking social support and lower levels of avoidance results in increased levels of social adaptation

(Desmond & MacLachlan, 2006). Home visits by the respective health care practitioners (e.g. the occupational therapist or physiotherapist) may be necessary to assess various forms of activity that the person has to or may have to engage in at home (Calle-Pascual et al, 1997; Engstrom & Van de Ven, 1999). People with a lower limb amputation often have to give up their hobbies due to the amputation and most of them find it difficult to spend the day in a meaningful manner (Zidarov et al, 2009; Bosmans et al, 2007). However, the majority of people with a lower limb amputation may live independently at home (Schoppen et al, 2003).

2.8.2 Relationships in the family

People with a lower limb amputation may end up having close relationships with their partners as a result of the lower limb amputation and their children may be more caring than before the amputation (Bosmans et al, 2007). It has been reported that children visit more frequently after the operation and during the rehabilitation phase and the visits cease later on. Partners of persons with an amputation are reported to be more caring with the person after the amputation (Bosmans et al, 2007).

There is no difference in the duration of the diabetes and level of social support received from family and friends (Kim et al, 2004). For example, people receive the same support from their relatives and friends following a lower limb amputation. People with amputation may need help from their partners or domestic helpers most of the time. The impact of amputation on the balance of interpersonal relationships and loss of status within the family may surface. People with a lower limb amputation handle social relationships in different ways, e.g. phantom pain does not influence social relationships, however, dependency hampers people in carrying out their daily activities of shopping, working, pursuing hobbies, participation in sport and visiting family and friends thus hampering them in achieving status and affection (Bosmans et al, 2007)

2.8.3 Role in the community

People may be anxious and feel less confident about having to re-establish themselves in the community and this can even result in immobility (Kamel, 2000; Engstrom & Van de Ven, 1999). People feel “low” in society and even inferior to others “I feel low in society, inferior to others, have to accept any job, life plans have changed” “here (in Rwanda) nobody values a disabled person” (Amosun et al, 2005). Their study was not explicit in determining whether when a person feels low, that means a low self esteem, low confidence, or low morale. Mobility impaired people report the least distress in relationships in their lives but more distress in their ability to participate in community activities and the ability to work (Misajon et al, 2006).

2.8.4 Income

Occupation concerns may arise and unemployment is high in this group of people (Poljak-Guberina et al, 2005). A paid job can play a role in the person’s achievement of status and behavioral confirmation depending on the kind of occupation they were involved in before the amputation. People report better social well-being in cases where they could retain or substitute their job for another as opposed to cases where there was no substitution. Although some people with a lower limb amputation return to their original occupation following the operation, they tend to work at a reduced pace (Bosmans et al, 2007).

People with a lower limb amputation may also report a need for vocational training especially in the fields of carpentry, motor mechanics, computer skills and making of prostheses and orthoses. Most people with a lower limb amputation report the desire to be given disability grants (Amosun et al, 2005). The income implications of LLA mainly include disability grants and small business as the main source of income. Financial compensation for motor vehicle accident victims is generally unsuccessful (Kubheka, 1993). In a study done in KwaZulu-Natal, South Africa, most people amputated due to traumatic causes in South Africa are unemployed (Kubheka, 1993).

2.8.5 Impact of LLA on employment and occupation

Welfare and job security are common concerns. The amputation also brings up concerns about low standards of living and confusion about the future. Concerns about dependence, hoping to get a disability grant and failure in life are expressed (Kamel, 2000). The level of education has an effect on the thoughts and feeling of respondents. Educated people tend to express more thoughts and feelings than their less educated counterparts. Educated people are more worried about losing their jobs as they have put in a lot of effort to achieve their current positions and less educated people are worried about losing their salaries as they lose their jobs (Kamel, 2000). In their study, there was no mention of people hoping to receive a disability grant as reported by Kubheka, (1993).

About 66% of people with a lower limb amputation are reported to return to work. The number of those who return to the same occupation varies from 22% to 67% and people may have to change their occupation in order to be successfully reintegrated into the workplace (Burger & Marincek, 2007). People with a lower limb amputation end up having to look for jobs that are less physically demanding and these need a higher level of education. The person’s ability to return to work is determined by, age, gender, level of education, amputation level, multiple amputations, co-morbidities, reason for amputation, persistant stump problems, the time it take to obtain a permanent prosthesis, wearing comfort of the prosthesis, walking distance and restrictions in mobility, salary, higher job involvement, good support from the employer, and good social support network. In general, however people with a lower limb amputation have problems returning to work (Burger & Marincek, 2007).

Factors related to return to work after a LLA

People under the age of 45 with amputation have a good return to work rate compared to those over 45. Females have a higher chance of being unemployed following a lower limb amputation than males, (Burger & Marincek, 2007). But Burger & Marincek, (2007) did not report the reasons for this discrepancy, for example, their study did not mention whether there was a difference in levels of education or the nature of the jobs that were available to male and females. People with a lower level of education before the amputation have a lower rate of return to work and same have to change their jobs (Burger & Marincek, 2007). Some work at a slower pace while others have to be changed in the nature of the job they did preoperatively (Bosmans et al, 2007).

High amputation level e.g. an above knee amputation compared to a person with a below knee amputation, multiple amputations compared to a single primary amputation, presence of co-morbidities, reason for amputation, persistant stump problems e.g. stump and phantom pain, the time it takes to obtain a permanent prosthesis, wearing comfort of the prosthesis, walking distance and restrictions in mobility, all have a negative impact on return to work and as a result, a person may not return to work (Burger & Marincek, 2007). People who have social benefits and a low pre-injury income less often return to work (Burger & Marincek, 2007).

Salary, higher job involvement, good support from the employer, and a good social support network also influence return to work for people with a lower limb amputation. Having a high annual salary is associated with return to work (Burger & Marincek, 2007). This may be because they still feel that they are valuable to the employer or that these conditions are an incentive. Also, a high paying job might be related to high levels of education and thus, a sedentary job. Their study did not specify the nature of occupation, the social support and employer support that the people with LLA had in order to achieve the high rate of return to work.

2.9 Quality of life in people with a lower limb amputation

People with current ulcers who have not been amputated report lower health related quality of life than people who have healed primarily without an amputation. People with maximal minor amputation have higher EQ-5D scores than people with current ulcers with no previous amputation and people with a major amputation report lower EQ-5D scores than both people with minor amputations and those with an ulcer that healed primarily without amputation (Tennvall & Apelqvist, 2000). Preoperatively, people are mostly unsatisfied with their health and physical functioning and they tend to report better satisfaction with relationships with other people (Zidarov et al, 2009). This may be because they feel that functional independency is important to them so that they do not find themselves dependent on others or limited in what they would like to do.

People with a lower limb amputation show significantly worse scores of quality of life compared with population norms (Eiser et al, 2001). People with a lower limb amputation are mostly unsatisfied with their physical functioning and they tend to expect improvement before discharge and the months to come (Zidarov et al, 2009). The study by Zidarov et al, (2009) however, had a small sample size (n=29) and their participants had to follow a specific and structured rehabilitation programme post operatively, that is, "participants received an individualized program from a multidisciplinary team. Their program included daily physical therapy and occupational therapy for preprosthetic and prosthetic training and psychological support to the participants and the family; additional family support and sociovocational orientation was provided by the social worker, and leisure activities were offered in and out of the rehabilitation center. Once a week, all participants met their rehabilitation team to set rehabilitation objectives for the up coming week." This may have influenced the results differently compared to just observing participants without any specific intervention.

People with a lower limb amputation can report similar quality of life outcomes as those with a limb salvage procedure (Eiser et al, 2001). The majority of people with lower limb amputation report a high subjective well-being (Bosmans et al, 2007). The study by Eiser et al, (2001) compared people with LLA with normal people, hence the significant difference while the study by Bosmans et al, (2007) only reported on people with LLA. This implies that the latter study could well have found high QOL values but not higher than the normal population.

Factors influencing QOL for people with lower limb amputation include pain, body image, functional independence, social functioning, emotional role, general health and mental health (Zidarov et al, 2009; Bosmans et al, 2007; Pell et al, 1995). The study by Pell et al, (1995) only reported on quality of life of people with claudication and they had not undergone amputation but their results give a clear indication of how the preoperative pain and functional limitation negatively influences QOL. The study by Zidarov et al, (2009) studied their participants preoperatively and followed them up to three month after the amputation, however, they had a small sample size. The study by Bosmans et al, (2007) had controls matched for age and gender.

2.10 Summary of the literature

The existing literature shows that lower limb amputation has a multifaceted outcome. In general, people with a lower limb amputation respond, adapt and cope differently following this devastating operation. Therapeutic effects cannot be compared based only on functional recovery resulting from the use of a prosthetic device and physical rehabilitation but should also be based on quality of life. It may be difficult to lead a life with an amputation and phantom pain. People often find themselves dealing with hardships ranging from trying to come to terms with the amputation to them adapting to the prostheses, and some, the possibility of a re-amputation. The availability and condition of assistive devices does not always predict satisfaction and good subjective well-being of people with a lower limb amputation. Another reality faced by people, their families and friend, and the health care practitioners is the high death rate following amputation.

2.11 Instruments for measurements

2.11.1 Household Economic and Social Status Index (HESSI)

The HESSI is used to characterize the social and material environment in which a child is raised. The score reflects the status of a household rather than that of the mother (Barbarin & Richter, 2001). The HESSI was developed in South Africa for assessing children. This index has not been modified for use in adults or people with a lower limb amputation. However, it explores the household and socio-economic status so well that it gives the whole home situation, so therefore seems appropriate for adults as well.

Traditionally, socio-economic status has been based on occupational and educational status, so as to capture information on the differences in financial and social resources of the household. This approach was justified by the historical association between income and occupational status. Another point is that, different levels of education were often associated with distinctive patterns, values, access to information and lifestyles. These will then influence problem-solving and socialization (Barbarin & Richter 2001). It appears that, occupation and income alone do not give a precise description of what the person will or will not have.

The HESSI is designed to profile the constituency of the family and single or multiple independent households living in close proximity is determined by whether they share meals and eat from the same pots (Barbarin & Khomo, 1997). The unit for social and economic assessment in the interview is the household. However the household structure is complex and the determination of what constitutes its membership is not always straight forward, e.g. some members of the family could live in the house while others live in the attached garage or adjacent room and cook separately while they all share the outside flush toilet or the attached room or garage may be rented by persons unrelated by blood and marriage (Barbarin & Khomo, 1997).

The HESSI is a self-report measure that combines multiple indicators of the material and social resources available in South African households. The level of education and the occupation of the principal wage-earner including material resources such as financial assets (home ownership, savings, life insurance), security and adequacy of the food supply, the type of accommodation, monthly utility expenses and possession of consumer goods such as televisions, refrigerators and cars is assessed (Barbarin & Richter, 2001).

Theoretically, consumption is a measure of standard of living or the material adequacy/deprivation experienced by a household. In this index, these material indicators are selected to represent a broader universe of material goods needed in daily living. In the South African context, a family low on material consumption might be living in a single room, garage or shack and have none or few of its material needs met. Low consumption scores may mean living in a galvanized tin or cardboard shack without a toilet, running water, electricity, heat or a refrigerator as well as travelling to most places on foot and occasionally using a public vehicle or train when money is available (Barbarin & Richter, 2001).

Although these situations were studied in children, one may well be able to modify and use this index for adults especially when one considers that the children studied live with adults (e.g. their parents and or the extended families). The study by Barbarin & Richter, (2001) shows that the median household size is seven but only twenty-five percent of the children had more than one biological sibling and thirty-four percent of children resided with their biological fathers. In this setting one may well see that in South Africa, especially around

Johannesburg, the household and living conditions are not that of a typical family elsewhere in the world and are unique (Barbarin & Richter, 2001).

2.11.2 Barthel Index (BI)

The BI is suitable for people with amputation, stroke, spinal cord injuries, neurological conditions such as multiple sclerosis, burns, cardiac problems and the elderly (Finch et al 2002). The instrument is used to determine functional abilities and capacity. The BI is a reliable, valid and widely used tool that assesses eight self care activities including bowel and bladder management and two mobility activities using an ordinal scale (Beck et al, 2008). The BI may have a considerable inter-observer disagreement (95% CI) (Sainsbury et al 2005). However, Sainsbury et al, (2005) studied elderly people only. Typical reliability consistency of Cronbach’s alpha=0.87 at admission and 0.92 at discharge for stroke people undergoing rehabilitation is found (Finch et al, 2002). These Cronbach’s alpha scores imply high consistency and reliability of the BI.

The interrater Pearson correlation coefficient on a sample of 25 people with mixed diagnosis is observed to be 0.99 ($p<0.001$). Kappa scores among five therapists can range from 0.70 to 0.88. When looking at the scores for observation of the task compared with interviews a Pearson’s correlation coefficient of 0.88 ($p=0.001$) was found (Finch et al 2002). These correlation coefficient scores imply a high positive interrater result of the BI and the Kappa scores mean that a strong interrater agreement was achieved.

The repeatability of testing among 50 people by two different interviewers on two different occasions two to three weeks apart gives a Kappa score of 0.98. The intrarater reliability of five therapists has been seen with Kappa scores of 0.84 to 0.97 and the Spearman’s correlation coefficient ranges from 0.95 to 1.00 (Finch et al, 2002). This implies that there is a good correlation between the interrater and intrarater reliability scores. The Kappa scores mean that a strong interrater agreement was achieved.

When using the BI, the bowel control item is the most unreliable item but generally however, the reliability of the BI is dependent on the mode of administration (face-to-face, testing, telephonic, by post (self reported), by observing day-to-day performance) and the type of statistical test used (Sainsbury et al, 2005). This scale is less reliable in people with cognitive impairments. There may be considerable inter-rater disagreement when using this scale (Sainsbury et al, 2005). Agreement is low when comparing the scores of interview versus testing (Sainsbury et al, 2005). Thus, for consistency and good reliability, researchers must use one mode of administration.

The BI may generally be scored high by students compared to therapists. There is however good student-therapist reliability in BI total scores and a moderate to excellent student-therapist reliability in the individual item scores (Yang et al, 2008). The BI is reliable especially when administered using a face-to-face interview and telephone and on testing but its reliability is also dependent on the statistical method used in the study, however, there is no consensus on the preferred statistical method (Sainsbury et al, 2005).

2.11.3 Comparison of the BI with other scales

When comparing three popular ADL scales (the Katz Index of ADL, the Barthel Index, and the Kenny Self-Care Evaluation), the BI is the only scale that includes all eleven of the most commonly used variables (Finch et al, 2002). Thus, the BI covers the participant comprehensively.

A greater proportion of people with initial scores of above 40% gets discharged home compared to those under 40% and those with initial scores of more than 60% tend to stay for shorter periods in hospital than those with scores less than

60%. People who are considered to have recovered after six months may differ according to the definition of recovery (Finch et al, 2002). Fifty-seven percent may recover when recovery is defined by a BI score>90%, compared to other functional outcome measures (National Institute of Health set at≤1, Fugl-Meyer set at>90, Women SF-36 set at>66, Men SF-36 set at>, Rankin scale set at≤1 and at≤2. The BI is better able to discriminate between people who obtain lower Rankin scale scores than those with higher Rankin scores (Finch et al, 2002). Thus the BI is the scale of choice considering the above comparison as it detects change easily.

Comparing five different outcome measures (representing 10 different outcome measurement strategies) shows a standardized response mean (SRM) of 0.99 for the BI. The Barthel SRM ranked fourth highest among the 10 strategies (with a higher SRM representing greater sensitivity to change). In people with severe stroke the BI is very sensitive to change in function while among the moderately or the mildly affected people the BI performed as well as other instruments (Finch et al 2002). Miller et al, (2002) used the BI in people with LLA following vascular and nonvascular disease to establish their disability status. They included people with both below knee amputation and above knee amputation unilaterally. Their study, however did not establish the reliability of the BI on people with LLA. They had follow up from three months to 12 months and they had a large sample size (n=435). The BI is useful in detecting improvement and recovery in people with LLA when their mental status is intact (Brunelli et al, 2006). Their findings were significant (p=0.05) but they stated a weakness in that, their study was retrospective.

2.11.4 EuroQoL (EQ-5D)

The EQ-5D provides a descriptive profile and a single index value of health status for use in the clinical and economic evaluation of health care and population surveys. This instrument was designed to complement other health related quality of life measures such as the 36- Item Short Form Health Survey, Nottingham Health Profile, Sickness Impact Profile, or disease specific instruments (Finch et al 2002). This instrument is suitable for use in people with rheumatic disorders, strokes, osteoarthritis, Parkinson's disease, low back pain, intermittent claudication, and acute elderly people (Finch et al 2002). The EQ-5D is an easy to use generic measure of health related quality of life (Dhillon et al 2005). The EQ-5D is designed to characterize the person's current health status (Liles et al 2006). Another advantage of using the EQ-5D is that, the results obtained from this instrument can be used for health-economic evaluation, and it requires less time for administration. The SF-36 is another good and generic instrument for measuring quality of life but it does not have the two qualities mentioned above (Tennvall & Apelqvist, 2000).

Estimates of interrater agreement for EQ-5D (index) in an interview based administration give a Kappa 0.05 to 0.64 and proxy (Finch et al 2002). The individual items give mobility, 0.48; self-care, 0.62; usual activities, 0.37; pain 0.30; anxiety/depression, 0.05. These Kappa scores mean that a slight to moderate interrater agreement on the EQ-5D and the individual items show a moderate agreement for mobility, substantial agreement for self-care, fair agreement for usual activities, fair agreement for pain and a slight agreement for anxiety/depression item. The EQ5-D VAS gives an intraclass correlation coefficient (ICC) of 0.32 and a proxy when interview based (Finch et al, 2002).

There is a high correlation between EQ-5D Index or VAS or other frequently used outcomes measures in rehabilitation (Finch et al 2002). However the EQ-5D Index is potentially weak in its ability to be sensitive to change especially because of its bimodal distribution of scores that transposes into a ceiling or floor effect (Finch et al 2002). This means that, the EQ-5D has the tendency to score participants on the extreme top or bottom of the scale, which is potentially misleading for data analysis.

In the South African context, the EQ-5D is available in Afrikaans, English, Sesotho, Xhosa and Zulu. There are no publications on the validity and reliability of the EQ-5D in Afrikaans, Sesotho and Zulu but there is a validated and reliable Xhosa version (Louwagie et al, 2007; Wouters et al, 2009).

2.12 International Classification of Functioning (ICF) and its applicability to people with LLA

There are no studies based on the ICF in people with a lower limb amputation (Burger & Marincek, 2007). However, the relevance of the ICF in people with a lower limb amputation is evident when one considers the aims and the framework of the ICF as presented by the World Health Organization (WHO), (2001). Currently, a project is underway to develop and validate Core Sets for persons following amputation based on the International Classification of Functioning, Disability and Health as a way to specify functioning (Kohler et al, 2009). However, because the project is not complete, the ICF could not be used in this study.

The current ICF model is useful but does not covered people with amputations adequately and comprehensively. It only covers a limited amount on function, while a full description would ensure adequate classification, prognostication and estimate parameters on progress of people with an amputation (Kohler et al, 2009). They have since outlined the proposed development process for the ICF Core Sets for people with amputations. The process commences in October 2009 and the process is expected to finish in the year 2011 (Kohler et al, 2009).

Conclusion

The ICF for people with amputation will be a useful tool for all the stakeholders (people with amputation, the health care service providers, the researchers and the WHO). Health care service providers in working with people with amputation will be able to devise standardized programmes and use a common and universal language when caring for the people with amputation.

Chapter 3: Methodology

3.1 Introduction

This study comprises of two parts.

Part I: Quantitative aspect

This section outlines the step by step process that was undertaken in order to meet the objectives of this study. This section thus, contains information of how the demographic, household socioeconomic status, the function and quality of life of the participants was established both preoperatively and postoperatively.

Part II: Qualitative aspect

This section outlines the step by step process that was undertaken in order to conduct in-depth interviews and obtain information of the feelings and experiences of the participants three months after the amputation.

3.1.1 Study design

This is a longitudinal pre and post test study design. The study was conducted over one year (01 June 2008 to 01 June 2009). Participants were interviewed at baseline and at three months post operatively.

3.1.2 Participants

Participants were drawn from the pre-operative lists of people scheduled for first time major LLA at the three major hospitals in the Johannesburg metropolitan area, namely: Chris Hani Baragwanath, Helen Joseph and the Charlotte Maxeke Johannesburg Hospitals. These hospitals are a part of the University of the Witwatersrand teaching complex.

3.1.3 Sample size calculation

The names of the participants scheduled for lower limb amputation at the site were retrieved from the respective surgical/ vascular surgery department wards. Consecutive sampling was employed to enter participants into the study. Effect change to be detected in the EQ-5D= 12 (Pickard et al, 2007), with a standard deviation (±SD) of ±22 (results of the pilot study in Chapter 4), alpha=5%, power of 85.5% and a drop out of 15% with n=73. A sample of n=73 was thus considered sufficient for the study (Tennval and Apelqvistl, 2000). Moreover, this sample is sufficient according to the central limit theorem. According to this theorem, the sampling distribution of the mean can be considered an approximation of the normal distribution if $n \geq 30$. So if n=30 or more, the sampling distribution of the mean can be described using the standard normal curve. When $n<30$, the sampling distribution is a rough estimate to the normal distribution to detect any changes in the way the clients present (Polgar and Thomas, 2008).The calculation is illustrated in Appendix AD.

3.1.4 Inclusion criteria

Participants were included:

- If they were due for a first time unilateral lower limb amputation or simultaneous bilateral LLA during the study period.
- The participants were between the ages of 36-71 year of age.

3.1.5 Exclusion criteria

The following participants were excluded:

- Those who were due to have an amputation as a result of traumatic or a congenital birth defect.

- Those who had co-morbidities that interfered with function pre-operatively, and that would potentially impact on their recovery e.g. participants with major physical co-morbidities e.g. strokes, Parkinsonism etc.
- Those with cognitive impairments and therefore not able to follow the explanations about the study and participate in the interviews.

3.1.6 Ethical considerations and confidentiality

Ethical approval from the University of The Witwatersrand Committee for Research on Human Subjects was obtained (Appendix AF). Permission to conduct the study at each hospital was obtained (Appendix AH,AI and AJ). Participants were briefed about the study using an information leaflet which was also handed out (Appendix O, P & Q) and willing participants were then given English, Zulu or Sotho consent form to sign (Appendix R, S & T). All identifying information was kept on a separate page.

3.1.7 Instruments

Four instruments were utilized to achieve the objectives of this study:
A demographic questionnaire (Appendix A) was designed in English. The questionnaire was administered by the researcher in English and Zulu or research assistant for Sotho speaking participants. Closed ended questions were included to gather both the biographical and medical background of participants. The questionnaire was translated into Zulu and Sotho (Appendix B & C) to allow for participants who preferred Zulu and Sotho as a medium of communication.

The instrument gathered two sets of information.
Section one included demographic details. This section gathered information regarding the participant's date of birth, age, the unit providing care to the participant, gender, race, marital status, geographical location, occupation, mode of transport used, social habits (drinking and smoking) and source of income.

Section two included the medical history and co-morbidities. This section of the questionnaire was designed to gather information on the participant's medical history including the aetiology of the amputation, the type/ levels of amputation due, compliance with medical treatment and at follow up the questionnaire had an extra item to gather data on the status of the lower limbs.

EQ-5D (Appendix D, E, F)

The EQ-5D is a generic measure of health related quality of life (Liles et al 2006, Dhillon et al, 2005). This instrument was developed by the EuroQol Group in order to provide a simple, generic measurement of health for clinical and economic appraisal. The Euro Quality of life version (EQ-5D) is a five item instrument used to measure the participant's quality of life (www.euroqol.org). The instrument covers the areas of mobility, self-care, usual activities, pain/discomfort, anxiety /depression. Each of the five items is scored by placing a tick in one of the three boxes available in each of the groups where the respondent indicates which statement best describes their own state of health on that particular day. At the end, the respondent is given an opportunity to rate their own state of health on that day by making a mark indicating their state of health on a number line scale ranging from zero to one hundred where zero indicates the worst imaginable state of health and one hundred indicates their best imaginable state of health.

In South African this instrument is available in English, Zulu, and Sotho (Appendix D, E, and F). Copies of the instrument were received from the EuroQol Executive Office and permission to use them was granted (see attached letter of permission in Appendix AK) (www.euroqol.org).

The researcher did not attempt to translate these instruments into Zulu and Sotho but rather used the best available versions that the EuroQol Group recognizes to be the best for this region of Africa and South Africa to date.

Although the Sotho and the Zulu version were obtained from the EuroQol group (www.euroqol.org), there is no literature on their validation and reliability.

Wouters et al, (2009) and Louwagie et al, (2007) show that despite searching for publications on the validity and reliability of the EQ-5D in these two languages, nothing is available, with the exception of the Xhosa version. However, for the purpose of this study, these instruments have been recognized as the official version fully recognized by the world body regulating and monitoring the use of this instrument and its translated versions. In this study the researcher used the copies obtained from the EuroQol group as they have strict guidelines and criteria to accept versions from different regions of the world (www.euroqol.org). Moreover, they were part of the pilot study.

Modified HESSI (Appendix G)

This instrument was used to establish the household economic and social status of the respondent. The method of administration is a personal interview (Barbarin & Khomo, 1997). The tool is divided into three sections. Section one covers the marital status, the number of people in the household including their ages. Section two establishes the social status in terms of the level of education, occupation, and their access to finance. Section three explores the nature of the living circumstances in terms of the type of accommodation, facilities available in the house, ownership and expenditure pertaining to accommodation and savings. This instrument was developed for use in South Africa and has been widely used in South Africa (Barbarin & Khomo, 1997). The original questionnaire was designed in English and then translated, back-translated and checked in three other major languages in South Africa: Zulu, Sotho and Afrikaans.

However, because of the close proximity and frequent interactions among speakers of the eleven most common languages in South Africa, the vernacular of urban African is not a pure form of any single language. Therefore in daily usage, words from multiple languages, including English can be interspersed with one another (Barbarin & Richter, 2001). Thus in this study the researcher did not use the translated versions of the index and also especially because the data were collected by the same person with the exception of the Sotho interviews. This allows the advantage to use colloquial speech in the wording during interviews (Barbarin & Richter, 2001). Generally the questionnaire covers social and economic aspects of adequacy of food, shelter, utilities, durable consumer goods, social status, occupation, level of education and family structure. The frequency of responses is calculated using percentages (Barbarin & Khomo, 1997).

Modifications done to the HESSI

QUESTION Ia. Marital status of “mother” was changed to marital status of “participant”

QUESTION IIa. “Mother’s” education was changed to “participant’s” education

QUESTION IIb. Education of “mother’s” partner was changed to education of “participant’s” partner.

Barthel Index (Appendix H, I & J)

The Barthel Index (BI) is a 10 item functional scale used to measure functional independence and amount of nursing care needed. In this scale the participant is examined in the areas of bowel function, bladder function, personal hygiene, moving from wheelchair to bed and return, getting on and off the toilet, bathing self, walking on level surface/ propelling a wheelchair, ascending and descending stairs, dressing and feeding. It is intended for adult long-term participants. This tool has been used in participants with strokes, spinal cord injury, burns and people with a lower limb amputation among other conditions. The instrument requires about 20 minutes to complete if the activities are being observed and about five minutes if the interviewer is recording verbal information. The instrument can be administered by any health care professional or a trained interviewer (Cole et al, 2000). The BI may be administered by means of a personal interview, physical testing, observing day to day performance, by telephonic interview and by post, or self report (Sainsbury et al, 2005). In this scale the participant can score anything from zero to 20 points where 20 is the maximum full normal functional independence.

3.1.8 Procedures

3.1.8.1 Pilot study

After ethical clearance and hospital permission was granted, the demographic questionnaire and the modified HESSI (Appendix A, B, C & G) were piloted at one of the study sites (Charlotte Maxeke Johannesburg Hospital). Content and construct validity was established in consultation with the academic staff of the Physiotherapy Department of the University of the Witwatersrand and following that a small group of participants were interviewed to check validity and reliability. This was done on one day and then repeated four days later to check the reliability. This was done to test content validity and reliability of the items in the instruments and the accuracy of the translated Zulu and Sotho versions.

3.1.8.2 Data collection

Quantitative data

Data collection commenced as soon as ethical clearance was granted. A letter was sent to the hospital management applying for permission to conduct the study (Appendix N). All quantitative data were obtained in the form of interviews. Each interview session took about 30 minutes. The first set (baseline data) of data collection was in the form of interviews done pre-operatively using the questionnaires (Appendix A,B,C,D,E,F,G,H,I & J). The second set of data collection was done post-operatively in the form of interviews using the questionnaires (Appendix A, B, C, D, E, F, G, H, I & J). The post-operative data collection phase was conducted at three months (12 weeks) after the operation. Participants were phoned once every fortnight by the researcher during the 12 weeks to remind them about the study. This was done to minimize loss to follow up. Participants were either seen during their hospital visits or visited at their homes for follow up interviews.

3.1.9 Data analysis

3.1.9.1 Quantitative data

The information gathered from the demographic and medical history questionnaire, the EQ-5D, HESSI and the Barthel Index was subjected to statistical testing for analysis using the SPSS Version 17.0 and STATA 10.0. The significance of the study was set at p=0.05. All continuous data are presented as means, medians, standard deviations and confidence intervals (CI 95%). Categorical data are presented as frequencies. Pre and post operative differences were analyzed using Wilcoxon Signed-rank test. A median regression analysis (both the univariate and multivariate regression) was done to establish factors influencing QOL. Pre and post operative differences in the EQ-5D items and the BI items were analyzed using Chi square/Fischer's exact depending on the data. Data were pooled for presentation as statistical figures in tables (Polgar and Thomas, 2008; Hicks, 2005). Per protocol analysis were used.

EQ-5D

This instrument was analysed as per EuroQol Group guidelines (www.euroqol.org). In the descriptive system, the levels of perceived problems are coded as 1, 2, and 3 depending on whether the top, middle or lower box was ticked. In the scale, an example would be that of "Mobility" where 1= no problem with the activity in question, 2= some problem with the activity and 3= extreme problem. Each dimension should be scored only once and missing values can be coded as 9. Following this the participant scored him/herself on the number line. The five items have been presented as frequencies and percentages. Pre and post operative differences in the EQ-5D items were analyzed using Chi square/Fischer's exact depending on the data. The VAS scores have been presented as means, standard deviations and Wilcoxon Signed-rank test was employed to examine the significance in the difference between the preoperative and postoperative median VAS score as the data were not normally distributed (see Appendix AM) (Polgar and Thomas, 2008; Hicks, 2005).

Barthel Index

When analyzing the BI, the study was set at a score of 12 (60%) for participants considered functionally independent. Finch el al, (2002) refers to 60% as a cut off between independence and marked dependence, 40% or less as severe dependence and 20% or less as total dependence.

The ten items have been presented as frequencies and percentages. Pre and post operative differences in the BI items were analyzed using Chi square/Fischer's exact depending on the data. The mean total BI scores have been presented as means, medians and standard deviations and Wilcoxon Signed-rank test was employed to examine the significance in the difference between the preoperative and postoperative median BI score as the data were not normally distributed (see Appendix AM) (Polgar and Thomas, 2008; Hicks, 2005).

Modified HESSI

This instrument was analyzed descriptively. Frequencies and percentages of responses were calculated according to the frequency of similar or different responses given by the participants. The scores were then presented in tables to show the nature of the household and social status of the various participants (Polgar and Thomas, 2008; Hicks, 2005; Barbarin & Khomo, 1997).

3.2 Part II: Qualitative aspect

3.2.1 Participants

Key informants were selected for semi-structured in-depth interviews (n=12). This process ought to obtain information from a participant who is knowledgeable about the particular experiences, encounters and the impact of the amputation on their lives (Greenberg and Rosenheck, 2008). Individuals interviewed were those who provided useful insights into their experiences. The key informants chosen were of different characteristics in terms of the level of amputation, personality (those who were lively and outspoken and those who were silent in nature), the minority groups in the study (e.g. the colourerd race) and socio-economic status (Green et al 2006). In this study, participants were recruited and interviewed until no new information was obtained (Bhandari et al, 2003). Sufficient in-depth interviews were conducted until saturation of data was reached.

3.2.2 Ethical considerations

The nature of the in-depth interview was explained to the participant and the participant was given an information sheet (Appendix U, V, and W). Following this, permission to conduct the in-depth interview (Appendix AA,AB, and AC) was sought and in addition permission to use an audio tape was obtained (Appendix X,Y,Z).

The raw data (both text and audio) of the study was kept in a locked safe in the Department of Physiotherapy, University of the Witwatersrand. Only the researcher and the supervisor had access to the data.

3.2.3 Data collection: In-depth interviews with key informants.

Semi-structured interviews with key informants were conducted to collect qualitative data on the specific domains of feelings, experiences, functional, and psycho-social impact of LLA on these participants (Bhandari et al, 2003). In these sessions, open ended questions and probe questions were used to gather data from key informants as outlined in Appendix K, L & M. Participants were given the opportunity to explain and narrate their experiences on each of the items and nonverbal communication was observed and has been reported. This included their mood, facial expression, gestures and attitude while reporting. This section explored the independence and coping abilities of the participant with regard to home environment and infrastructure, the mobility profile including the impact of the limb loss on the participant's mode of transport, self care and usual activities.

The research assistant was trained on how to use the instruments and obtain information from the participants. The use of a research assistant was solely for his role in the in-depth interview for Sotho speaking participant. The researcher conducted all the other interviews.

Participants were reminded that the information they provided was being recorded on tape. Each in-depth interview took about one hour. Participants were briefed about the study including the process to be followed and the various themes to be covered in the in-depth interview. Then an information leaflet containing the information about the study and the in-depth interview was provided (Appendix U, V & W).

Willing participants were then given a consent form for participation in the in-depth interview (AA, AB & AC) and another consent form accepting the use of an audio-tape during the proceedings (X, Y & Z) to sign. All the in-depth interviews were recorded on tape to maximize data collection. Probe questions were used for clarity and facilitation of the in-depth interview. All participants were told that there was no right or wrong input, participants were encouraged to say whatever they felt or had experienced.

3.2.4 Data analysis

In-depth interviews were conducted at the three study hospitals until saturation of data was reached. Following this, a grounded theory approach was used to generate or discover theory using open and axial coding and theoretical sampling. The tape recordings were transcribed (Krueger and Casey, 2000). The Zulu and Sotho data were transcribed and then translated into English by a translator who is fluent in both languages. Following this, a second person (familiar with the study) verified the translations for their contextual sense (Krueger and Casey, 2000). This was processed together with the field notes taken at the in-depth interview.

Open coding: The transcripts were read through three times to establish common concepts. Line by line reading and analysis were done to ensure a thorough and verifiable identification of these concepts (Thomas, 2006).

Axial coding: These concepts were then grouped in discrete categories. Following this, similar categories were grouped in broader categories and appropriately coded in order to reduce the data in such a way that comparisons could be made across all in-depth interviews. The themes that emerged were then identified (Krueger and Casey, 2000): Relations and associations between the categories were made so that the most important themes from the data could be outlined.

Reliability

Transcripts were checked to ensure that they did not contain obvious mistakes made during transcription. Line by line coding was done to draw the various concepts from the data. All efforts were made to ensure that there was no drift in the definition of codes or a shift in the meaning of codes during processing. Data were constantly compared with codes. Codes were cross-checked by comparing results that were independently derived by two coders (Creswell, 2009).

After the initial coding was complete, a second coder was given the evaluation objectives, the categories developed, and the descriptions of each category with the raw data attached. This was done to check the clarity of the categories. Following this process the second coder allocated the same text segments with minor suggestions for alterations to improve clarity (Thomas, 2006). The exact language of the in-depth interviews was analyzed within the meaningful segments of speech. Similarities found in various data sources were identified. Data were compared and contrasted from different sources in the study (Denzin and Lincoln, 2000; Krueger and Casey, 2000). The two coders were independent and then the categories were brought together to see the amount of overlap between the categories. A high rate of overlap was achieved indicating no further discussion and analysis to develop coding for this study (Thomas, 2006).

Validity

Triangulation was used to enhance the quality of the research, particularly credibility, trustworthiness and the authenticity of the data (Creswell, 2009; Krefting, 1991). Data collected by various means were compared (e.g. in-depth interviews, participant observations). Triangulation of data sources was used to maximize the range of data that might contribute to complete understanding of the concept. The time and space of the participant interviews were varied, e.g. participants were interviewed on different days (i.e. weekdays and weekends), different settings (i.e. home and hospital settings), different groupings of people (by race and socioeconomic status) (Krefting, 1991). During interviewing, credibility was enhanced by reframing of questions, repetition of questions and probing questions on the matters raised by the participants (Krefting, 1991). During data analysis, themes were established based on converging several sources of data or perspectives from participants (Creswell, 2009).

Member check: Tapes were played back to the participants for their comments and additions to the original interview. During these sessions, quotes from their interview and how they had been interpreted was available for the participants to comment to ensure that what they said during the interview was interpreted in the way they would like it understood.

Trustworthiness- Data saturation: sufficient in-depth interviews were conducted until there was no longer new data coming from the participants. Specificity and emotions, expressions, feelings, perceptions, gestures and non-verbal cues are described in a narrative style (Krueger and Casey, 2000). In addition, the results are discussed and critically analyzed with reference to the modern literature in lower limb amputation research.

Reflexivity

Efforts were made to ensure that the researcher's gender, culture, history and socioeconomic origin did not affect the interpretation of the data (Creswell, 2009). Information found during the study but contrary to the general perspectives of the themes was discussed. This assisted in adding to the credibility of the data presented in this study and allows the study to be more realistic and valid (Creswell, 2009).

Chapter 4: Quantitative results

4.1 Introduction

This section presents the quantitative findings of the study. The section starts by presenting the results of the pilot study and the amendments made to the instruments in preparation of the main study.

Then, the main study results are presented in terms of the preoperative (baseline) and postoperative (follow-up) results. These include the demographic details, quality of life, the functional status of the participants, their household economic and social status and the factors influencing their quality of life.

4.2 Results of the pilot study

After the questionnaires were returned by the five physiotherapy lecturers, there were a few changes and or recommendations to change some areas of the demographic questionnaire and the Modified HESSI.

<u>Demographic questionnaire</u>

In this instrument, a suggestion was made to include:

1. A question on compliance with treatment in the medical history section

“**Question 2.4** If yes, are you on treatment as prescribed by the doctor? “

Yes	No

2. A correction in numbering on the questionnaire and these were changed as per the suggestions.

These two amendments were then made.

<u>Modified HESSI</u>

In this instrument, a suggestion was made to use the term “grade” instead of “standard” when referring to education levels and for the section on material at home, digital video display (DVD) player was added as an option to video cassette recorder (VCR) as some people may have newer technology.

There were no amendments done to the instruments after they had been administered to the 10 participants during the pilot study. All the participants understood the questions well and answered all the questions during the pilot study. The demographic description of the pilot study sample is in Table 4.1 below

Table 4.1 Description of the pilot study sample (n=10)

Age	
Mean (±SD)	57.8 (±7.16)
Gender	
Males	n=7 (70%)
Females	n= 3 (30%)
Income status	
No income	n= 3 (30%)
Still employed	n= 2 (20%)
Receiving a disability grant	n= 2 (20%)
Receiving old age pension	n= 3 (30%)
Housing status	
Hostel	n= 1 (10%)
Room	n= 1 (10%)
Shack	n= 2 (20%)
Home not shared with other families	n= 2 (20%)
Home shared with other families	n= 4 (40%)
Social habits	
Smoking	
Yes	n=9 (90%)
No	n=1 (10%)
Use of alcohol	
Yes	n=5 (50%)
No	n=5 (50%)
Level of amputation	
Unilateral BKA	n=7 (70%)
Unilateral AKA	n=3 (30%)

Most (70%) of the participants in the pilot study were males, 30% of the whole sample had no form of income and 20% of the sample lived in a shack. Most (90%) of the participants were smokers and 50% used alcohol. The majority (70%) of the sample had a unilateral BKA.

Quality of life and functional scores of the pilot sample (EQ-5D VAS and BI Scores) are presented in Table 4.2 below.

Table 4.2 Pilot study EQ-5D VAS and BI Scores (n=10)

Mean EQ-5D VAS (±SD)	61.9 (±22.27)
Mean BI (±SD)	17.7 (±2.06)

The mean EQ-5D VAS for the pilot study sample was 62% and participants were generally functionally independent with a preoperative mean BI score of 18.

4.3 Results of the main study

The flow diagram of the participants in the study is seen in Figure 4.1 below.

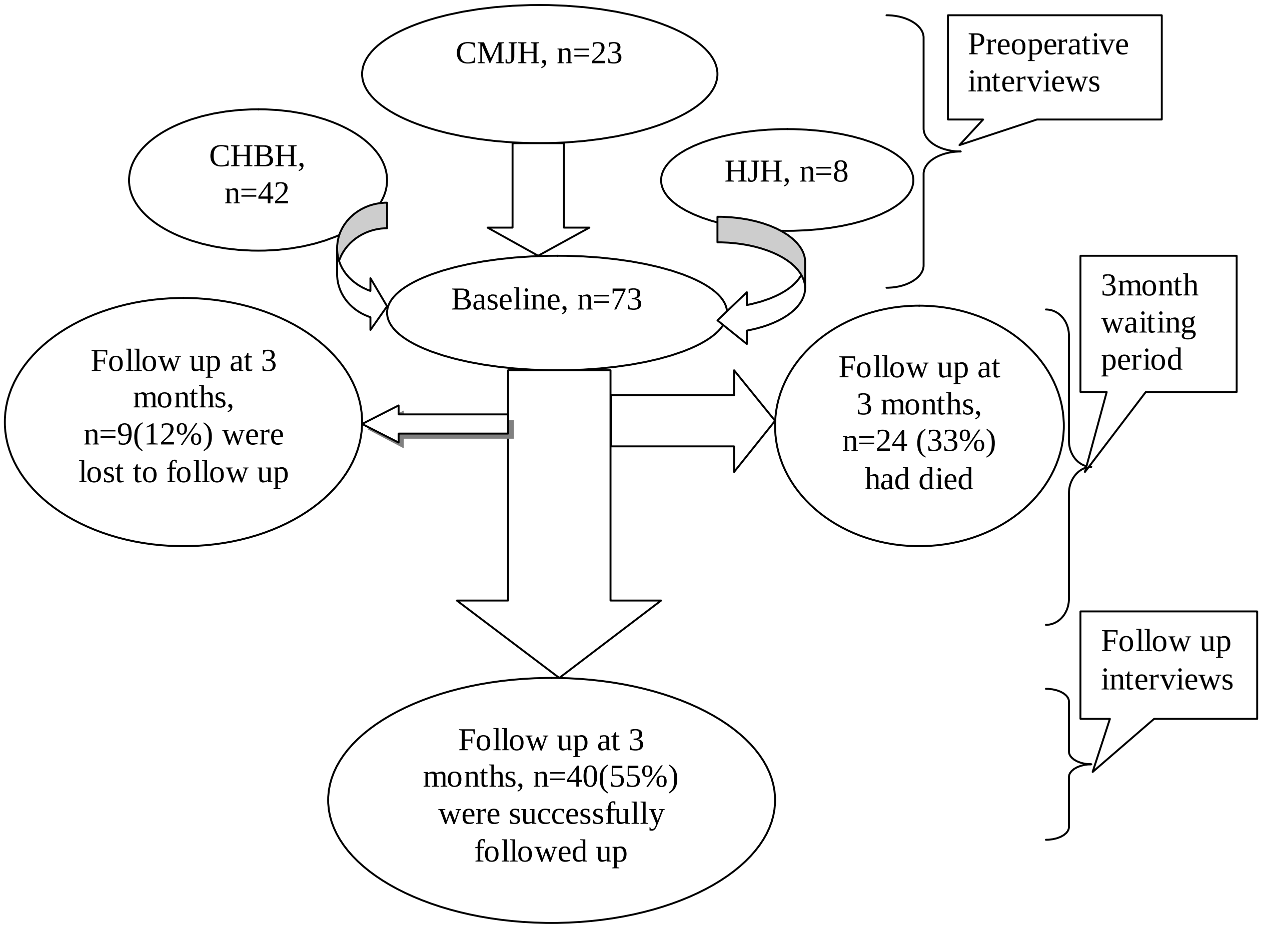

Figure 4.1 The flow diagram of participants from the time they were recruited to the last follow up encounter three months later.

4.4 Reasons for lost to follow up

P1- was not contactable on the telephone number that she had provided to the researcher. The researcher then visited her but could not find the two residential addresses she had provided.

P2- was not contactable on the telephone number that he had provided to the researcher. The researcher then visited the participant but could not find the residential address he had provided.

P3- did not have a telephone number. The researcher visited the participant but could not find the residential address she had provided.

P4- did not have a telephone number. The researcher visited the participant but could not find the residential address he had provided.

P5- this participant was from Lesotho and was not contactable on the telephone number he had provided. He had only provided a Lesotho home address.

P6- was not contactable on the telephone number that she had provided to the researcher. The researcher visited the participant but could not find the residential address she had provided.

P7- was not contactable on the telephone number that she had provided to the researcher. The researcher visited the participant but could not find her at the residential address she had provided, and the researcher was told by the people he found there, that there were two other similar addresses in the informal settlement/dwelling area and the researcher could not locate them.

P8- was not contactable on the telephone number that she had provided to the researcher. The researcher visited the participant but could not find the residential address she had provided.

P9- refused to continue with the study, therefore he was lost to follow up due to noncompliance.

4.5 Comparison of the demographic details for the participants who survived and those who died.

Twenty four participants out of the 73 accepted into the study died. This represents a 33% death rate. Forty participants survived for the duration of the study. Table 4.3 below describes the participants who died postoperatively in comparison to those who survived.

Table 4.3 Description of participants who died postoperatively in comparison of those who survived.

	Preoperatively	**Preoperatively**
	n=40 (survivors)	**n= 24 (Deaths)**
Age		
Mean (±SD)	52.9(±8.61)	58.54 (±7.27)
Gender		
Male	n=27 (67.5%)	n=17 (70.8%)
Female	n=13 (32.5%)	n=7 (29.2%)
Race		
African	n=30 (75%)	n=14 (58.3%)
White	n=5(12.5%)	n= 8 (33.3%)
Coloured	n=0 (0%)	n= 1 (4.2%)
Indian	n=5(12.5%)	n= 1 (4.2%)
Social habits		
Smoking		
Yes	n=21(52.5%)	n= 10 (41.8%)
No	n=19(47.5%)	n= 14 (58.3%)
Use of alcohol		
Yes	n=21(52.5%)	n= 9 (37.5%)
No	n=19(47.5%)	n= 15 (62.5%)
Mode of transport		
Dependent on public transport	n=24(60%)	n= 8 (33.3%)
Used their own cars.	n=12(30%)	n= 12 (50%)
Hire a private vehicle	n=3(7.5%)	n= 2 (8.3%)
Relative's car	n=1(2.5)	n= 2 (8.3%)
Level of amputation		
Unilateral BKA	n=26(65%)	n= 13 (54.2%)
Unilateral AKA	n=14(35%)	n= 11 (45.8%)

4.6 Summary of participant's clinical characteristics (those who died, n=24)

About 46% of the participants had hypertension, 67% had diabetes, and 50% reported peripheral vascular disease. Only 4% reported arthritis and chronic heart diseases respectively. Other clinical conditions reported (a combined category), (13%) included renal failure, and presence of a retroviral disease and oncology. Participants who died were significantly older than those who survived (p=0.009) (see Appendix AN).A significantly higher percentage of participants who smoked died (p=0.03) and did those who drank alcohol (p=0.02) (Appendix AN).

Table 4.4. Comparison of quality of life between the participants who survived (n=40) and those who died (n=24)

	Preoperative	**Preoperative**	
	n=40 (survivors)	n=24 (deaths)	p-value
EQ-5D Mobility			NS
No problem	n= 35(87.5%)	n= 17 (70.8%)	
Some problems	n= 4 (10%)	n= 6 (25%)	
Extreme problems	n= 1(2.5%)	n= 1 (4.2%)	
EQ-5D Self-care			NS
No problem	n= 36 (90%)	n= 18 (75%)	
Some problems	n= 4 (10%)	n= 6 (25%)	
Extreme problems	n= 0 (0%)	n= 0 (0%)	
EQ-5D Usual activities			NS
No problem	n= 31 (77.5%)	n= 15 (62.5%)	
Some problems	n= 6 (15%)	n= 7 (29.2%)	
Extreme problems	n= 3 (7.5%)	n= 2 (8.3%)	
EQ-5D Pain/discomfort			NS
No problem	n= 10 (25%)	n= 12 (50%)	
Some problems	n= 13 (32.5%)	n= 4 (16.7%)	
Extreme problems	n= 17 (42.5%)	n= 8 (33.3%)	
EQ-5D Anxiety/depression			NS
No problem	n= 17 (42.5%)	n= 9 (37.5%)	
Some problems	n= 14 (35%)	n= 6 (25%)	
Extreme problems	n= 9 (22.5%)	n= 9(37.5%)	

NS-not significant. p=0.05 significant

Before the amputation, there were no significant differences in the EQ-5D scores for the participants who died compared to those who survived. Moreover, there was no significant different in the EQ-5D median VAS score between the two groups (p=0.4) (see Appendix AN).

Table 4.5 Preoperative comparison of functional status between the participants who survived (n=40) and those who died (n=24)

Item score	Preoperative n=40(100%) (survivors)	Preoperative n=24 (100%) (deaths)	p-value
BI-Bowel			
0	n=0(0%)	n=0 (0%)	0.008
1	n=0(0%)	n=4 (16.7%)	
2	n=40(100%)	n=20 (83.3%)	
BI-Bladder			
0	n=0(0%)	n=0(0%)	0.04
1	n=1(2.5%)	n=4(16.7%)	
2	n=39(97.5%)	n=20(83.3%)	
BI-Grooming			
0	n=0(0%)	n=1(4.2%)	NS
1	n=40(100%)	n=23(95.8%)	
BI-Toilet use			
0	n=0(0%)	n=1(4.2%)	NS
1	n=5(12.5%)	n=4(16.7%)	
2	n=35(87.5%)	n=19(79.2%)	
BI-Feeding			
0	n=0(0%)	n=1(4.2%)	NS
1	n=0(0%)	n=1(4.2%)	
2	n=40(100%)	n=22(91.7%)	
BI-Transfer			
0	n=1(2.5%)	n=1(4.2%)	0.03
1	n=2(5%)	n=4(16.7%)	
2	n=1(2.5%)	n=4(16.7%)	
3	n=36(90%)	n=15(62.5%)	
BI-Mobility			
0	n=2(5%)	n=1(8.2%)	0.001
1	n=1(2.5%)	n=4(16.7%)	
2	n=0(0%)	n=5(20.8%)	
3	n=37(92.5%)	n=14(58.3%)	
BI-Dressing			
0	n=0(0%)	n=0(0%)	0.02
1	n=1(2.5%)	n=5(20.8%)	
2	n=39(97.5%)	n=19(79.2%)	
BI-Stairs			
0	n=4(10%)	n=5(20.8%)	NS
1	n=3(7.5%)	n=5(20.8%)	
2	n=33(82.5%)	n=14(58.3%)	
BI-Bathing			
0	n=1(2.5%)	n=3(12.5%)	NS
1	n=39(97.5%)	n=21(87.5%)	

NS-not significant, p=0.05 significant

Before the amputation, the group who died had significantly poorer function in the items of bowel control (p=0.008), bladder control (p=0.04), transfer (p=0.03), mobility (p=0.001) and dressing (p=0.02). The people who died were generally of poorer functional status than those who survived as seen by the median total BI scores (p=0.01) (see Appendix AN)

4.7 Household economic and social status of the participants who died

Table 4.6 illustrates the preoperative and postoperative household economic and social status respectively.

Table 4.6 Household economic and social status of those who died (n=24)

Participant's marital status	
Never married, not now living with a partner.	n= 4 (16.7%)
Married, but not living now with a partner (e.g. divorced, separated)	n= 2 (8.3%)
Widowed	n= 3 (12.5%)
Never married, but now living with partner	n= 1 (4.2%)
Married and currently living with partner	n= 14(58.3%)
Nature of Income	
No income	n= 5 (20.8%)
Still employed	n= 9 (37.5%)
Receiving a disability grant	n= 3 (12.5%)
Receiving old age pension	n= 6 (25%)
Private pension	n= 1 (4.2%)
Participant's level of education	
Less than grade 5	n= 6(25%)
Primary school (grade5-6)	n= 0(0%)
Junior Secondary (grade 7-9)	n= 5(20.8%)
Senior Secondary (grade 10-11)	n= 9(37.5%)
Matric/ High School graduate/vocational training diploma.	n= 2(8.3%)
1-2 yr College, Technikon	n= 1(4.2%)
3-4 years of University	n= 0 (0%)
PhD; M.D; D.D.S, or other doctoral degree.	n= 1(4.2%)
Housing status	
None- homeless	n= 0(0%)
Shack	n= 1 (4.2%)
Hostel	n= 1 (4.2%)
Room, Garage	n= 2 (8.7%)
Flat Cottage	n= 1 (4.2%)
Home shared with other family(ies)	n= 4 (17.6%)
Home that is not shared with other families.	n= 14 (60.9%)
Other (please specify):-----------	n= 0 (0%)

For the participants who died, 58% of the participants were married and currently living with their partners. The rest of the participants were either never married, not living with a partner, married but not living with a partner (e.g. divorced, separated), widowed, never married, but now living with a partner.

Twenty-one percent of the participants had no form of income. Those who had an income included those who were receiving private pensions, old age pensions, a disability grants, and those who were still employed preoperatively. Interestingly, 13% of these were receiving a disability grant preoperatively. The level of education ranged from no formal education to a doctor of philosophy (PhD). A high percentage of participants (38%) had secondary education (grade 10-11), while 25% had less than grade 5. Only one participant lived in a shack, 61% lived in a home that was not shared with other families.

Table 4.7 Household economic and social status of those who survived (n=40)

Participant's marital status	
Never married, not now living with a partner.	n=6 (15%)
Married, but not living now with a partner (e.g. divorced, separated)	n= 7(17.5%)
Widowed	n= 5 (12.5%)
Never married, but now living with partner	n= 5 (12.5%)
Married and currently living with partner	n= 17(42.5%)
Nature of Income	
No income	n= 16(40%)
Still employed	n= 12(30%)
Receiving a disability grant	n= 4 (10%)
Receiving old age pension	n= 7 (17.5%)
Private pension	n= 1 (2.5%)
Participant's level of education	
Less than grade 5	n= 10(25%)
Primary school (grade5-6)	n= 1(2.5%)
Junior Secondary (grade 7-9)	n= 10(25%)
Senior Secondary (grade 10-11)	n= 14(35%)
Matric/ High School graduate/vocational training diploma.	n= 4(10%)
1-2 yr College, Technikon	n= 1(2.5%)
3-4 years of University	n= 0(0%)
PhD; M.D; D.D.S, or other doctoral degree.	n= 0(0%)
Housing status	
None- homeless	n= 1 (2.5%)
Shack	n= 7(17.5%)
Hostel	n= 1(2.5%)
Room, Garage	n= 3(7.5%)
Flat Cottage	n= 5(12.5%)
Home shared with other family(ies)	n= 3(7.5%)
Home that is not shared with other families.	n= 20(50%)
Other (please specify):-----------	n= 0(0%)

For the participants who survived, 43% of the participants were married and currently living with their partners. The rest of the participants were either never married, not living with a partner, married but not living with a partner (e.g. divorced, separated), widowed, never married, but now living with a partner.

Forty percent of the participants had no form of income. Those who had an income included those who were receiving private pensions, old age pensions, a disability grants, and those who were still employed preoperatively. Interestingly, 10% of these were receiving a disability grant preoperatively. The level of education ranged from no formal education to college education. A high percentage of participants (35%) had secondary education (grade 10-11), while 25% had less than grade 5. Only one participant was homeless, 18% lived in a shack, 50% lived in a home that was not shared with other families.

4.8 Participants' demographic details

Table 4.8 below describes the participants preoperatively and postoperatively.

Table 4.8 Description of participants preoperatively and postoperatively.

	Preoperatively	**Postoperatively**
	n= 40	**n= 40**
Age		
Mean (±SD)	52.9(±8.61)	53.2 (±8.49)
Gender		
Male	n=27 (67.5%)	n=27 (67.5%)
Female	n=13 (32.5%)	n=13 (32.5%)
Race		
African	n=30 (75%)	n= 30 (75%)
White	n=5(12.5%)	n= 5 (12.5%)
Coloured	n=0 (0%)	n= 5 (12.5%)
Indian	n=5(12.5%)	n= 0 (0%)
Social habits		
Smoking		
Yes	n=21(52.5%)	n= 9 (22.5%)
No	n=19(47.5%)	n= 31 (77.5%)
Use of alcohol		
Yes	n=21(52.5%)	n= 8 (20%)
No	n=19(47.5%)	n= 32 (80%)
Mode of transport		
Dependent on public transport	n=24(60%)	n= 16 (40%)
Used their own cars.	n=12(30%)	n= 7 (17.5%)
Hire a private vehicle	n=3(7.5%)	n= 12 (30%)
Other	n=1(2.5)	n=1 (2.5%)
Level of amputation		
Unilateral BKA	n=26(65%)	n= 19 (47.5%)
Unilateral AKA	n=14(35%)	n= 21 (52.5%)

4.9 Summary of participant's clinical characteristics

About 60% of the participants at baseline had hypertension, 64% had diabetes, and 48% reported peripheral vascular disease. Only 4% and 1% reported arthritis and chronic heart diseases respectively. Other clinical conditions reported (a combined category), (16%) included renal failure, and presence of a retroviral disease and oncology.

About 63% of the participants postoperatively had hypertension, 65% had diabetes, and 48% reported peripheral vascular disease. Only 3% reported arthritis and no participant had a chronic heart disease postoperatively. Other clinical conditions reported (a combined category), (15%) included renal failure, and presence of a retroviral disease and oncology.

4.10 Preoperative and postoperative quality of life

Table 4.9 below shows the preoperative and postoperative quality of life.

Table 4.9 Preoperative and postoperative quality of life.

	Preoperative	**Postoperative**	
	n=40	n=40	p-value
EQ-5D Mobility			0.04
No problem	n= 35(87.5%)	n= 30 (75%)	
Some problems	n= 4 (10%)	n= 2 (5%)	
Extreme problems	n= 1(2.5%)	n= 8 (20%)	
EQ-5D Self-care			NS
No problem	n= 36 (90%)	n= 38 (95%)	
Some problems	n= 4 (10%)	n= 2 (5%)	
Extreme problems	n= 0 (0%)	n= 0 (0%)	
EQ-5D Usual activities			0.001
No problem	n= 31 (77.5%)	n= 14 (35%)	
Some problems	n= 6 (15%)	n= 14 (35%)	
Extreme problems	n= 3 (7.5%)	n= 12 (30%)	
EQ-5D Pain/discomfort			0.003
No problem	n= 10 (25%)	n= 12 (30%)	
Some problems	n= 13 (32.5%)	n= 24 (60%)	
Extreme problems	n= 17 (42.5%)	n= 4 (10%)	
EQ-5D Anxiety/depression			NS
No problem	n= 17 (42.5%)	n= 24 (60%)	
Some problems	n= 14 (35%)	n= 8 (20%)	
Extreme problems	n= 9 (22.5%)	n= 8 (20%)	

NS-not significant. p=0.05 significant

Following the amputation, mobility was significantly reduced three months postoperatively (p=0.04). Participants were also found to have problems with usual activities (p=001), showing a significant limitation. The majority of the participants reported a significant improvement in pain or discomfort (p<0.003) compared to the preoperative status. There was no improvement in QOL from preoperative status to three months postoperatively (p=NS (0.6), as measured by the EQ-5D VAS score. Data are illustrated in Appendix AN.

4.11 Preoperative and postoperative functional status

Table 4.10 below illustrates preoperative and postoperative functional status.

Table 4.10 Preoperative and postoperative functional status.

Item score	**Preoperative n=40(100%)**	**Postoperative n=40 (100%)**	**p-value**
BI-Bowel			
0	n=0(0%)	n=0 (0%)	0.04
1	n=0(0%)	n=4 (10%)	
2	n=40(100%)	n=36 (90%)	
BI-Bladder			
0	n=0(0%)	n=0(0%)	NS
1	n=1(2.5%)	n=5(12.5%)	
2	n=39(97.5%)	n=35(87.5%)	
BI-Grooming			
0	n=0(0%)	n=0(0%)	
1	n=40(100%)	n=40(100%)	
BI-Toilet use			
0	n=0(0%)	n=1(2.5%)	NS
1	n=5(12.5%)	n=4(40%)	
2	n=35(87.5%)	n=35(87.5%)	
BI-Feeding			
0	n=0(0%)	n=0(0%)	
1	n=0(0%)	n=0(0%)	
2	n=40(100%)	n=40(100%)	
BI-Transfer			
0	n=1(2.5%)	n=0(0%)	NS(0.4)
1	n=2(5%)	n=1(2.5%)	
2	n=1(2.5%)	n=0(0%)	
3	n=36(90%)	n=39(97.5%)	
BI-Mobility			
0	n=2(5%)	n=2(5%)	0.04
1	n=1(2.5%)	n=8(20%)	
2	n=0(0%)	n=0(0%)	
3	n=37(92.5%)	n=30(75%)	
BI-Dressing			
0	n=0(0%)	n=0(0%)	NS
1	n=1(2.5%)	n=1(2.5%)	
2	n=39(97.5%)	n=39(97.5%)	
BI-Stairs			
0	n=4(10%)	n=14(35%)	p<0.001
1	n=3(7.5%)	n=13(32.5%)	
2	n=33(82.5%)	n=13(32.5%)	
BI-Bathing			
0	n=1(2.5%)	n=3(7.5%)	NS
1	n=39(97.5%)	n=37(92.5%)	

NS-not significant, p=0.05 significant

Following the amputation, mobility and bowel control were significantly reduced in most participants three months postoperatively ($p=0.04$). Participants were also found to have a decreased ability to negotiate stairs ($p<0.001$), showing a significant limitation. There was a non-significant change in the ability to transfer ($p=0.4$). There was a decline in function from preoperative status to three months postoperatively as measured by the total BI score ($p<0.001$). Data are illustrated in Appendix AO.

4.12 Household economic and social status

Table 4.11 and 4.7 illustrates the preoperative and postoperative household economic and social status respectively.

Table 4.11 Postoperative household economic and social status (n=40)

Participant's marital status	
Never married, not now living with a partner.	n= 6 (15%)
Married, but not living now with a partner (e.g. divorced, separated)	n= 9 (22.5%)
Widowed	n=5(12.5%)
Never married, but now living with partner	n=5 (12.5%)
Married and currently living with partner	n=15 (37.5%)
Nature of Income	
No income	n= 21 (52.5%)
Still employed	n= 2 (5%)
Receiving a disability grant	n= 7 (17.5)
Receiving old age pension	n= 8 (20%)
Private pension	n= 2 (5%)
Participant's level of education	
Less than grade 5	n= 10(25%)
Primary school (grade5-6)	n= 1(2.5%)
Junior Secondary (grade 7-9)	n= 10(25%)
Senior Secondary (grade 10-11)	n= 14(35%)
Matric/ High School graduate/vocational training diploma.	n= 4(10%)
1-2 yr College, Technikon	n= 1(2.5%)
3-4 years of University	n=0 (0%)
PhD; M.D; D.D.S, or other doctoral degree.	n=0(0%)
Housing status	
None- homeless	n= 1 (2.5%)
Shack	n= 7 (17.5%)
Hostel	n= 1 (2.5%)
Room, Garage	n= 3 (7.5%)
Flat Cottage	n= 3 (7.5%)
Home shared with other family(ies)	n= 3 (7.5%)
Home that is not shared with other families.	n= 22 (55%)
Other (please specify):-----------	n=0 (0%)

During the postoperative stage, 38% of the participants were married and currently living with their partners. The majority of the participants were either never married, not living with a partner, married but not living with a partner (e.g. divorced, separated), widowed, never married, but living with partner.

Most (53%) of the participants had no form of income. Those who had an income included those who were receiving private pensions, old age pensions, a disability grants, and two were still employed postoperatively (5%). The level of education ranged from no formal education (25%) to college or technikon level for the participants who survived the operation (3%). The highest percentage of participants in all instances (35%) had secondary education (grade10-11), while 25% had less than grade 5. Only one participant was homeless, 18% lived in a shack, 55% lived in a home that was not shared with other families. For comparison with their preoperative status, refer to Table 4.7.

4.13 Factors influencing QOL

Table 4.12 below illustrates factors influencing QOL.

Table 4.12 Factors affecting QOL (n= 40)

		Univariate			Multivariate		
Item score	Median VAS	Coefficient	p-value	95% CI	coefficient	p-value	95% CI
EQ-5D mobility							
1- Constant	70	70	Reference	-	53.57	Reference	-
2-	65	-20	NS	-58.82 18.82	-23.39	0.039	-45.58 -1.21
3-	40	-30	p<0.001	-43.58 -16.42	-23.03	p<0.001	-33.73 -12.34
					Female 14.7	0.049	0.06 29.23
BI mobility							
0- Constant	50	50	Reference	-	-	Reference	-
1-	40	-10	NS	-	4.56	NS	-20.50 29.62
2-	-	-	-	-	-	-	-
3-	70	20	0.004	6.76 33.24	27.06	0.029	2.88 51.24
					Female 15.6	0.029	1.7 29.48
BI transfer							
0- Constant	40	40	Reference	-	40	Reference	-
1-	45	10	NS	-	-5.35e-14	NS	-14.49 14.49
2-	50	10	-	-	-5.66e-14	NS	-27.56 27.56
3-	73	30	p<0.001	15.03 44.97	30	0.003	11.12 48.89
BI stairs							
0- Constant	50	50	Reference		56.67	Reference	-
1-	80	30	NS	-19.49 79.49	46.33	0.005	15.18 77.49
2-	70	20	NS	-12.90 52.90	15.33	NS	-11.22 41.89
3-	-	-	-	-	-	-	-

Reference-scores are compared to first score in each section hence reference value does not have confidence intervals. NS- Not significant, p=0.05 Significant. BI-Barthel Index. Variables tested in the multivariate analysis were gender, age and race.

Participants who had extreme problem with mobility preoperatively had a median VAS of 30 less than those who had no problem with mobility in the EQ-5D item postoperatively and this was statistically significant (p<0.001). When the mobility in the EQ-5D was adjusted for gender in the multivariate analysis, female participants had a median VAS of 15 greater than their male counterparts postoperatively (p=0.05) at 95% CI. However, females who has some problem or extreme problem with mobility as measured by the EQ-5D preoperatively had a median VAS of 23 less than those that has no problem with mobility (p=0.04) at 95% CI and (p<0.001) at 95% CI.

Participants who were independent in mobility in the BI mobility preoperatively had a postoperative median VAS of 20 greater and those who were dependent and this was statistically significant (p=0.004). When the mobility on the BI was adjusted for gender in the multivariate analysis, female participants had a median VAS of 16 greater than their male counterparts postoperatively (p=0.03) at 95% CI.

Participants who were independent with transfer in the BI mobility preoperatively had a postoperative median VAS of 30 greater than those who were dependent and this was statistically significant (p<0.001).

Conclusion

The above findings show that people with LLA in the Johannesburg metropolitan area who had no problem with mobility preoperatively (EQ-5D mobility item), who were independent with mobility (BI mobility item) preoperatively, who were independent with transfer preoperatively (BI transfer item) had a higher postoperative quality of life (postoperative EQ-5D- VAS) compared to people who were dependent or had problems with these functions preoperatively. Being female was also a predictor of higher reported quality of life compared to being male in these items. The results presented in this Chapter have been discussed in Chapter Five.

Chapter 5: Discussion of quantitative results

5.1 Introduction

This chapter discusses the results presented in Chapter Four. The main focus of the discussion is on the functional status, the quality of life, the household and social status and some of the demographic characteristics both preoperatively and postoperatively.

5.2 Preoperative and postoperative BI scores (preoperative and postoperative physical functioning)

In this study, participants generally reported high scores in terms of their overall functional independence (median total BI= 20) both preoperatively and postoperatively (postoperative median total BI= 19). However, they experienced a significant reduction in functional status compared to their preoperative status. This is consistent with findings by Zidarov et al, (2009). However, their study did not use the BI to assess function. Most notable in this study is that, although the function was significantly reduced, the participants were generally still functionally independent (Finch et al, 2002).

More participants showed a significant reduction in the items of mobility and ability to negotiate stairs. These findings are similar to those by Zidarov et al, (2009). The results by Zidarov et al, (2009), showed at participants had poor scores of physical functions (ability to go outside, overall fitness) at baseline and remained poor at three months follow up. People with LLA need intensive rehabilitation to optimize their recovery and in is study, participants were not receiving enough rehabilitation.

In this study, a significant number of participants reported poor bowel control function following the amputation. According to Smith, (2005), poor bowel function as a result of lower limb amputation may occasionally occur. There is currently very little literature on poor bowel function as a result of, or associated with lower limb amputation and Smith, (2005) referred to hip disarticulation or a transpelvic amputation levels. Thus, this may not be relevant for this study as none of the participants in this study had such a high operation). However, a possible explanation could be that, due to their poor mobility and transfer status already described, these participants could not get to the toilet early enough.

Participants did not appear to be receiving sufficient rehabilitation. Their appointments for rehabilitation were often far apart from each other and mostly, the participants were unable to attend rehabilitation sessions. This may have contributed to the decline in function after the operation rather than just being a pure outcome of LLA.

5.3 Preoperative and Postoperative QOL scores

In this study, participants generally reported high scores in terms of their overall quality of life (median VAS= 60) both preoperatively and postoperatively, median VAS= 70. There was no change in QOL (VAS score). These results show that the QOL did not change when comparing the same participants before and after the amputation. This may be because there was no intervention given or there was poor recovery following insufficient rehabilitation.

Zidarov et al, (2009) and Bosmans et al, (2007) showed an improvement in QOL. The study by Zidarov et al, (2009) may, however, be difficult to compare with this study, not only because of the small sample size (n=29) but also due to the fact that their participants had to follow a specific and structured rehabilitation programme post operatively, that is, *"participants received an individualized program from a multidisciplinary team. Their program included daily physical therapy and occupational therapy for preprosthetic and prosthetic training and psychological support to the participants and the family; additional family support* *and sociovocational orientation was provided by the social worker, and leisure activities were offered in and out of the rehabilitation center. Once a week, all participants met their rehabilitation team to set rehabilitation objectives for the up coming week."* Such a program did not exist in is study. Participants were either able to or unable to go to the hospital after discharge and thus, the high QOL scores seen in the study by Zidarov et al, (2009) may have been influenced by their intervention whereas in this study, participants were poorly rehabilitated.

Another difficulty in comparing the two studies was that, they used different outcome measures for QOL, namely the EQ-5D in is study and the Subjective Quality of Life Profile (SQLP) in theirs. The advantage in comparing is study with the one by Zidarov et al, (2009) is that, their design was such that participants were interviewed preoperatively and then both studies had a follow up at three month postoperatively.

In a study by Tennvall & Apelqvist, (2000), the results were different from those of this study with participants with major amputation reporting lower EQ-5D index scores and VAS scores. However the study by Tennvall & Apelqvist, (2000), revealed these inferior scores when compared with groups of people with a primary healed ulcer without amputation and participants with a maximal minor amputation. The advantage in comparing this study with the one by Tennvall & Apelqvist, (2000), is that they used the EQ5-D, although they had a small sample size (n=26) for participants with a major LLA and also, participants were not studied from their pre-amputation stage. Thus the low EQ-5D score was perhaps showing deterioration in the participant's health. Moreover they included participants with diabetes only.

Participants reported a significant decrease in pain/discomfort by the time of follow up. These findings are different to those by Mosaku et al, (2009), Bosmans et al, (2007), Burger & Marincek, (2007), Hanley et al, (2007), Eiser et al, (2001), Pell et al, (1993). People with a lower limb amputation have pain and discomfort. In this study, the significance in the decrease in pain/discomfort was detected.

5.4 Household economic and social status

Most were single both preoperatively and postoperatively and generally, the participants were of low socioeconomic status. This finding is similar to Godlwana et al (2008), Resnick et al, (2004), Hennis et al, (2004) that, low income and being single (whether divorced, widowed, never married) are associated with a high incidence of LLA in people with diabetes and those with vascular diseases. In this study, participants were generally unemployed both preoperatively and postoperatively which is similar to the finding of Burger & Marincek, (2007), Amosun et al, (2005), Poljak-Guberina et al, (2005), Kubheka, (1993). The people in this study were generally of low or no formal education. This would then make it difficult for them to either return to work if they had a physical job or find it difficult to get employment (Burger & Marincek, 2007).

5.5 Factors influencing QOL

In this study, factors influencing QOL were mobility and functional independence. Zidarov et al, (2009); Bosmans et al, (2007) and Pell et al, (1995) showed similar findings. This study showed that having no problem with mobility preoperatively (EQ-5D mobility item), being independent with mobility (BI mobility item) preoperatively, being independent with transfers preoperatively (BI transfer item) predict a higher quality of life (postoperative EQ-5D- VAS) compared to people who were dependent or had problems with these functions preoperatively.

Although the scales used in this study were unable to report factors such as social functioning and general heal as seen in the literature (Zidarov et al, 2009; Bosmans et al, 2007; Pell et al, 1995), these are closely related to mobility issues and thus, the findings in is study can be assumed to have addressed these items. (This was also addressed extensively in the qualitative section of this study, where limitations in mobility were consistently reported to limit social interaction and involvement).

The quantitative aspect of this study also did not address factors such as body image, emotional role, and mental health as seen in the literature (Zidarov et al, 2009; Bosmans et al, 2007; Pell et al, 1995). (However, e qualitative aspect of this study addressed these items extensively where some participants reported concerns about body image, psycho-emotional and mental problem as seen in the literature).

5.6 Gender and race

In this study, there were more males than females and this is consistent with the literature, (The Global Lower Extremity Study, 2000). In this study, the majority of the participants were African (71%) as is also seen in the literature. Studies show an association between the incidence of LLA and race (Dillingham et al, 2002, Feinglass et al, 2005). These studies reported that black people are twice as likely to have a LLA as a result of PVD than other races. It is however difficult to conclude that LLA is more prevalent in this community compared to whites, coloured and Indian populations in Johannesburg as this finding could largely (but not entirely) be because African participants are recipients of public hospital services compared to other races who tend to be able to afford private health care, as they have medical aids.

Racial differences in the incidence of lower limb amputation are consistent regardless of the presence of diabetes (Dillingham et al, 2002). On the other hand in a study by Gujral, et al, (1993), white participants were seen to have a higher incidence of LLA compared to Asians. This may be as a result of the different lifestyles and dietary habits that the different races indulge in or as a result of possible genetic predisposition. This study by Gujral et al, (1993) was conducted in the United Kingdom.

In a study conducted by Henry, (1993), white male participants underwent their first LLA ten years later than their coloured counterparts and white females have a lower risk of being amputated earlier, on average fifteen years later than their coloured counterparts. However, her study was done at a single centre that was previously predominantly associated with servicing these racial groups in South Africa at the time.

5.7 Comparison between those who died and those who survived

In this study, 33% (n=24) of participants of the original n=73 had died by the time of follow up at three months. Generally, lower limb amputation has been seen to have a high mortality rate. Other studies show that the survival rate varies across countries but mortality rate is generally high (Papazafiropoulou et al, 2009, Wong, 2005, de Godoy et al, 2005, Resnick et al 2004, Nehler et al, 2003, Spichler et al, 2001). None of these studies were conducted in Africa but there was a high mortality rate in a study done in Brazil, which is a developing country, and thus may reflect a similar picture to that of South Africa (de Godoy et al, 2005). These studies had follow ups ranging from two weeks postoperatively to five years postoperatively, while this study only detected the deaths during a three month period.

Papazafiropoulou et al, (2009) found that old age and higher anatomical level of amputation are associated with poor survival and the mortality rate is higher in both people with LLA with or without diabetes.

In this study, the group who died had significantly more smokers than those who survived. Davis et al, (2006) reported that current smoking at baseline is a significant predictor of death from cardiac causes in people with lower limb amputation. In this study, the researcher was unable to associate each cause of death with a specific clinical pathology e.g. cardiac cause but observed that smokers were at a high risk of dying. In this study, the group who died had significantly more participants who drank (alcohol) than those who survived. Naschitz& Lenger, (2008) report that moderate alcohol consumption (drinking) has a cardiovascular protective effect, however, an increased risk of cardiovascular related death has been observed among heavy drinkers.

In this study, participants who died were generally older than those who survived. This finding is similar to those by Papazafiropoulou et al, (2009), Back-Pettersson& Bjorkelund, (2005), De Godoy et al, (2005), Wong, (2005), Otiniano et al, (2003). Participants who had poor scores in the BI scores of bladder and bowel control, and dressing had poorer survival status compared to those who were good at these functions. These findings were comparable with those by Otiniano et al, (2003). Participants who had poor scores in the BI scores of transfers, mobility had a poor survival status compared to those who were goods at these functions. These findings were comparable with those of Leung & Wong, (2004). In their study, poor preoperative mobility and low preoperative BI scores were predictors of death. In this study, the amount of alcohol drank was not recorded, so although significantly more participants drank alcohol, the amount is not known.

5.8 Researcher's experiences regarding lost to follow up

In this study, some participants could not be followed up, owing to the poor geographical settlements seen in some parts of the Johannesburg metropolitan area. In informal settlements such as Orange Farm and other areas with shacks, there are no street names and the people live on plots and one plot may have many shacks and different families. The challenge was in locating them. In some areas, the order of the house numbering was not sorted in a normal numerical order making finding the dwellings exceptionally difficult.

These challenges and difficulties regarding follow up were similar to those that faced Richter et al, (2009). Reasons included participant migration, incorrect contact details, and loss of interest in the study, all resulting in failure of the researcher to follow up the participants. Another challenge found by Richter et al, (2009) was that of participants giving different names for the study compared to the name they use in the community of origin, e.g. a participant may give an English name for enrolment to the study but at home, he/she is know by his/her traditional name. Although the Richter et al, (2009) study was done as a follow up of participants on a birth to 20 cohort, the challenges faced were similar to the ones in is study. Generally, participants could not afford to attend appointments due to financial constraints and the researcher had to find them at their homes.

5.9 Conclusion

The QOL improved although function had deteriorated. Poor compliance with rehabilitation and poor access to rehabilitation after the amputation may have resulted in this decline in function. Poor social backgrounds resulted in poor compliance with rehabilitation due to financial constraints. Poor decentralization of rehabilitation facilities meant the participants who had no financial resources could not afford to return to the hospital for rehabilitation. This was also confounded by loss of income following the LLA.

Chapter 6: Qualitative results and discussion

6.1 Introduction

This chapter serves to outline the outcomes of the in-depth interviews with key informants. Following analysis of the in-depth interview, three main themes emerged after the categorization of the various concepts expressed by the key informants. These were: a psychological theme, social theme and a religious theme.

6.2 Psychological Theme

6.2.1 Negative psychological impact

Psychologically the participants dealt with a lot of hardships following a lower limb amputation. The new life experience, having to face the world without a limb brought different psychological reactions. Participants went into a state of shock and disbelief. The reality of not knowing what to expect following an amputation was a concern. Not knowing what the difference will be now that they had to live with an amputation and how the amputation was going to impact on their lives was a concern. In these situations, they did not know what adjustments they needed to make and what adaptation they had to make in order to factor the amputation smoothly into their lives. They did not know what difficulties they had to face and there were perceived uncertainties about life in the future.

Others participants may have accepted the new condition gradually. Participants may be withdrawn, feeling that coping in their new chapter of life will be overwhelming (Engstrom & Van de Ven, 1999). This was the case with participant C2 during his early stages while he was still in the hospital. The amputation initially resulted in misery and a state of doubt whether he would ever be the same again. The reality of not knowing what to expect following an amputation is a concern. Engstrom & Van de Ven, (1999) reported that these participants may go into a state of shock following an amputation and may need specialized therapeutic intervention. They may feel dependent and hopeless. This is consistent with the findings in this study. Mosaku et al, (2009) and Engstrom & Van de Ven, (1999), reported that people with lower limb amputation experience anxiety and depression following amputation of the lower limb. Schoppen et al, (2003) further reported that 19% and 11% of people with a lower limb amputation might be depressed at two weeks and six weeks respectively after amputation.

In this study, depression was reported but it was somehow reported in passing and as a phenomenon around times of trying to cope. In this regard, Desmond & MacLachlan, (2006) also reported that greater use of problem solving and social support seeking strategies results in lower levels of depression and extensive use of avoidance, results in higher levels of reported depression.

C2 *" Well I think initially the thought and the idea of losing a leg, I was not sure what sort of impact its gonna have in your life. I think initially when the shock settles and you get used to the idea you start wondering what life is gonna be like. How much difference is gonna make, and what changes you gonna have to go through, the difficulties that you gonna have to experience, the adjustment you will have to make".*

"Personally for me, aammhh, the shock is the disbelief that something like this could ever happen to me. I found it very hard to come to terms with it"

In the initial stages participants went through miserable moments of trying to live with the amputation. They had to cope with the idea of not having a leg, trying to come to terms with it.

C8 *"I wasn't the same initially. I was always miserable. I used to think, why should the world be so unkind to me? What have I done ?"*

C1 *"You will be asking yourself questions like I said. Why? Why me?"*

For some participants, these experience and encounters also made them feel that they have been wronged or rather, they did not feel that they deserve to lose their limb. They expressed a sense on unfairness by the event. These findings are similar to those by Kamel, (2000) where participants questioned the merits of how they ended up with an amputation as opposed to any other person in the society

C2 *"I have been cheated out of a lot of things. I feel that I miss out of a lot of things"*

Participants found it stressful to deal with the amputation. They found the amputation limiting in terms of involvement and participation in normal activities. This by any means resulted in them feeling inadequate and not the same again.

C5 *"Sometimes I get a bit stressed because of the amputation that I can't really do normal things and I have to use a wheelchair all the time."*

C2 *"So from an emotional point of view there are a lot of things that go through your mind that you tend to worry about some things that you're less of a person now that you have this disability. People treat you differently and you're not sure if people are being genuine or they look at you and think you're less of a person at the end of the day. So I think from a psychological point of view, you generally sit and think about all these things. There is a lot of things that go through your mind."*

Participants found it hard to go through, especially because it's a new experience in their lives. In some instances there was uncertainty about their health status. This was especially the case in situations where the condition was progressive like in peripheral vascular disease or in people amputated following diabetes. Participants started worrying about the implications of the condition on future goals and how they should plan their lives. They were worried about the bearing of the amputation on advancing their lives, their ambitions and prospects. They felt that the amputation will potentially put them at a disadvantage while exploring their ambitions during the process of reintegration into society.

This is consistent with the findings by Kamel, (2000), where participants expressed uncertainties about their futures and were concerned about the implications of the amputation on their jobs and position in the community. They felt that they had to accept any job and they their life plans had changed (Amosun et al, 2005).

C1 *“For me it was hard, one leg gone, you will never get it again”. “Its hard to go through” “Now I got my licence, now I don’t know if I should renew it in 2011 again. I don’t know how will I be that time”.*

C2 *“Will people discriminate against you because of your disability? What sort of difficulties you’ll encounter and you’re worried about should you I get a job at a particular company, what sort of environment will that company provide. Can you adapt and cope with the surrounds and the environment?”*

6.2.2 Falls

Participants have stability problems and this may result in falls. This is not the only source of falls. Others had phantom limb sensations and this resulted in taking a stride on the stump forgetting they no longer have the full limb and thus end up falling. These were devastating experiences and they had a fear of falling and tried to avoid being embarrassed by falling in public. They even imagined themselves falling in public and people feeling sorry for them. Apart from the emotional impact, falls can also result in injuries, especially to the stump. During these periods, participants developed various coping mechanism. These included learning to fall safer, e.g. on their back rather than the stump, having two pairs of crutches if they live in a double storey house, where one pair is kept on each floor and they move on their bottom on the staircase to the next floor to eliminate the risk of falling.

Use of toilet facilities whether at home or in public settings was also perceived as a risk of falling especially during the transfers while they use a toilet. Participants were afraid of falling especially in the initial stages following the amputation. They often had to adjust the way they used to do things, like using a bath rather than a shower. Even with these kinds of adjustments, they had to be very careful during the transfers in an out of the bath while they are wet, as they slip and fall. Participants end up modifying activities like dressing to make this easier and they perceived this as something that reduces their frustration and even reduces the risk of falling. Similar findings have been reported by Bosmans et al, (2007) where participants had to relearn usual activities such as going to the toilet, (un)dressing and washing.

C2 *"Well I think with the amputation being so fresh in my mind. Generally you do things without thinking and it's a natural thing that I turned and lost my balance because I didn't realize that the leg wasn't there. In the initial stages thats one of the difficult things, is to get used to not having that leg e.g. when you get out of bed the natural thing is to put both feet out and get out on the left leg and then realizing that there is no left leg."*

C1 *"Its hard to go to the toilet. You know how you must transfer and make sure you don't fall"*

"Sitting in a wheelchair, you wanna go to the toilet, it's a long story that"

C2 *"I think just in terms of moving around, having to get up at night and going to the toilet you have to find your crutches first. To make sure that you switch the light on you need to be able to walk in the dark without knocking into anything. "*

"walking especially shopping you have to assess the floors, the tiles, make sure you don't fall because its gonna be an embarrassment more than anything else."

"I then quickly adopted a situation where I got myself a second pair of crutches. I keep one downstairs and one upstairs so when I move around the living quarters downstairs I would live the crutches downstairs"

"You know I had to maneuver myself such that if I get out of the bath, I make sure I don't slip"

“I could make sure that I would wear clothes that would be easy to put on e.g. shorts with elastic rather than the belt, I would wear t-shirts rather than shirts when there was no buttons to tie. I would wear slippers rather than shoes or takkies, that was easier to put on so I sort things that would be easy rather than things that are difficult and would frustrate myself.”

“So the initial stages were a bit scary but as time progresses you tend to learn and you become a lot cleverer at doing things, generally over a period of time you fall safer.

C9 *“I am used to crutches now, I used to fall and hurt myself”*

Participants thought that they are in denial, hence the falls. They did not know that this phenomenon is also something they were likely to have following the transection of a nerve bundle.

C2 *“I am not sure if I want still in denial about not having the leg or in my mind its just one of the difficulties in having to accept or not realizing that there wasn’t a leg so you generally wanna do things that you did previously and those are some of the difficulties that I deal with”*

In public places, people got sympathetic and felt sorry for the participants at times.

C9 *“In the street people are sympathetic e.g. in public transport at the taxi rank.”*

6.2.3 Body image

Participants with a lower limb amputation are conscious about their image. A lower limb amputation changes ones’ physical appearance so much that they feel that the general public will perceive them differently. Some, therefore, tried to preserve their normal physical appearance to the best of their ability. They insisted on ensuring that they wore long pants with the prostheses to make sure that when they go out, people who do not know would not notice. They were also conscious about how children tend to stare at them in public places. Even among family members they felt that, although they are supported, the family is impressed when they see them wearing a prosthesis. For example, they felt that once their prosthesis is on, the public will not recognize that their do not have a leg and also family members gave compliments that suggest that the participant looks like they have the normal limb in place.

People with LLA may have psychological difficulties in coming to terms with the stump. Some participants may not look at the stump for some time and may deny to themselves that amputation has been performed whereas others may accept the new condition gradually (Engstrom & Van de Ven, 1999). In this study, some people showed concerns about their self image as a result of the amputation. This is consistent with the findings by Kamel, (2000). The difference being that, the study by Kamel, (2000) detected the views on self image early in that interviews were done preoperatively as opposed to this study where these were only detected at follow up, three months later. According to Engstrom & Van de Ven, (1999), people may feel that their body image has been distorted and some will never fully acknowledge and accept the new situation.

Lower limb amputation has notably resulted in, changes in perception of body image, and social function (Engstrom & Van de Ven, 1999; Resnick at al, 2004; Zidarov et al, 2009). In the study by Zidarov et al, (2009) participants mostly had poor body image but those with an above knee amputation reported a poorer perception of body image than those with a below knee amputation, while in this study, this was expressed by participants with an above knee amputation and with a below knee amputation. In this study, both these were men. Although the measures were different in the two studies the results are similar.

C2 *“all I am waiting for is a prosthesis because once I have that on and I have long pants on and I don’t have crutches with me no body is gonna notice that I have got a disability and I just found that with time your confidence grows, your body strength grows, your mental strength grows. Everything* *just improves, gets better, gets stronger and you don't even think about it after a while."*

C4 *"Well I can be happy if I can get the artificial leg and crutches that's all"*

This participant was still using a walking frame.

On the other hand participants look forward to getting their prostheses. They hope that they will walk again and return to their normal state.

C9 *"Soon I am getting the fake leg and I'll throw away the crutches."*

Participant looking sincere when using the word "fake leg". He did not seem to have chosen it based on hating the current status but rather it's the only word that came up to his mind. But he was happy that he wouldn't be using the crutches anymore.

Another aspect that came across affecting image is the lack of consideration by society for the participants. This may be in the form of making jokes about the amputation. People in the community make inconsiderate comments about the amputation. At times the participant started worrying about these consequences even before discharge from the hospital. This situation can be frustrating to the participant and they may react with anger, rage and disappointment towards their community.

C12 *"in the streets people say a lot of things, some of which hurt me."*

"People tend to make jokes about your situation and they do not even know you. This seems to fascinate some of them and others empathize with you. Others understand that this is no playing matter"

"I have tried to stop these jokes in the beginning when I had just been back from the hospital. I used to really take them personal, I used to get furious or aggressive."

"When I was still in the hospital, I used to think, what will the community say? What will my girlfriends say?"

In this instance the participant was advised by someone (elder in the community) in the community not to internalize and or listen to these unfair statement directed at them.

C12 *“This person sat me down and told me that I must disregard such things. You must avoid such, and ignore such people, God will sort them out.”*

6.2.4 Pain

In a study by Kamel, (2000), participant’s pain was the main focus of their despair and walking was the main focus of their hope. In this study, participants did not seem to establish any relationship between pain and functional limitation. All limitations were generally of mobility with stability and balance challenges rather than pain inhibiting their function. In this study, some participants experienced a great deal of pain and discomfort following lower limb amputations. This may include rest pain in the stump or even pain from ischaemic changes of the contralateral leg. This is also the case in participants with peripheral vascular disease where the other leg is starting to show signs of vascular disease while the participant is recovering from the leg that was amputated. The pain is unbearable and so uncomfortable that it can have an impact on sleep and result in sleep disturbances. According to Engstrom &Van de Ven, (1999) and Resnick at al, (2004), participants are likely to experience pain following a lower limb amputation. Although these findings are not local, one sees a common phenomenon. Engstrom & Van de Ven, (1999) states that this can be ongoing pain or later pain. In this study, both ongoing pain and recent onset of pain were reported during the in-depth interviews. It is, however interesting to note that Bosmans et al, (2007) found that people with a lower limb amputation report higher subjective well-being in spite of suffering severe phantom pain whereas those with hardly any pain rated their subjective well being as low. In this study, both the preoperative and the postoperative VAS scores were generally elevated although they reported pain and phantom sensations.

C1 *“The pain wakes you up in the middle of the night. You sit up, you scream like a baby, you cry”.*

Participant showing a lot of frustration while sharing this information

C4 *“Actually, ever since my operation. Firstly, I don’t sleep well, and now I have lots of pain at night.”*

Other forms of discomfort and pain experienced by participants were those related to the vulnerability of the stump during the use of the prosthesis. The newly issued prosthesis may result in discomfort due to friction against the skin of the stump. The rubbed areas on the stump where the skin has come off result in bleeding. This situation may also predispose the person to secondary infection of the stump. Furthermore, such discomforts can result in participants having reservations about using the device.

C2 *“This Saturday I had to go out and wore the prosthesis again, I experienced a great deal of discomfort with it.”*

“The stump muscle was extremely sore and I realized that it was all the walk”.

“I walked up six flights of stairs that Saturday so I know that I had over exerted myself”.

6.2.5 Suicidal thoughts

Some participants had suicidal thoughts during their recovery time postoperatively. They went to extreme psycho-emotional conflicts of views about their existence. At some point during the early days postoperatively they did not see the need to be in this life and they contemplated taking their on lives. This is an interesting finding especially that in another local study by Kamel, (2000), some were reported as having given up and feeling that it was better to die. In this study, one participant was considering committing suicide and the study by Kamel, (2000) did not follow up to establish if participants were suicidal postoperatively.

C8 *"I used to lack courage initially. I used to even think of suicide but my girlfriend said I mustn't take my own life."*

6.2.6 Incontinence

Other emotional experiences experienced by participants following an amputation included faecal incontinence. This rather challenging psycho-socio-physical problem puts a person in a compromising position. This was an unexpected outcome, in a study by Misajon et al, (2006) mobility impaired participants report the least distress in self care. The results from Misajon et al, (2006) were however from mobility impaired participants and not those with a lower limb amputation in particular. It is comparable with people with LLA studies as amputation impacts on mobility.

C7 *"Developed bowel incontinence immediately after the amputation. This really hurts me emotionally. The medical staff is not aware of this problem because I have not made them aware of it."*

Participant very tearful and miserable during the interview

6.3 Positive psychological impact

Some participants dealt with a lot of psychological issues while others seemed to have found the best solutions for their limb condition by having an amputation. They just sounded like this operation is all they had been waiting for and now that they have had it, they are happy and are coping well. Some people felt that nothing much had changed in their lives except not having two legs. They at times saw that the operation had to be done for their own survival and the betterment of their lives. This form of acknowledgement and acceptance was also a finding in the study by Kamel, (2000) reporting that people were happy and convinced that it was better to go for the operation. Mac Neill et al, (2008) showed that, participants coped well following a lower limb amputation. The study by Kamel, (2000) revealed that a number of participants felt like they were forced to accept the operation as they had no other choice. This was the case in some instances in this study where a participant felt that he just had to live with it and it had to be done. The problem with comparing the study by MacNiell et al, (2008) is that it was done on participants with bilateral transtibial amputations while this study involved both participants with unilateral and bilateral amputations of varying levels. The advantage of the MacNiell et al, (2008) study was that it was done on people that were amputated as a result of diabetes and peripheral vascular disease, which is similar to this study.

C11 *"No pains, I don't feel anything else. Its like losing a leg is not a problem. I help myself with whatever. Life goes on. I feel alright, the amputation has had no impact on my life. It has made no difference."*

"I am coping well, I move around, I bath myself and do some cooking"

"I have no stress, nothing. I must learn to live with this and that's all"

Participant very cheerful during the interview and did not seem concerned about any aspect of his life

C10 *"I do things like I did before, the difference is that it is time consuming, it now takes long to do an activity but not much has changed."*

"It hasn't really hit me. Life has been normal"

"Everything is normal. Everything is in place."

In this study, in some instances, participants were able to draw positive inspirations from the amputation. They tried to live a positive life, keeping a positive attitude. They were able to see that there is still a life after the amputation. There is still a lot to live for. Some even modified their lifestyles e.g. ceased smoking and drinking, eating healthier and looking at life such that they could get the best of it. They learnt to accept that they had the amputation now and the best they can do is live with it and maximize on life.

Participants also felt that they did not have a choice but to accept the current status and not accepting it will result in more struggle. One sees a sense of perceived internal conflict by the participant who decides not to accept the amputation. They did not see themselves living with a condition that they had not accepted. They also did not accept it on the basis of merit but rather felt compelled to accept it. At times, other than the stress and misery, they had episodes of depression. They had to deal with losing a leg and their mood swings in a negative direction and they strive to keep positive.

In this study, some participants had accepted the amputation and this is in line with Engstrom & Van de Ven, (1999) stating that there are have varying ways of adjusting, coping and adapting to a lower limb amputation. In a study by Desmond & MacLachlan, (2006), individuals who employ more avoidance behaviour as a coping strategy were reported to have lower levels of adjustment to amputation, and disease related amputation resulted in lower levels of general adjustment. However, in this study although all the participants were amputated due to a disease cause, some had employed positive coping strategies by the time of follow up although some had reported problem with acceptance in the initial stages. This again may be as a result of the long period since amputation and thus is consistent with the findings by Desmond & MacLachlan, (2006) that time elapsed since amputation show significant relationships with adjustment limitation and participants adjust positively with time.

Desmond & MacLachlan, (2006) reported that age and level of amputation predicted the ability to adjust with younger and high level of amputation adjusting poorly, that is, younger people with an above knee amputation with less time elapsed since amputation are associated with less favourable levels of adjustment to the limitations. This was not the case with this study as adjustment and acceptance was distributed evenly across the key informants. However, the disadvantage of comparing this study with that by Desmond & MacLachlan, (2006) is that the latter studied participants with time elapsed since operation ranging from two months to about 66 year with a mean of about 42 years and this study was only up to three months post amputation.

Livneh et al, (1999) stated that active problem solving influences psychological adaptation with same reports of higher levels of adjustment and acceptance of disability and acknowledgement, with lower levels of depression and internalized anger. In this study, some participants showed a positive mentality and positive attitude towards recovery and it may therefore be anticipated that some had employed a positive approach to problem solving. Some were generally looking forward to facing their challenges although at times they expressed concern or inhibitions that were not related to acceptance e.g. financial limitation with participant C3. He was really showing determination but could not even afford to go back to the hospital for follow up on outstanding matters regarding his welfare.

C1 *"You must learn to accept it. Accepting is really something very special. If you accept it, you will have peace. This thing is there now. There is nothing I can do. There is nothing you can do about it, its something you have to accept. The main point is to accept, because if you don't accept it, then how are you going to live with it? Its not something you asked for. It just came. Now if you don't accept it, its gonna be harder."*

Participant showing a bit of frustration while reporting.

C2 *"Its taught me how to appreciate life better. I feel that I am appreciating and looking at things differently. I think first of all the mental aspect of it is what has helped me to get through a lot of the hurdles that I have experienced. From an eating perspective, I eat a lot healthier now. I do things a lot different now from I what I used to do. I think my life has improved in many respects. I don't look at my disability as a setback, I look at it as a challenge. I appreciate things that I have rather than being upset about things that I don't have. So what I do is I basically make the most of what I have and I try and maintain a positive attitude as much as I can. Its difficult but you do have your moments, at times you feel depressed and you feel down. And you feel like the things are just not working out for you. So I generally try and take a positive view and hope to get the good thing out of it and enhance my quality of life rather than to complain about it."*

C1 *"But you must approach it in a positive way. If you believe you will come through. The approach must be positive."*

C12 *"I have told myself that I will live with this and its part of my life. I have accepted it, its my life. I don't know, maybe it was a blessing in disguise, you see?"*

Strong mental strength was also important during recovery and the rehabilitation period. Not only the positive attitude and the determination from the person but also in the sense that it is a determinant of physical strength. Also it is largely influenced by the people that keep you company. Therefore is helps for the participant to be close to people who are supportive, people who care, people who give him/her the inspiration needed to face the reality of losing a leg and provide a force to pull through. In this study, these were in the form of a spouse, a parent, siblings, and friends. Another driving factor for the participants was that of keeping in mind that they had children to support and they needed to get better and be there for their children.

C2 "*And then I said to somebody once, I think its because I'm surrounded by people that have all this positive attitude and that positiveness tends to rub off on you so you can't help it by the time you face these you feel good mentally, you feel strong physically, emotionally and then you can't help it but feel good and I found that was one of my inspirations. And I think to a large extent, one of the things that kept me mentally focused also was my child, in particular my son, being a 12 year old at the time, I just knew that I needed to be strong because that was a lot of things that him and I needed to do I mean, we love doing things together, soccer, the outdoors."*

Other ways of coping, staying positive and avoiding destructive situations involved managing and handling stress well. Some participants made every effort to control their blood glucose levels.

C8 *"I think I am back to normal. I don't want to stress and my sugar goes up"*

“Now I feel as though nothing has happened. The amputation is at the back of my mind”.

On the other hand some people were happy immediately after the amputation. They expressed a lot of relief and satisfaction. The amputation does not bother them. They are especially happy considering what they were going through before the operation. They never thought that they would walk again and that they were currently walking left very little for them to be dissatisfied with.

C3 *“My operation is fine, I can say it was a success.”*

“I have no problem psycho-emotionally, I’m right. I get up and exercise. I do everything for myself.”

C4 *“I am much better now compared to before the operation, it was really bad, I couldn’t even eat”*

C6 *“I feel quite fine. The only thing that has changed is the loss of my leg”*

In other instances the participants felt that they were coping and they were doing well as far as the amputation is concerned. However, as a complete person they expressed other psycho-social issues that bothered them constantly and at times. As complete individuals they worried about other life matters that they actually felt the amputation may have an impact on, but they did not tend to be concerned about it much. These real life situations in Johannesburg, South Africa included being homeless and the participant worrying about their life in general. Some cases are those where they were worried about the well-being of other family members at home, e.g. a sister being sick.

C5 *“I am coping alright but I struggle to sleep at night. I think about a lot of things and I have a bit of hypertension because I think about my life, how long is it gonna be for me to cope with this situation?”*

This was a homeless participant and the researcher was fortunate enough to find him at a different hospital from the ones involved in the study (during follow up as the participant was in a primary hospital involved in this study during preoperative data collection). The social services were still looking for accommodation/ a *placement for him as it is against the legislation in South Africa to discharge patients to the streets. The hospital has to discharge a patient to an identified or given physical address.*

C3 *"After my discharge from the hospital, I faced a couple of challenges. At the moment my sister is in hospital for a couple of operations, they have operated on her too and now I only live with these three. My brother is also sick now, that also stresses me because I have to deal with all these."*

"No, I am well, the operation doesn't bother me, I have no pains, I am not taking any pain killers".

C10 *At the beginning it was a life changing experience. I had to make adjustments in my life. Now I am coping well. I have no anxiety, I am back to 100%. I can say life is normal now as though I have a leg. I do everything without anybody's help*

6.4 Social Theme

6.4.1 Impact on financial resources

In this study, people with a lower limb amputation also faced socio-economic challenges. Some were under the age of sixty and would have liked to work and support their families. Some were worried about being unemployed and the impact this had on their roles in the family. However, not all the unemployed participants expressed the need for a disability grant. Some were worried about the financial implications of rehabilitation as they were unemployed. In other instances same did not even have the money to visit the health centre to arrange and start processing their disability grant.

Some felt that, not having a medical aid reduced their chances of getting good medical attention or rather the nature of the help they got was not the same compared to somebody on medical aid. These participants did not like being dependent. In the case of those who are parents, they did not like being a burden on their children, especially where the children's wages are low. Poljak-Guberina et al, (2005) and Kamel, (2000) have reported that this group of people tends to express financial concerns and that unemployment is high in this population. This study was done in Europe but in South Africa the same financial impact was reported by Kubheka, 1993. However the study by Kubheka, (1993) was done on participants who had been amputated due to a traumatic cause. In that study, some of the participants worried about being unemployed and the impact this has on their roles in the family. Bosmans et al, (2007) reported that their participants were happy to have a job and this helped them achieve some status in their society and they therefore report better social well-being. In studies by Amosun et al, (2005) and Kubheka, (1993), participants expressed a need for a disability grant. Both these studies and this study were conducted in developing countries. Of note, is that in these countries participants tend to hope for a form of financial compensation following this operation. They do not like being dependent. As in the study by Amosun et al, (2005) in this study participants express that they would like to have a job.

C3 *"Now I am bothered by the fact that I am not working. All the responsibilities here at home are with my children."*

"Food is hard to get sometimes but generally I help myself with a lot of things. My son doesn't get paid well. My daughter in-law gets R175 per week and my son drives the machine and gets paid R300 per week. Even when my little daughter passed away in January we borrowed R1000 from my son's employer and now he deducts money monthly from my son"

"I just need to see the doctor and get my pension, just the letter from the doctor. Now I currently don't have the means to go there for the doctor to give me that letter, that unsettles me a bit."

C2 *"If you look at my condition as it is, I worry about the fact that I am unemployed at the moment and knowing that I have children that I need to provide for. You tend to worry about how does this impact on you finding some form of employment."*

C1 *“I am unemployed and I don’t know if Tambo Memorial Hospital gives physio how much it costs now. So no one will give you a free leg to at least make you walk because I don’t know how to get money.”*

“Ahh, I think its difficult without medical aid. Where you gonna get help from?”

C5 *“But I am hoping for if I can get a disability grant, then I can try to save some money to get the artificial leg, then I can put my life back to normal again. And see if I can find a job and get contact with my family”*

Some participants lost their income as they could no longer cope with their previous occupation. These findings are similar to those by Burger & Marincek, (2007). Issues of dependence have been reported not only in this study but also by Kamel, (2000). The study by Kamel, (2000) reported on matters of uncertainty and confusion about the future and found that the educated participants tend to worry more about losing their occupational position than their less educated counterparts who hope for a disability grant.

C6 *“I can’t do fitting tiles, I cannot do mechanical work, and repairing shoes.”*

6.4.2 Family support

In this study, the families and relatives were very supportive. They tried their utmost best to be there for the participants. This included the spouse, the parents and friends. These close people intervened very early and then gave continued and valuable support to the participants. The nature of this support ranged from psycho-emotional to physical demands. Participants lost skills like driving, particularly a manual transmission gearbox car. This is just one of the few examples where a spouse or a friend had to pick up and drop them to various places to engage in their usual activities. Participants appreciated this but they also expressed that they did not like being dependent and it was very inconvenient at times.

Desmond & MacLachlan, (2006) found that high levels of seeking social support and lower levels of avoidance as a coping strategy improve social adaptation. In a study by Bosmans et al, (2007), participants were seen to have improved relationships with their partners and relatives following a lower limb amputation. The study by Bosmans et al, (2007) reported that children of people with LLA were more caring and visited frequently after the operation. This was the case with C2 in this study. People with amputation may need help from their partners or domestic helpers most of the time.

The impact of amputation on the balance of interpersonal relationships and loss of status within the family was a concern in this study and in the literature (Bosmans et al, 2007; Kim et al, 2004). In South Africa, findings by Kubheka, (1993) indicated that people were somewhat blamed by their families for their amputation.

C1 *"My whole family was supporting me."*

"My wife is always there for me"

C9 *"The family cares and they are supportive. They also hire someone to help me. They are very helpful."*

C2 *"From the family side I have been very blessed as I said you know, small things that you tend to take for granted e.g. my mother as old as she is, she would make sure that she makes sandwiches at home and send them to the hospital, to make sure that I have enough to eat."*

"I have a sister in Zululand, she would phone me as much as she could. My other brother we are not generally close but now we are getting along well. I realize what its done for my relationship with a lot of family members. As far as my friends are concerned they have done remarkable things. I wouldn't be where I am today if it wasn't for my friends. I would hate to single out any of them but with the things that they have done for me they have made sure that I was short of nothing in terms of whether it be friends or company, anything that I needed materialistically and anything that I needed in any shape of form. My girlfriend has been there

for me, she has been a pillar of strength for me. The patience that she has had for me during all this time. I think very few people would be able to do that for you, so I just been blessed by the support, comfort."

"Another major adjustment is increased dependence on people to do things for you e.g. driving, I can't drive a manual so I have had to depend on people to pick me up and take me where I needed to go. That became difficult."

C6 *"My wife and daughter help with all washing and cooking Washing my clothes and making bed."*

C11 *"My girlfriend helps to do my dressings"*

This participant's stump still needed some dressings at three months during follow up

6.4.3 Impact on hobbies and usual activities

In this study, people with a lower limb amputation faced challenges and limitations including social interaction during their time of reintegration to the society of origin. At times they were unable to join fellow family members in social outings and events. In other instances they loved doing certain activities together before they had an amputation and after the amputation they were unable to continue with shared activities like dancing. The instances where they decided to join in an outing, they chose to remain in the car while friends and family enjoy the particular event. In other instances they had to assess the nature of the terrains to be visited and decide they would be able to manage that day e.g. rough or uneven terrains, tiles in the shopping malls, staircases at a friend's house or at theatre and some of the paving at taxi ranks. In these instances they either used a wheelchair or crutches. Those people who were using crutches did not only consider the physical demands but also the risk of falling and even worse, sustaining an injury.

These findings are consistent with those by Bosmans et al, (2007) who reported that dependency hampers participants in carrying out their daily activities of shopping, working, pursuing hobbies, participation in sport and visiting family and friends thus hampering them in achieving status and affection. In this study participants reported that they were not happy that they had to give up activities they previously enjoyed with their partners. Similar impact on activities of daily living and the negative impact an amputation has on one's involvement in enjoyed activities and leisure have been reported in the literature (Taylor et al, 2005, Eiser et al, 2001, Pell et al, 1993). However, the study by Eiser et al, (2001), involved participants who had an oncology related amputation (osteosarcoma or Ewing's sarcoma) and these participants were recruited over a period of 18 years. Thus, this study may not be comparable. In this study, the only participant with a cancer related amputation had died by the time of follow up.

In this study, mobility and daily living were consistently reported to be a major factor in social-wellbeing and participation in enjoyed activities, which confirms that, mobility and daily living are important elements of Health-Related Quality of Life (HRQOL). Therefore declining mobility may have a greater negative impact on HRQOL than any other distinct disease state (Groessl et al, (2007). However, the study by Groessl et al, (2007) was conducted on participants who were identified as being at risk of disability. Although the latter study was a randomized controlled trial, none of the participants had a lower limb amputation. While the researcher is mindful of that weakness, the study still explored important aspects that may affect participants with a lower limb amputation as these participants are at risk of disability as well. One has to bear in mind when comparing with the study by, Pell et al, (1993) that they participants were recruited over a 10 year period and these limitations still manifested in the 23% of the initial participants operated on over that 10 years.

In this study, participants sometimes opted out of social outings. They preferred not to go out citing reasons related to mobility and the physical demands of maneuvering themselves around once they get to the place that is being visited. These findings are consistent with those from studies by Taylor et al, (2005), Eiser et al, (2001), Pell et al, (1993) although this study was conducted in a developing country while the other studies were done in developed countries. However the findings by Taylor et al, (2005) reported characteristics that predicted poor mobility to be, over the age of 70, a high anatomical level, dementia or those who have a homebound ambulatory status preoperatively. Their study had a higher mean age and also, participants in this study were generally of ambulatory status preoperatively.

In the South African context, a study by Kamel, (2000) revealed that participants reported withdrew from social interaction as they were pessimistic, worried, desperate, anxious, and sad. In a study by Bosmans et al, (2007), people with a lower limb amputation frequently reported loss of walking, loss of biking and driving a car as concerns. Similarly this study showed that participants withdrew from engaging in anything that results in physical demands needed during functioning.

No participant expressed mobility problems specially related to difficulties while using public transport as was the case with Kamel, (2000). However, in this study, they expressed problems regarding affordability of transport when they had to hire and go somewhere. At no point did they cite a physical concern (e.g. problem during transfers from frame to inside the vehicle).

As seen with two participants (C3, C9), despite all the challenges faced by people following lower limb amputation some participants remain independent in activities of daily living (Mac Neill et al, 2008). Participant C2 was also demonstrated how he had since tried to return to activities such as cooking. Another interesting comparison of this study to that by Mac Neill et al, (2008) is that the latter study reported independence in 85% of their participants and these had bilateral transtibial amputation using prostheses. However, they were interviewed four years after the amputation.

C1 *"I know my wife would like to dance, now I can't dance with her. So that is things that we shared together. So she won't go to dance any more and she will stay with me until I am feeling better."*

"My social life, you can't just walk where you want to, you must plan. If my wife asks if you wanna go somewhere I rather say no, you don't wanna say she must go alone because it looks like she doesn't care, which is not true. Sometimes I want to go but I can't go."

"I don't wanna go there. Its gonna be inconvenient for me because I am in a wheelchair and they have got steps there. Its gonna be in and out. Rather leave me. Some people will say no, I mustn't be like that. I'm not, I'm a guy. I like to socialize but since this I'm out of it."

C2 *"So basically all I do is socialize with people whenever we go places, I generally just sit in the car, I don't get out on the car because its difficult for me to get around hopping in one leg."*

C10 *"I can't drive, my social life hasn't been the best. Not being able to drive curtails a lot of things. You haven't got the leisure you used to have."*

6.5 Religious Theme

The faith of the participants

In this study, participants tended to put their faith in God. They felt that God had decided that they had to get the amputation and therefore God will take care of them. They did not see the need to question anything and they said that God had all the answers. They felt that through praying, they will overcome. This coping skill was expressed in a way that suggested that they did not have much to worry about as far as the amputation was concerned as God will lead the way. They relied on faith and their family and friends also prayed for them. In a study by Kamel, (2000), participants felt that the event of having an amputation was unfair and that they were being punished by God. Participants asked why it had to be them that had to undergo an amputation. It seems that many had a strong belief in God following LLA and that they tend to leave a part of the responsibility in the hands of God as their saviour and the one that will assume the responsibility of protecting them.

C1 *"Although you don't know where it comes from, God knows why. I believe I shouldn't ask questions because its only him who knows its not you or anybody else. So you must pray and believe that one day you will be walking again".*

"This is what I wanna do and God will care"

"You must pray and I think God will do the rest"

C2 *"I managed to get used to the idea with the help and prayers of my friends and family. I think that was the main thing, otherwise it was difficult."*

These participants were of the view that if they did not believe in God, then He will not help them, He will not be there to guide and protect them. They wanted to position themselves in a way that will make God take good care of them. There was a strong belief that if they were in any way rebelling against God or questioning His work, they would not have His blessings.

C1 *"Like I said, you must believe that you will be the person you wanna be, but you must believe otherwise God will never help you."*

"If you accept it and not ask questions, you can pray to God and live with it then you'll be a better person."

"Its only God who knows and then why?"

Prayers played a vital role in assisting them accept and cope will this devastating experience. The strong belief and faith, the mental and the emotional well-being, the acceptance of the stump prepared them for recovery and rehabilitation.

C2 *"Anyway, he prayed for me and talked to me, he encouraged me."*

"I remember when he came I couldn't stop crying. I said pastor they cut my leg and he spoke to me and gave me encouragement then I felt much better."

This participant was sharing a divine story where both the pastor and his friend came and shared the word of God with him at different times and *the friend even left a bible with him to read scriptures where he would draw strength from.*

They constantly prayed and trusted in God to see themselves improved and as back to a normal state of health as possible.

C8 "*I am praying to God that I must be the same as before"*

C5 *"I'm very much into Christianity so that also helps me and I know a miracle can still happen, I can get my life back to normal"*

They generally attributed some of their encounters, experiences and challenges to the grace of God. They felt that if it were not for God looking after them, they would find it even more difficult.

C2 *"So the fallings I've done, I've done at home and fortunately I haven't had any injuries with that and that has been a blessing."*

6.7 Conclusion

Participants had varying psychological reactions three month after the LLA. Some were battling with issues of body image, pain, risk of falling and poor functional independence. Others were happy with the outcome of the amputation and reported to be coping well. Both negative and positive coping strategies were demonstrated by the participants

The participants had supportive families and friends. They also had poor financial resources and this had a negative impact of their ability to return to hospital for rehabilitation. Some participants had given their lives to God, so He would be responsible for the well-being.

Chapter 7: Conclusion, challenges and recommendations

7.1 Introduction

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

7.2 Conclusion

Most people were functionally independent both before and after the amputation although there was a decline in functional independence after the amputation. The quality of life was generally improved showing that LLA had a positive outcome for this population. Higher postoperative QOL for these participants was predicted by: not having a problem with mobility preoperatively (EQ-5D mobility item), being independent with mobility (BI mobility item) preoperatively, and being independent with transfers preoperatively (BI transfer item). Females had a higher quality of life compared to males. Generally, most participants had come to terms with the amputation and were managing well while others expressed that they were struggling with reintegration to their community of origin three months postoperatively with both functional and psychosocial challenges.

The participants in this study were generally from a poor socioeconomic background. Most people had not completed secondary education and lived in poorly structured and previously disadvantaged communities in the areas of Orange farm, Kliptown, Lenasia, parts of Soweto, and Alexandra township. Family support was prominent following the amputation. Others were unemployment and others found it difficult to return to work.

Participants had faith in God and believed that He would lead and protect them.

Lower limb amputation had a high mortality rate in this study in the Johannesburg Metropolitan area of Gauteng, South Africa. The multivariate analysis revealed that being female is a positive predictor of the individual's QOL although there was no change in the reported QOL from before to after the amputation.

7.3 Challenges during the study

- The unforeseen high mortality rate during the waiting period made it difficult for the study to obtain a conclusive result in terms of the original power at which it was set. However, according to the central limit theorem, a sample of 30 participants in generally considered the minimum one can pursue for statistical analysis and in this study, lost of participants to either death or difficulty tracing them led to a final number of participant (n=40), which is above the 30 recommended. The other possibly challenge as regards sample size calculation in this study is that the calculation is informed by international literature, whom their mortality rates is not so high as seen in this study..
- Participants not contactable on the telephone numbers they had provided
- Participants not having telephones
- Participant refusing the follow up interviews
- Participants not having the financial means to attend rehabilitation at their hospitals and thus the follow up was affected as this were initially scheduled to happen during such visits.
- The poor geographical/ informal settlements resulting in almost no physical addresses for some participants
- This study did not gather enough and useful data on the items related to the impact of financial resource, compliance with either medical treatment, rehabilitation and prosthetics issuing to see if that could explain the outcome of these participants, thus the research depended on informal observations during data collection.

7.4 Recommendations

7.4.1 Clinical recommendations

The hospitals offering postoperative rehabilitation to people with LLA should have a structured and holistic rehabilitation programme that takes into account problems such as people not being able to continue rehabilitation because they do not have the financial means to go to the centres. The programme should include intensive home visits, especially to optimize reintegration back to the community. Rehabilitation should be decentralized, i.e. people with LLA must be able to access the services at their local clinics and not have to travel to central hospitals.

The government should attempt to provide the means to ensure that their policies regarding people with disabilities (e.g. after LLA) are implemented, such as to optimize the return to work. This should further incorporate vocational training for those who could not return to their original occupation due to the nature of the work they did preoperatively.

People with LLA should be encouraged to be actively involved in their recovery. They should take the initiative to inform the service providers of the problems they face and how they would like them solved so as to make the system friendly to the special and dynamic needs of society.

7.4.2 Recommendations for research

- Futures studies should overestimate the sample size in order to accommodate the possibility of the high death rate following LLA in studies done on participants with similar characteristics to those of the people of the Johannesburg Metropolitan area, South Africa.

- Future studies should look at the amount and nature of rehabilitation provided for people with LLA during their recovery period and more specially identify problems of access to rehabilitation experienced by people with LLA.
- A future study should be conducted, where the participants receive a structured rehabilitation program, appropriate to the specific access needs of people with LLA, to find out its impact on their functional status and QOL.
- A future study should be conducted, extending the follow up period to six and 12 months respectively.
- Future studies should attempt to gather enough and useful data on the items related to the impact of financial resource, compliance with medical treatment, rehabilitation and prosthetics issuing to see if that could explain the outcome of these participants.

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Appendix A **PARTICIPANT'S CODE:………………………**

INSTRUCTIONS: The interviewer must fill in or mark (X) as appropriate

Section 1: Demographic details

1.1. Age._______ Date of birth .______________Hospital name.______________

1.2. Race:

African	**Coloured**	**Indian**	**White**	**Other.**

1.3. Gender:

male	female

1.4. How far is the nearest clinic/hospital from your home? _____________

1.5. How do you travel?

Own car	Relative's car	Public transport	Hire private transport	Other, please specify

1.6. Where do you get your money for travel? _________________________

1.7. Occupation._______________________

Income:

Private pension	Old age pension	Disability grant	Still employed	Other, please specify

1.8. Smoking history: did you smoke?

Before the operation	yes	no	After the operation	yes	no

If yes, how often per day?

1-5	6-10	11-20	21-30	Over 30

1.9. Do you drink alcoholic drinks?

Before the operation	yes	no	After the operation	yes	no

1.10. If yes, how often do you drink?

A few times a month	**Once a week**	**3-4 times a week**	**everyday**

Section 2: Medical information

2.1 What is the reason for your amputation? ________________________________

2.2 What amputation will you have?

BKA		Left leg	
AKA		Right leg	

2.3. Do you have any of these conditions?

Hypertension	Arthritis	Chronic heart disease	Diabetes	Peripheral vascular disease	Others, please specify

2.4 If yes, are you on treatment as prescribed by the doctor?

Yes	No

2.5 Post-operative surgical history

What lower limb amputations do you have currently? _____________________

Appendix ABC- Participant's contact details leaflet

Participant's code------------

Instruction: To be kept separate from the participant's questionnaires

The information in this box will only be used for follow up purposes.

Physical address of the participant: --

Telephone numbers of the participant: --

Appendix B (Sotho) **PARTICIPANT'S CODE:………………………**

INSTRUCTIONS: The interviewer must fill in or mark (X) as appropriate

Section 1: Demographic details

1.1. Dijara (Mengwaga).___________ Letsatsi la matswalo .______________Lebitso la sepetlele.______________

1.2. Mohlobo:

Motho o ntsho	**O Coloured**	**Mo India**	**Motho o mosweo**	**O mongwe**

1.3. Bongwe:

monna	mosadi

1.4. Sepetlele kapa kliniki ya kgaufi e kgole ha kaakang le lehae la hao? _____________

1.5. O tsamaya/sepela ka eng?

Koloi ya ka	Koloi ya wa leloko	Dinamelwa tsa setshaba	Ke hira sepalangwa/koloi	Sengwe, hlalosa:

1.6. O thola/fumana kae tshelete ya ho tsamaya/sepela? ________________________________

1.7. Mosebetsi.________________________

Mogolo:

Phenshene ye ke ikeleditseng yona	Phenshene ya botsofadi	Mphiwafela wa bohole	Ke sa sebetsa/bereka	Sengwe, hlalosa:

1.8. Ka ho khoha: O ne o kgoha motsoko ?

Pele o etsa karo/opereshene	Eya	Aowa	Moraho ha ho etsa karo/opereshene	Eya	Aowa

Ha ebe o ne o kgoha, o ne o kgoha ha kae ka letsatsi?

1-5	6-10	11-20	21-30	Over 30

1.9. O nwa dinotagi/bojwala naa?

Pele o etsa karo/opereshene	Eya	Aowa	Moraho ha ho etsa karo/opereshene	Eya	Aowa

1.10. Ha ebe o ya nwa, o nwa ha kae?

Ga mmalwanyana ka kgwedi	**Ha nngwe ka beke**	**3-4 ka beke**	**matsatsi ohle**

Section 2: Medical information

2.1 Lebaka le etsang hore o kgaolwe seripa sa mmele ke lefeng? __________________________________

2.2 Seripa sa hao sa mmele se ilo kgaola/segwa ho fihla kae?

BKA		Leoto le le tshehadi	

AKA		Leoto le le tona	

2.3. Naa o na le malwetsi a latelang?

Madi a maholo	Bolowetsi bja marapo	Bolwetsi bja sebaka se setelele bja pelo	Bolwetsi bja tswekere	Bolwetsi bja methapo ya madi	Mangwe, hlalosa,

2.4. Ha o na le bo bong bja malwetsi a ka hodimo, a naa o fumana kalafi ho tswa ho Ngaka?

Eya	Aowa

2.5 Karo ya mmele ye o e entseng moraho ha ho kgaolwa leoto

Leoto la hao le kgaotswe ho fihla kae sebakeng sa joale?________________________

Appendix C (Zulu) **PARTICIPANT'S CODE:………………………**

IMIYALO: Umhloli kafanele agcwalise ngo (X) ngokufanele

Ingxenye 1: Imininingwano ngawe

1.1. Iminyaka yakho.___________ Usuku lokuzalwa .______________Igama Lesibhedlela______________

1.2. Ubuhlanga:

owomdabu	**Ungum Coloured**	**uyiIndia**	**ungumlungu**	**Omunye umhlobo**

1.3. Ubulili:

isilisa	isifazane

1.4. Ikude kangakanani ikliniki noma isbhedlela esiseduzane nasekhaya? _____________

1.5. Ufika kanjani ezindaweni?

Ngemoto yakho	Ngemoto yesihlobo	Izimoto zawonkewonke	Uqasha imoto eqondene nawe	Okunye, ngicela ucacise

1.6. Uyitholaphi imali yokugibela? ________________________

1.7. Umsebenzi.________________________

Umholo:

Impesheni eqondene nawe	Impesheni yokuguga	Impesheni yokulimala/ukugula	Usasebenza	Okunye, ngicela ucacise

1.8. Ububhema ugwayi?

Ngaphambi kokusikwa	yebo	cha	Emveni kokusikwa	yebo	cha

Uma kunjalo, ubhema kangaki ngosuku?

1-5	6-10	11-20	21-30	Over 30

1.9. Uyaphuza uphuzo oludakayo?

Ngaphambi kokusikwa	yebo	cha	Emveni kokusikwa	yebo	cha

1.10. Uma kunjalo, uphuza kangaki?

Izikhathi ezimbalwa ngenyanga	**Kanye ngeviki**	**Kathathu noma kane ngeviki**	**Nsukuzonke**

Ingxenye 2:

2.1 Yini imbangela yokunqunywa? ___________________________________

2.2 Uzonqunywa kuphi?__________________

ngezansi kwedolo (BKA)		Umlenze	

		wangasenxele	
ngenhla kwedolo(AKA)		Umlenze wangasokudla	

2.3. Unazo yini ezinye zalezigulo?

i high blood	Isifo samathambo	Isifo senhliziyo	ushukela	Isifo semithambo yegazi	okunye

2.4. Uma kunjalo, ziyelashwa yini ngudokotela?

Yebo	Cha

2.5 Imininingwano yasemuva kokunqunyulwa umlenge.

Mange imilenze ihlizwe kuphi?___________________________________

Appendix D EQ-5D (English)

Health Questionnaire

(English version for South Africa)

By placing a tick in one box in each group below, please indicate which statements best describe your own state of health TODAY.

Mobility

I have no problems in walking about ☐

I have some problems in walking about ☐

I am confined to bed ☐

Self-Care

I have no problems with self-care ☐

I have some problems washing or dressing myself ☐

I am unable to wash or dress myself ☐

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities ☐

I have some problems with performing my usual activities ☐

I am unable to perform my usual activities ☐

Pain/Discomfort

I have no pain or discomfort ☐

I have moderate pain or discomfort ☐

I have extreme pain or discomfort ☐

Anxiety/Depression

I am not anxious or depressed ☐

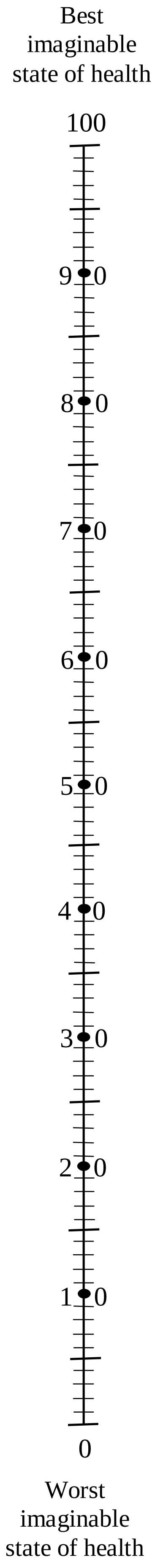
I am moderately anxious or depressed ☐

I am extremely anxious or depressed ☐

To help people say how good or bad their state of health is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale, in your opinion, how good or bad your own health is today. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your state of health is today.

**Your own
state of health
today**



Appendix E EQ-5D (Sotho)

Lenane la Dipotso la tsa Bophelo bo botle

(Phetolelo ya Sesotho)

(Sesotho version for South Africa)
(Best available)

Ka ho tshwaya ka hara lebokoso le le leng sehlopheng se seng le se seng mona tlase, bontsha hle hore na ke dipolelo dife tse hlalosang ka botlalo boemo ba bophelo ba hao kajeno.

Ho tsamaya

Ha ke na bothata ba ho tsamaya ☐

Ke na le bothata bo itseng ba ho tsamaya ☐

Ke hlola betheng ☐

Ho itlhokomela

Ha ke na bothata ba ho itlhokomela ☐

Ke na le bothata bo itseng ka ho itlhatswa kapa ho itentsha/ikapesa ☐

Ha ke kgone ho itlhatswa kapa ho itentsha/ikapesa ☐

Mesebetsi ya setlwaheli *(mohlala: mosebetsi, boithuto, mosebetsi wa ka tlung, mesebetsi ya lelapa, kapa ya ho iketla)*

Ha ke na bothata ba ho etsa mesebetsi ya ka ya setlwaheli ☐

Ke na le bothata bo itseng ho etsa mesebetsi ya ka ya setlwaheli ☐

Ha ke kgone ho etsa mesebetsi ya ka ya setlwaheli ☐

Ho opelwa le ho se ikutlwe monate

Ha ke opelwe kapa ho se ikutlwe monate ☐

Ha ke opelwe hakaalo kapa ho se ikutlwe monate ☐

Ke opelwa hampe kapa ha ke ikutlwe monate ho hang ☐

Ho tshwenyeha kapa ho wa ha maikutlo

Ha kea tshwenyeha kapa hona ho wa maikutlo ☐

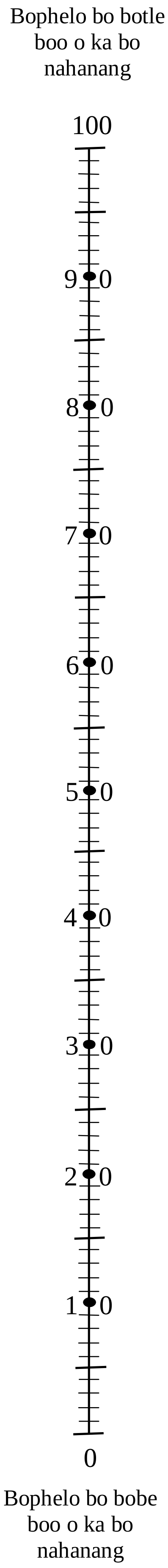
Ha kea tshwenyeha hakaalo kapa ke wele maikutlo ☐

Ke tshwenyehile hampe kapa ke wele maikutlo haholo ☐

Ho thusa batho ho bolela hore na boemo ba bophelo bo botle kapa bo bobe, re takile sekala (se batlang se tshwana le themometa) seo ho sona boemo bo botle haholo boo o ka bo nahanang bo tshwailweng ka 100 boemo bo bobe ka ho fetisisa boo o ka bo nahanang bo tshwailweng ka 0.

Re ne re ka rata ha o ne o ka bontsha sekaleng sena ka moo bophelo ba hao bo leng botle kapa bo leng bobe ka teng kajeno, ho ya ka wena. Etsa hona hle ka ho seha mola ho tloha lebokosong hle ka tlase ho ya fihla kae kapa kae sekaleng ho bontsha ka moo boemo ba hao ba bophelo bo leng botle ka teng kapa bo leng bobe ka teng kajeno.

Boemo ba hao ba bophelo kajeno



Appendix F (EQ-5D Zulu)

Uhlelo Lwemibuzo Ngempilo

(Zulu version for South Africa)

Ngokufaka uphawu ebhokisini elilodwa kulelo nalelo qoqo elingezansi, sicela ukhombise ukuthi yisiphi isitatimende esichaza kahle kakhulu isimo sempilo yakho namhlanje.

Ukuhamba/ukunyakaza

Anginazinkinga ukuzihambahambela ☐
Nginezinkinga ezithile ukuzihambahambela ☐
Ngihlala ngisembhedeni/ngisocansini ☐

Ukuzinakekela

Anginazinkinga ngokuzinakekela ☐
Nginezinkinga ezithile zokuzigeza noma ukuzigqokisa ☐
Angikwazi ukuzigeza noma ukuzigqokisa ☐

Imisebenzi ejwayelekile (*isibonelo: ukusebenza, ukutadisha, umsebenzi wasendlini, imisebenzi yomndeni noma eyokungcebeleka)*

Anginazinkinga ukwenza imisebenzi yami eyejwayelekile ☐
Nginezinkinga ezithile ukwenza imisebenzi yami eyejwayelekile ☐
Angikwazi ukwenza imisebenzi yami eyejwayelekile ☐

Izinhlungu/ukungaphatheki kahle

Anginazinhlungu noma ukungaphatheki kahle ☐
Nginezinhlungu noma ukungaphatheki kahle okulingene nje ☐
Nginobuhlungu obedlulele nokungaphatheki kahle ☐

Ixhala/ukudangala

Anginalo ixhala noma ukudangala ☐
Nginexhala noma ukudangala okulingene nje ☐
Nginexhala nokudangala ngokweqile ☐

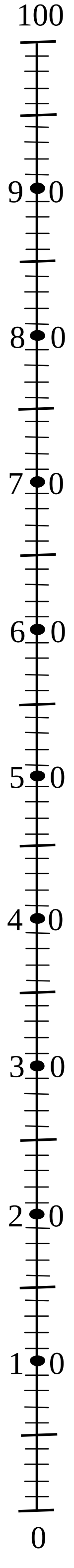
Ukuze sisize abantu basho ukuthi isimo sempilo yabo sihle noma sibi kangakanani, sidwebe isikali (esifana netemometha) okuqoshwe kuso isimo esihle kakhulu ongase usicabange sabekwa ku 100 naleso esibi kakhulu saba ku- 0.

Singathanda ukuba ukhombise kulesi sikali ukuthi yinhle noma yimbi kangakanani impilo yakho namhlanje, ngokwakho ukubona. Siza wenze lokhu ngokudweba umugqa osuka ebhokisini ngezansi uye kunoma yiliphi izinga esikalini elikhombisa ukuthi sihle noma sibi kangakanani isimo sempilo yakho namhlanje.

Isimo sakho

Sempilo

namhlanje



APPENDIX G

MODIFIED HOUSEHOLD ECONOMIC AND SOCIAL STATUS INDEX (MODIFIED HESSI)

(Modified Barbarin, et al, 1997)

1. Family structure/Household Composition

Ia. Marital Status of Participant

1. Never married, not now living with a partner.
2. Married, but not living now with a partner (e.g. divorced, separated)
3. Widowed
4. Never married, but now living with partner
5. Married and currently living with partner

Ib Household Membership. How many people currently reside in the household?

____

Number 18 and older________________________

Number 6-18 yrs old ________________________

Number under 6 yrs old____________________

Ic Are there adult relatives now residing in the household? No Yes.

If yes who are they in relationship to the Participant? ____________

II. Social Status (Education, Occupation)

A. Participant's Education: What is the highest level of education attained by participant?

1. Less than grade 5
2. Primary school (grade5-6)
3. Junior Secondary (grade 7-9)
4. Senior Secondary (grade 10-11)
5. Matric/ High School graduate/vocational training diploma.
6. 1-2 yr College, Technikon
7. 3-4 years of University
8. PhD; M.D; D.D.S, or other doctoral degree.

B Education of participant's Partner : What is the highest level of education attained? (answer only if Ia was answered)

1. Less than grade 5

2. Primary school (grade 5-6)
3. Junior Secondary (grade 7-9)
4. Senior Secondary (grade10-11)
5. Matric/ High School graduate/vocational training diploma.
6. 1-2 yr College, Technikon
7. 3-4 years of University
8. PhD; M.D; D.D.S, or other doctoral degree.
9. Other (please specify):---

What are names, occupation and industry of the primary wage earners in the house?

Name	**Occupation**	**Industry**
1.		
2.		
3.		

Access to Finance: who in the family earns money? Check all that apply.

--------Participant
--------Partner
--------Parent of participant
--------Child of participant
--------Parent Pension
--------Sibling/Aunt/Uncle
other, please specify---

III. Housing Accommodation: In what type of housing do you live?

0 None- homeless
1. Shack
2. Hostel
3. Room, Garage.
4. Flat Cottage
5. Home shared with other family(ies)
6. Home that is not shared with other families.

Other (please specify):---------------------------------

B. Does your home have

1.	A separate kitchen?	No	Yes
2.	A separate bathroom?	No	Yes

(a) In your home how many separate rooms are there just for sleeping?

(Circle one number) 0 1 2 3 4 or more.

(b) What type of toilet facilities does your home have:

0. None
1. Pit or bucket
2. Outside flush toilet
3. Inside flush

(c) Do you own or rent a home

0 Neither
1 Rent
2 Purchasing on Bond
3 Own

(d) How much do you pay monthly for rent or bond?

R________

For service Charges R_______.

(e) For Electricity:

(highest in the last year)R_______

(The lowest) R_______

Does the place you live in have a….. ?

(a)	Refrigerator	No	Yes
	Television	No	Yes
	Telephone	No	Yes
	Car	No	Yes
	VCR/DVD player	No	Yes
	Washing Machine	No	Yes
	Microwave	No	Yes

(h) In the past, have your children gone hungry because you did not have food?

3 No, never
2 Rarely
1 Often
0 All the time

Savings :

(a) Do you have savings or participate in a saving plan? No yes

(b) Do you have life insurance No yes

Appendix H (Barthel Index English)

BARTHEL ADL INDEX

Bowels 0 = incontinent (or needs to be given enema)
1 = occasional accident (once a week)
2 = continent

Bladder 0 = incontinent, or catheterised and unable to manage alone
1 = occasional accident (maximum once per 24 hours)
2 = continent

Grooming 0 = needs help with personal care
1 = independent face/ hair/ teeth/ shaving (implements provided)

Toilet use 0 = dependent
1 = needs some help, but can do something alone
2 = independent (on and off, dressing, wiping)

Feeding 0 = unable
1 = needs help cutting, spreading butter, etc.
2 = independent

Transfer (bed to chair and back)
0 = unable, no sitting balance
1 = major help (one or two people, physical)
2 = minor help (verbal or physical)
3 = independent

Mobility 0 = immobile
1 = wheelchair dependent, including corners
2 = walks with help of one person (verbal or physical)
3 = independent (but may use any aid; for example, stick)

Dressing 0 = dependent
1 = needs help but can do about half unaided
2 = independent (including buttons, zips, laces, etc.)

Stairs 0 = unable
1 = needs help (verbal, physical, carrying aid)
2 = independent

Bathing 0 = dependent
1 = independent (or in shower)
Total 0-20 Total**……/20**

Appendix I (Barthel Index Sotho)

LENANE LA BARTHEL ADL

Mala: 0 = ho sitwa ho itshwara / ho itaola (o hloka ho nehwa sepeiti /lehlaka)
1 = kotsi ka mohlomong (ha nngwe ka beke)
2 = ho itshwara / itaola

Senya: 0 = ho sitwa ho itshwara, kapa o kentswe lelana mme ha o kgone ho le sebedisa o le mong
1 = kotsi ka mohlomong (boholo ha nngwe dihoreng tse 24)
2 = ho itshwara / itaola

Ho itlhwekisa 0 = o hloka thuso ya ho itlhwekisa
1 = o ikemetse mabapi le sefahleho/ moriri/ meno/ ho kuta ditedu (ha ho nehelanwe ka disebediswa)

Ho sebedisa ntlwana 0 = o tshepetse
1 = o hloka thuso e itseng, empa o ka etsa ntho e itseng o le mong
2 = o ikemetse (ka nako tse ding, ho tena, ho itlhakola (fefa)

Ho ja 0 = ha o kgone
1 = o hloka thuso ya ho seha, ho tlotsa sereledi, jj.
2 = o ikemetse

Ho fetisetsa (ho tloha betheng ho ya setulong le ho kgutlela)
0 = ha o kgone, ha ho tekatekano ya ho dula
1 = thuso e kgolo (motho a le mong kapa ba babedi, matla)
2 = thuso e nyane (ya ho bua kapa matla)
3 = o ikemetse

Ho tsamaya 0 = ha o kgone ho tsamaya
1 = o tshepetse ho setulo sa ho tsamaya, ho kenyeletsa dihuku
2 = o tsamaya ka thuso ya motho a le mong (ka puo kapa matla)
3 = o ikemetse (empa o ka sebedisa sesebediswa sa thuso (aid) sefe kapa sefe; mohlala, seikokotlelo)

Ho tena /apara 0 = o tshepetse
1 = o hloka thuso empa o ka etsa halofo ya ho tena o sa thuswa

2 = o ikemetse (ho kenyeletsa dikonopo, diziphu, maqhwele, jj.)

Ditepisi (mehato) 0 = ha o kgone
1 = o hloka thuso (ka puo, matla, thuso ya ho rwala)
2 = o ikemetse

Ho tola 0 = o tshepetse
1 = o ikemetse (kapa ka shawareng)

paloyohle 0-20

Appendix J (Barthel Index Zulu)

i-INDEKSI KA- BARTHEL YOKWENZA OKUHAMBISANA NEMPILO YANSUKU ZONKE (I-ADL)

Amathumbu 0 = ukuhluleka ukuzilawula (kumbe udinga ukuchathwa)
1 = ingozi ethe gqwa (kanye ngesonto)
2 = uyakwazi ukuzilawula

Isinyi 0 = uyehluleka ukuzilawula, kumbe usebenzisa ikhathetha futhi awukwazi ukuzenzela uwedwa
1 = ingozi ethe gqwa (akudluli kusikhawu esisodwa emahoreni angama 24)
2 = uyakwazi ukuzilawula

Ukuzicwala 0 = udinga usizo ngokuzilungisa
1 = uyazilungisa ubuso/izinwele/amazinyo/ukushefa (iziilungisi zihlinzekiwe)

Ukusebenzisa indlu yangasese
0 = udinga ukwelekelelwa
1 = udinga ukwelekelelwa okuthize, kodwa kukhona okwazi ukuzenzela ngokwakho
2 = awudingi ukwelekelelwa (kuyaguqu-guquka, ukuzigqokisa, ukuzesula)

Ukuzifunza 0 = awukwazi
1 = udinga usizo ukusika, ukugcoba ibhotela, etc.
2 = awudingi ukwelekelelwa

Ukuzithutha(kusuka embhedeni kuya esihlalweni nokubuya)
0 = awukwazi, angikwazi ukuzihlalela
1 = Kudingakala usizo olukhulu (lomuntu oyedwa kumbe ababili, izikhwepha)
2 = Kudingakala usizo oluncane (ngenkulumo kumbe ngezikhwepha)
3 = awudingi ukwelekelelwa

Ukunyakaza 0 = akunyakazeki
1 = udinga usizo lwesihlalo esihambayo, kumbandakanya amajika

2 = uhamba ngokwelekelelwa umuntu oyedwa (ngenkulumo kumbe ngezikhwepha)

3 = awudingi ukwelekelwa (kepha ungayisebenzisa noma iyiphi insiza; isibonelo, udondolo)

Ukugqoka 0 = udinga ukwelekelwa

1 = udinga usizo kepha uyakwazi ukugqoka isigamu ngaphandle kosizo

2 = awudingi ukwelekelwa (kumbandakanya izinkinobho, awoziphu, imichilo, njalo njalo.)

Izitebhiso 0 = awukwazi

1 = udinga usizo (ngenkulumo, ngezikhwepha, nosizo lokuthwalwa)

2 = awudingi ukwelekelwa

Ukuzigeza 0 = udinga ukwelekelwa

1 = awudingi ukwelekelwa (kumbe eshaweni)

sekukonke 0-20

Appendix K

In-depth interview on the Psycho-social and physical impact

Probe questions may be used to facilitate the conversation.

3.1 Please share your experiences and feelings about the impact of your amputation in your life.

3.2 What are your experiences about your general function since you returned home after the operation?

3.3 Are there any other issues you would like to add?

Appendix L (Zulu)

Imibuzo ebuza kabanzi kulabo ababandakanyeka kucwaningo esimeni sakho nenhlalakahle yakho

Ngibe ngimbuze ngezinto okhuluma ngazo ngenkathi ukhuluma.

3.1 Sicela usichazele kabanzi ngezinto ohlangabezana nazo kanye nendlela ozizwa ngayo, okungumthelela mayelana nokunqunyulwa umlenze.

3.2 Zini ohlangabezana nazo sukela wabuyela ekhaya emva kokunqunyulwa umlenze?

3.3 Ingabe kukhona okunye enifisa ukukusho?

Appendix M (Sotho)

In-depth interview on the Psycho-social and physical impact

Dipotso tse keneletseng di ka botswa/botsiswa ho tsamaisa poisano.

3.1 Ka kopo/kgopelo hle abelana maitemohelo le maikutlo ka tsela yeo ho kgaolwa ha setho sa hao sa mmele ho amileng bophelo ba hao.

3.2 Maitemohelo a hao ke a feng malebana le bokgoni ba hao ka kakaretso ha e sale o kgutlile hae moraho ha karo ya mmele/ophereshene?

3.3 Naa ho na le taba tse dingwe tse o tla ratang ho di kenyeletsa?

Appendix N

University of the Witwatersrand
Department of Physiotherapy

The Hospital Manager: -----------------Hospital

Dear Prof/Dr/Sir/Madam

APPLICATION FOR PERMISSION TO CONDUCT A STUDY AT YOUR HOSPITAL.

I am Lonwabo Godlwana, a lecturer and a masters student in the Department of Physiotherapy at Wits. Your hospital is one of the 3 tertiary hospitals that I would like to study. I am requesting permission to conduct a research project that is towards fulfillment of a Master of Science in Physiotherapy degree.
Title of study: The Impact of Lower Limb Amputation on Quality of Life: A study done in the Johannesburg Metropolitan area, South Africa
Aim of the study: To determine the impact of lower limb amputation on QOL in participants attending the three tertiary hospitals of the Johannesburg metropolitan area (Chris Hani Baragwanath hospital, Helen Joseph hospital and the Johannesburg hospital) during their reintegration to the society/community of origin.
Methods: This prospective pre- (amputation) test post- (amputation) test study will be done. A combination of quantitative and qualitative study design. Participants will be interviewed on aspects of QOL, functional independence, household economic and social status before undergoing a LLA and 3months after the intervention again the participants will be contacted to undergo the same interviews and some will be sampled for participation in in-depth interview discussions. The researcher is hoping to get about 73 (n=73) in all 3 hospitals combined.

The study has been approved by the University of the Witwatersrand Ethics Committee.
Ethical clearance no. M080422. Here attached is a copy of the participant information sheet and Ethical Clearance Certificate.

Kind regards

Researchers:

Lonwabo L Godlwana-Researcher	Supervisor: Prof AV Stewart
Tel: 011 717 3707/072 373 2156	Tel: 011 717 3718
Fax: 011 717 3719	Email:aimee.stewart@wits.ac.za
Email: Lonwabo.Godlwana@wits.ac.za	

Appendix O

Information document

Study title: The Impact of Lower Limb Amputation on Quality of Life: A study done in the Johannesburg Metropolitan area, South Africa

Greetings- My name is Lonwabo Godlwana and I am doing research on the impact of lower limb amputation on quality of life

Introduction

We, Lonwabo Godlwana and Prof AV Stewart, are doing research on the impact of lower limb amputation on the quality of life of participants that have had a lower limb amputation. Research is just the process to learn the answers to a question. In this way we want to learn what is the impact of lower limb amputation on your quality of life.

Invitation to participate: We are inviting you to take part in this research study.
What is involved in the study? You will be required to undergo an interview (the interview is about 30 minutes) before going for operation. This will be about your details, quality of life, home circumstances and functional abilities. Three months after the operation you will again give us another interview also about 30 minutes on the some topics so we can see if there is a difference after the amputation. You may also be selected to participate in an in-depth interview discussion of about one and a half to two hours to tell us more about your experiences after the lower limb amputation.
Risks of being involved in the study: there are no physical or invasive tests in the study. You will only be required to answer questions in an interview. If you happen to need psychological support, you will be referred to the psychologists (Johannesburg Hospital 011 488 4481, Baragwanath Hospital 011 933 8934 and Helen Joseph Hospital 011 489 0766)
Benefits of being in the study: the results of the study may help in improving the methods used to care for people with a leg amputation. The results of the study will be availed to you once the study has been completed.
Participation is voluntary, refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled and you may discontinue at anytime without penalty or loss of benefit to which you are otherwise entitled.
Reimbursements "for out of pocket" expenses. All interviews will be scheduled on the some day as your visit to the hospital. In the event of you being required to visit only for this study, a taxi fare will be provided after the interview.
Confidentiality: All information will be kept confidential

Contact details of researchers:
Lonwabo L Godlwana-Researcher
Tel: 011 717 3707/072 373 2156
Fax: 011 717 3719
Email: Lonwabo.Godlwana@wits.ac.za

Supervisor: Prof AV Stewart
Tel: 011 717 3718
Email:aimee.stewart@wits.ac.za

Contact details of REC administration and chair for reporting complaints: Prof P Cleaton. Jones Wits Research Office, 10th Floor Senate House, East Campus at 011-717-1234
Fax: 011-339-5708

Appendix P (Sotho)

Lengwalo la hlahiso leseding

Sehloho sa patlisiso: Tsela yeo ho kgaolwa ha leoto ho amang boemo bja bophelo:Patlisiso e, e dirilwe ko tikologong ya Johannesburg, South Africa

Dumelang- Lebitso la ka ke Lonwabo Godlwana ke etsa dipatlisiso tsa hore naa ho kgaolwa ha leoto ho ama boemo bja bophelo bjang

Matseno
Rena, Lonwabo Godlwana le Prof AV Stewart, re etsa dipatlisiso tsa ho bona hore ho kgaolwa ha leoto ho ama boemo bja bophelo bja batho bjang. Dipatlisiso ke tsela feela ya ho re nea/fa dikarabo/diphetolo ho potso. Ka tsela ye re nyaka/batla ho ithuta hore ho kgaolwa ha leoto ho e seng ha kotsi ho ama boemo bja bophelo bja motho bjang.

Ho memiwa ho nka karolo: Re ho mema ho nka karolo mo dipatlisisong tsena.
Ho kenyeleditsweng mo dipatlisisong tsena? O tla tshwanela hore o botswe dipotso (tse tla nkang metsotso e ka bang 30) pele o kgaolwa leoto. Se e tla ba ka ha wena, maemo a bophelo bja hao, maemo a lapeng le bokgoni ba hao. Moraho ha kgwedi tse tharo o tla botswa dipotso hape tse tla nkang metsotso e ka bang 30 ka dihloho tse tshwanang le tsa pele ho karo hore re bone ha eba ho na le phapang moraho ha ho kgaolwa leoto. O ka kgethwa hape ho ba mo sehlotshwaneng sa dipuisano se tla nkang hora e le nngwe le seripa kapa tse pedi ho re bolella ka maitemohelo a hao moraho ha ho kgaolwa leoto.
Kotsi ya ho nka karolo mo dipatlisisong tsena: Ha hona diteko tsa mmele kapa tse kenelelang mmeleng mo dipatlisisong tse. O tla tshwanela feela ke ho araba/fetola dipotso ha o botswa/botsiswa.
Mohola wa ho nka karolo dipatlisisong tsena: dikarabo tse fumanwang ho tswa ho dipatlisiso tsena di ka thusa ho kaonafatsa tsela tseo di sebediswang ho hlokomela batho bao ba kgaotsweng leoto. O ka fumana dikarabo tse fumanweng mo dipatlisisong tsena ha ho feditswe ho etswa dipatlisiso. Ha ho ka tholwa ho re o maikutlo a hao a amehile hoo o hlokang thuso, o tla romelwa ho Mosaekolotsi (Johannesburg Hospital 011 488 4481, Baragwanath Hospital 011 933 8934 and Helen Joseph Hospital 011 489 0766).

O na le boikgethelo mo ho nkeng karolo, ha o hana ho nka karolo o ka se fumane kotlo kapa ho lahlehelwa ke ditokelo tseo di ho tshwanetseng le hona o ka tlohela ho nka karolo nako efe kapa efe ntle le kotlo kapa ho lahlehelwa ke ditokelo tseo di ho tshwanetseng.
Moputso ho tseo di ka hlokang hore o patele ho tswa potleng ya hao. O tla botswa dipotso ka matsatsi ao o neng o tlamehile ho tla sepetlele ka ona. Ha ho ka etsahala hore o tle sepetlela ho tlo botswa dipotso bakeng sa dipatlisiso tsena feela o tla fiwa/neiwa tshelete ya taxi moraho ha ho botswa dipotso.
Ho tla etswa ka hohle hohle hore hlahiso leseding e o tla fanang ka yona e bolokehe/e se ke ya tsejwa ke bohle.

Tsela ya ho ikopanya le babatlisisi:

Lonwabo L Godlwana-Mmatlisisi	Supervisor: Prof AV Stewart
Tel: 011 717 3707/072 373 2156	Tel: 011 717 3718
Fax: 011 717 3719	Email:aimee.stewart@wits.ac.za
Email: Lonwabo.Godlwana@wits.ac.za	

Tsela ya ho ikopanya le bakwaledi ba REC le modulasetulo wa bona ho kenya tletlebo/sello: Prof P Cleaton. Jones Wits Research Office, 10th Floor Senate House, East Campus at 011-717-1234   Fax: 011-339-5708

Appendix Q (Zulu)

Iphepha lolwazi

Study title: Umphumela wokunqunywa komumlenze esimweni sempilo: Inhlolovo enyenziwe eGoli namaphethelo, eNingizimu Afrika.

Ngiyanibingelela. – Igama lami uLonwabo Godlwana ngenza inhlolovo mayelana nemivuzo yokunqunywa unyawo esimweni sempilo (QOL)

Isingeniso
Thina, Lonwabo Godlwana and Prof AV Stewart, senza inhlolovo mayelana nezinga lokuthinteka ekunqunyweni komlenze esimweni sempilo kubantu. Inhlolovo iyidlela yokufunda izimpendulo emibuzweni esinayo. Ngalendlela sifuna ukufunda ukuthi yini izinga lokuthitheka kubantu abanqunywa imilenze ngaphandle kokulimala esimweni sempilo.

Isimemo sokuba yingxenye: Siyanimema ukuba nibe yingxenye yalenhlolovo**?**
Yini enyenziwayo kuloluphenyo? Kuzofanele ubuzwe imibuzo ngaphambi kokunqunywa (imizuzwana ewu30). Lemibuzo iyobe imayelana nawe, isimo sakho sempilo, isimo sasekhaya kanye nokwaziyo ukukwenza. Emveni kwezinyanga ezintathu uphinda futhi ubuzwe imibuzo isikhathi futhi esiyimizuzwana ewu30 kuzo futhi izihloko ezifanayo ukuze sibone ukuthi ukhona yini umehluko emveni kokunqunywa. Kungenzeka ukuba uqokwe ukuba yingxenye yesigejane ekudingideni okuzothatha ihora nemizuzu engamashumi amathathu ukuze usitshele kabanzi ngesipiliyoni emveni kokunqunywa. Uma udinga uxhaso ngokwenqondo, uzothunyelwa kwabasebenza ngenqondo, (Johannesburg Hospital 011 488 4481, Baragwanath Hospital 011 933 8934 and Helen Joseph Hospital 011 489 0766)

Izingozi zokuba yingxenye yophenyo. Akukho okuhlolwa komzimba ngisho okuhlukumezayo kuloluphenyo. Uzodingeka ukuba uphendulo imibuzo kuphela.
Izihlomulo zokuba yingxenye yophenyo: Imiphumela yaloluphenyo ingasiza ukuthuthukisa izindlela ezisethenziswa ukunakekela esibasizayo emveni kokunqunywa imilenze. Imiphumela yaloluphenyo izovezwa kuwena emveni kokuba uphenyo seluqediwe.
Akuphoqiwe ukuba ingxenye, ukwenqaba ekubeni yingxenye akunasijeziso okukanye ukulahlekelwa imihlomulo ethize, kanti ungayeka noma nini ngaphandle kwalokhu.
Ukukhokhelwa kwezimo eziphezu kwamandla. Zonke izinhlelo zemibuzo zizohlelwa ngosuku olufanayo lokuvakashela kwakho esibhedlela. Uma kufanele uvakashe nje maqondana nophenyo kuphela, imali yokugibela itekisi uyonikezwa**.**
Imfihlo: Lonke ulwazi oluthalakayo luyoba imfihlo.

Contact details of researchers:

Lonwabo L Godlwana-Researcher	Supervisor: Prof AV Stewart
Tel: 011 717 3707/072 373 2156	Tel: 011 717 3718
Fax: 011 717 3719	Email:aimee.stewart@wits.ac.za
Email: Lonwabo.Godlwana@wits.ac.za	

Contact details of REC administration and chair for reporting complaints: Prof P Cleaton. Jones Wits Research Office, 10th Floor Senate House, East Campus at 011-717-1234
Fax: 011-339-5708

Appendix R

Participant informed consent

Dear Participant

Your name was gathered from the hospital records (…………………..….hospital) from which you are booked for your leg operation. We request your permission to join the interview about your life before and after amputation.

DECLARATION

I………………………………………………. (Full names of participant) hereby confirm that I understand the contents of the information sheet about this study and the nature of the research project, and I consent to participating in the research project. I have been given the opportunity to ask questions from the researcher. I understand that I am at liberty to withdraw from the project at any time, should I so desire with no penalty or lost of benefit to which I am otherwise entitled.

SIGNATURE OF PARTICIPANT:……………………Date…………….
SIGNATURE OF WITNESS (in the case where the participant puts a mark (X))

……………………Date…………..

Contact details of researchers:

Lonwabo L Godlwana-Researcher	Supervisor: Prof AV Stewart
Tel: 011 717 3707/072 373 2156	Tel: 011 717 3718
Fax: 011 717 3719	Email:aimee.stewart@wits.ac.za
Email: Lonwabo.Godlwana@wits.ac.za	

Appendix S (Sotho)

Lengwalo la ho dumela ho nka karolo la monkakarolo

Monkakarolo yo a ratehang

Lebitso/leina la hao le thotswe/fumanwe ho tswa ditlankaneng tsa hao tsa sepetlele (…………………..….hospital) moo o beakanyeditsweng ho tla etsa karo/ophereshene ya hao ya leoto. Re kopa/kgopela tumelelo ya hao hore re ho botse dipotso/dipotsisho mabapi le bophelo bja hao pele le moraho ha ho kgaolwa leoto.

KANO

Nna………………………………………………. (Mabitso ka botlalo a monkakarolo) ke dumela hore ke utlisisa dikahare tsa lengwalo la hlahiso leseding ka ha dipatlisiso tsena, ebile ke dumela ho nka karolo mo dipatlisisong tsena. Ke neilwe/filwe monyetla wa ho botsa/botsisa mmatlisisi dipotso. Ke utlwisisa hore ke lokolohile hore nka ikgohela moraho mo dipatlisisong ka nako efe kapa efeng, ha ke batla/nyaka ntle le kotlo kapa ho lahlehelwa ke ditokelo tse di ntshwanetseng.

Saenilwe ke monkakarolo:……………………Letsatsi……………..
SAENILWE KE PAKI (ka sebaka seo monkakarolo a sebedisang letshwao (X))

……………………Letsatsi………..
Tsela ya ho ikopanya le babatlisisi:

Lonwabo L Godlwana-Mmatlisisi	Supervisor: Prof AV Stewart
Tel: 011 717 3707/072 373 2156	Tel: 011 717 3718
Fax: 011 717 3719	Email:aimee.stewart@wits.ac.za
Email: Lonwabo.Godlwana@wits.ac.za	

Appendix T (Zulu)

Isivumelwano sokuba yingxenye yenhlolovo

Sawubona

Igama lakho litholakale ezincwadini zasesibhedlela (……………………..…hospital), lapho okubekwe ukuthi uzohlinzwa umlenze wakho. Sicela imvume yakho ukuba sihlangane ngengxoxiswano mayelana nempilo yakho ngaphambi nangemva kokunqunywa kwakho.

ISIVUMELWANO

Mina ……................ ....(amagama aphelele kothatha ingxenye) ngiyaqiniseka ukuthi ngiyaqondisisa inqikithi yephepha lesivumelwano mayelana naloluphenyo kanye nenqubo yalenhlolovo. Kanti futhi ngiyavuma ukuba yingxenye yalenhlolovo. Ngilitholile ithuba lokubuza kwinhloli. Ngiyaqondisisa ukuthi ngingayeka nomanini kulenhlolovo uma ngifisa ngaphandle kokujeziswa noma ukulahlekelwa.

SIGNATURE OF PARTICIPANT:……………………Usuku…………….
Ufakazi (lapho oyingxenye ubeka u (X)

……………………Usuku…………..

Imininingwano yabancwaningi:

Lonwabo L Godlwana-Researcher
Tel: 011 717 3707/072 373 2156
Fax: 011 717 3719
Email: Lonwabo.Godlwana@wits.ac.za

Supervisor: Prof AV Stewart
Tel: 011 717 3718
Email:aimee.stewart@wits.ac.za

Appendix U

Information document for in-depth interviews

Study title: The Impact of Lower Limb Amputation on Quality of Life: A study done in the Johannesburg Metropolitan area, South Africa

Greetings- My name is Lonwabo Godlwana and I am doing a research on the impact of lower limb amputation of QOL

Introduction

We, Lonwabo Godlwana and Prof AV Stewart, are doing research on the impact of lower limb amputation on the quality of life of participants. Research is just the process to learn the answers to a question. In this way we want to learn what is the impact of non-traumatic lower limb amputation on participant's quality of life (QOL)?

Invitation to participate: We are inviting you to take part in a research study.

What is involved in the study? You will be required to be part of an in-depth interview discussion of about one and a half to two hours. This will involve sharing life experiences after your amputation with other participants who have had amputations. A tape recorder will be used to record the discussions.

Risks of being involved in the study: there are no physical or invasive tests in the study. You will only be required to share views and give as much information as possible.

Benefits of being in the study: the results of the study may help in improving the methods used to care for people with a leg amputation. The results of the study will be availed to you once the study has been completed.

Participation is voluntary, refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled and you may discontinue at anytime without penalty or loss of benefit to which you are otherwise entitled.

Reimbursements "for out of pocket" expenses. All in-depth interviews will be scheduled on the some day as your visit to the hospital. In the event of you being required to visit only for this study, a taxi fare will be provided after the in-depth interview.

Confidentiality: Efforts will be made to keep personal information confidential. Absolute confidentiality cannot be guaranteed as there are other participants in the in-depth interview.

Contact details of researchers:

Lonwabo L Godlwana-Researcher	Supervisor: Prof AV Stewart
Tel: 011 717 3707/072 373 2156	Tel: 011 717 3718
Fax: 011 717 3719	Email:aimee.stewart@wits.ac.za
Email: Lonwabo.Godlwana@wits.ac.za	

Contact details of REC administration and chair for reporting complaints: Prof P Cleaton. Jones Wits Research Office, 10th Floor Senate House, East Campus at 011-717-1234 Fax: 011-339-5708

Appendix V (Sotho) **Lengwalo la hlahiso leseding la puisano e tseneletseng**

Sehloho sa patlisiso: Tsela yeo ho kgaolwa ha leoto ho amang boemo bja bophelo:Patlisiso e, e dirilwe ko tikologong ya Johannesburg, South Africa

Dumelang – Lebitso la ka ke Lonwabo Godlwana ke etsa dipatlisiso tsa hore naa ho kgaolwa ha leoto ho ama boemo bja bophelo bjang

Matseno
Rena, Lonwabo Godlwana le Prof AV Stewart, re etsa dipatlisiso tsa ho bona hore ho kgaolwa ha leoto ho ama boemo bja bophelo bja batho bjang. Dipatlisiso ke tsela feela ya ho re nea/fa dikarabo/diphetolo ho potso. Ka tsela ye re nyaka/batla ho ithuta hore ho kgaolwa ha leoto ho e seng ha kotsi ho ama boemo bja bophelo bja motho bjang.

Ho memiwa ho nka karolo: Re ho mema ho nka karolo mo dipatlisisong tsena.
Ho kenyeleditsweng mo dipatlisisong tsena? Ho tla hlokahala hore o be leloko la dihlotshwana tsa dipuisano tse nkang hora e le nngwe le seripa kapa hora tse pedi. Sena se kenyeletsa ho abelana maitemohelo a bophelo moraho ha ho kgaolwa leoto le batho ba bangwe ba kgaotsweng ditho tsa mmele. Sehatisa lentswe se tla sebediswa ho hatisa dipuisano tsena.
Kotsi ya ho nka karolo mo dipatlisisong tsena: Ha hona diteko tsa mmele kapa tse kenelelang mmeleng mo dipatlisisong tse. O tla tshwanela feela ho abelana maikutlo a hao le hlahiso leseding ka tsela yeo o ka kgonang.
Mohola wa ho nka karolo dipatlisisong tsena: dikarabo tse fumanwang ho tswa ho dipatlisiso tsena di ka thusa ho kaonafatsa tsela tseo di sebediswang ho hlokomela batho bao ba kgaotsweng leoto. O ka fumana dikarabo tse fumanweng mo dipatlisisong tsena ha ho feditswe ho etsa dipatlisiso.
O na le boikgethelo mo ho nkeng karolo, ha o hana ho nka karolo o ka se fumane kotlo kapa ho lahlehelwa ke ditokelo tseo di ho tshwanetseng le hona o ka tlohela ho nka karolo nako efe kapa efeng ntle le kotlo kapa ho lahlehelwa ke ditokelo tseo di ho tshwanetseng.
Moputso ho tseo di ka hlokang hore o patele ho tswa potleng ya hao. O tla botswa dipotso ka matsatsi ao o neng o tlamehile ho tla sepetlele ka ona. Ha ho ka etsahala hore o tle sepetlela ho tlo botswa dipotso bakeng sa dipatlisiso tsena feela o tla fiwa/neiwa tshelete ya taxi moraho ha ho botswa dipotso.
Ho tla etswa ka hohle hohle hore hlahiso leseding e o tla fanang ka yona e bolokehe/e se ke ya tsejwa ke bohle. Empa re ka se ke ra fa bonnete bo tseneletseng bja hore e ka se tsejwe ke batho ba bang hobane ho tla ba le batho ba bang dithlotshwaneng tsena tsa dipuisano.

Tsela ya ho ikopanya le babatlisisi:

Lonwabo L Godlwana-Mmatlisisi	Supervisor: Prof AV Stewart
Tel: 011 717 3707/072 373 2156	Tel: 011 717 3718
Fax: 011 717 3719	Email:aimee.stewart@wits.ac.za
Email: Lonwabo.Godlwana@wits.ac.za	

Tsela ya ho ikopanya le bakwaledi ba REC le modulasetulo wa bona ho kenya tletlebo/sello: Prof P Cleaton. Jones Wits Research Office, 10th Floor Senate House, East Campus at 011-717-1234 Fax: 011-339-5708

Appendix W (Zulu)

Information document for in- depth interviews

Iphepha lolwazi

Study title: Umphumela wokunqunywa komumlenze esimweni sempilo: Inhlolovo enyenziwe eGoli namaphethelo, eNingizimu Afrika.

Sanibonani. Igama lami uLonwabo Godlwana,ngenza ucwaningo ngomthelelo wokunqunywa kwesitho somzimba sanga kwesingezansi esimeni sakho sempilo

Isingeniso

Thina,uLonwabo Godlwana no Professor Stewart,senza ucwaningo ngomthelelo wokunqunwa kwesitho somzimba sanga kwesingezansi esimeni sakho sempilo
Lolucwaningo indlela yokuba sithole izimpendulo zemibuzo.Ngaledlela sifisa ukuthola ukuthi yini umthelela wokunqunywa isitho somzimba sanga kwesingezansi esimeni sakho sempilo

Isimemo sokuthi ungenele: Siyakumema ukuthi ube yinxenye yalolucwaningo.

Yini equkethwe kulolucwaningo?

Uzocelwa ukuba uphendule imibuzo,ezobuzwa ngumcwaningi futhi inxenye yezinxoxo.Kuthatha ihhora nenxenye,kuyele emahoreni amabili.Kuphathelene ngokuxoxa ngezimo oke wabhekana nazo seloku wanqunywa isitho somzimba sanga kwesingezansi,kanti uzobe uxoxa nabanye abantu abanqunywe isitho somzimba sanga kwesingezansi .Sizosebenzisa isiqopha mazwi ukuza sigcine izinxoxo.

Bukhona yini ubungozi kulolucwaningo? Akukho okuhlolwa komzimba ngisho okuhlukumezayo kulololuphenyo. Uzodingeka ukuba uphendulo imibuzo kuphela.

Uzozuzani ngalolucwanigo?
Imphumela yalolucwaningo ingasiza ekuthuthukiseni izindlela ezikhona zokunakekela abantu abanqunywe isitho somzimba sanga kwesingezansi.Imiphumele yocwaningo izokwazi ukuthi uyithole uma ucwaningo soluphelile.

Ukuba yinxenye yocwaningo uyazikhetela.Awuphoqiwe.
Ngokwenqaba ukuba yinxenye yocwaningo ngeke ulahlekelwa yilutho,obungenzeka ukuzuze,kunjalo futhi uma uphuma phakathi lungaka pheli ucwaningo.

Izinxephezelo sezimali sezimali ongase uzisebenzise.
Izinxoxo nokuphendula imibuzo zizoba ngosuku olufanayo,kunosuku ovakasha ngalo esibhedlela.Uma kunesidingo sokuthi ufikele lolucwaningo kuphela,

uzonikezwa imali yokugibela uma usuqedile ukuba yinxenye yezinxoxo,waphendula imibuzo.

Imfihlo-Imizamo izokwenziwa ukugcina imininingwane yakho iyimfihlo. Ukufihla ngokugcwele akwethenjiswa,ngoba kunabaye abantu abzoba yinxenye yalezi zinxoxo.

Contact details of researchers:
Lonwabo L Godlwana-Researcher Supervisor: Prof AV Stewart
Tel: 011 717 3707/072 373 2156 Tel: 011 717 3718
Fax: 011 717 3719 Email:aimee.stewart@wits.ac.za
Email: Lonwabo.Godlwana@wits.ac.za
Contact details of REC administration and chair for reporting complaints: Prof P Cleaton. Jones Wits Research Office, 10th Floor Senate House, East Campus at 011-717-1234 Fax: 011-339-5708

Appendix X

Participant informed consent for using the tape recorder during the in-depth interview session

DECLARATION

I………………………………………………. (Full names of participant) consent to take part in the study and be tape recorded. I understand that I am at liberty to withdraw from the project at any time, should I so desire with no penalty or lost of benefit to which I am otherwise entitled.

SIGNATURE OF PARTICIPANT:……………………Date…………….
SIGNATURE OF WITNESS (in the case where the participant puts a mark (X))

……………………Date…………..

Contact details of researchers:

Lonwabo L Godlwana-Researcher
Tel: 011 717 3707/072 373 2156
Fax: 011 717 3719
Email: Lonwabo.Godlwana@wits.ac.za

Supervisor: Prof AV Stewart
Tel: 011 717 3718
Email:aimee.stewart@wits.ac.za

Appendix Y (Sotho)

Lengwalo la ho dumela ho nka karolo mo ho sebediseng ha sehatisa lentswe ka nako ya puisano e tseneletseng

KANO

Nna………………………………………………. (Mabitso ka botlalo a monkakarolo) ke dumela ho nka karolo mo dipatlisisong tsena le ho hatiswa lentswe. Ke utlwisisa hore ke lokolohile hore nka ikgohela moraho mo dipatlisisong ka nako efe kapa efeng, ha ke batla/nyaka ntle le kotlo kapa ho lahlehelwa ke ditokelo tse di ntshwanetseng.

Saenilwe ke monkakarolo:……………………Letsatsi……………..
SAENILWE KE PAKI (ka sebaka seo monkakarolo a sebedisang letshwao (X))

……………………Letsatsi………..
Tsela ya ho ikopanya le babatlisisi:

Lonwabo L Godlwana-Mmatlisisi	Supervisor: Prof AV Stewart
Tel: 011 717 3707/072 373 2156	Tel: 011 717 3718
Fax: 011 717 3719	Email:aimee.stewart@wits.ac.za
Email: Lonwabo.Godlwana@wits.ac.za	

Appendix Z (Zulu)

Isivumelwano sokusebenziza umshini wokulalela uma ukhuluma.

Mina ________________ (igama eligcwele) ngiyavuma ukuba yinxenye yale nxonxo.Ngiyazi ukuthi nginelungelo lokuphuma kulolucwaningo noma yinini,ngokuthanda kwami,futhi ngeke ngikhokhe luthi,ngeke ngijeziswe nokungase ngikuzuze ngeke ngikuthole.

SIGNATURE OF PARTICIPANT:…………………….Date……………..
SIGNATURE OF WITNESS (in the case where the participant puts a mark (X))
……………………. usuku……………

Indlela yokuxhumana nabacwaningi:

Lonwabo L Godlwana-Umcwaningo Umphathi cwaningo: Prof AV Stewart
Inombolo yocingo: 011 717 3707/072 373 2156 inombolo yocingo: 011 717 3718
Inombolo yesikhahlamezi: 011 717 3719
Email:aimee.stewart@wits.ac.za
Email: Lonwabo.Godlwana@wits.ac.za

Appendix AA

Consent form for being in the in-depth interview

Dear Participant
Greetings - My name is Lonwabo Godlwana and I am doing a research on the impact of lower limb amputation of QOL.

DECLARATION

I……………………………………………. (Full names of participant) consent to participate in the in-depth interview. I understand that I am at liberty to withdraw from the project at any time, should I so desire with no penalty or lost of benefit to which I am otherwise entitled.

SIGNATURE OF PARTICIPANT:…………………….Date…………….
SIGNATURE OF WITNESS (in the case where the participant puts a mark (X))

…………………….Date………….

Contact details of researchers:

Lonwabo L Godlwana-Researcher
Tel: 011 717 3707/072 373 2156
Fax: 011 717 3719
Email: Lonwabo.Godlwana@wits.ac.za

Supervisor: Prof AV Stewart
Tel: 011 717 3718
Email:aimee.stewart@wits.ac.za

Appendix AB (Sotho)

Lengwalo la ho dumela ho ba le puisano e tseneletseng

Monkakarolo ya ratehang
Dumela – Lebitso la ka ke Lonwabo Godlwana ke etsa dipatlisiso ka hore naa ho kgaolwa leoto ho ama boemo bja bophelo bjang.

KANO

Nna………………………………………………. (Mabitso ka botlalo a monkakarolo) ke dumela ho nka karolo mo dithotshwaneng tsa dipuisano. Ke utlwisisa hore ke lokolohile hore nka ikgohela moraho mo dipatlisisong ka nako efe kapa efeng, ha ke batla/nyaka ntle le kotlo kapa ho lahlehelwa ke ditokelo tse di ntshwanetseng.

Saenilwe ke monkakarolo:……………………Letsatsi…………….
SAENILWE KE PAKI (ka sebaka seo monkakarolo a sebedisang letshwao (X))

……………………Letsatsi………..
Tsela ya ho ikopanya le babatlisisi:

Lonwabo L Godlwana-Mmatlisisi	Supervisor: Prof AV Stewart
Tel: 011 717 3707/072 373 2156	Tel: 011 717 3718
Fax: 011 717 3719	Email:aimee.stewart@wits.ac.za
Email: Lonwabo.Godlwana@wits.ac.za	

Appendix AC

Isivumelwano sokuxoxa kabanzi nathi ngodaba lokunqunyulwa umlenze.

Sanibonani. Igama lami uLonwabo Godlwana,ngenza ucwaningo ngomthelelo wokunqunywa kwesitho somzimba sanga kwesingezansi.

Isifungo.

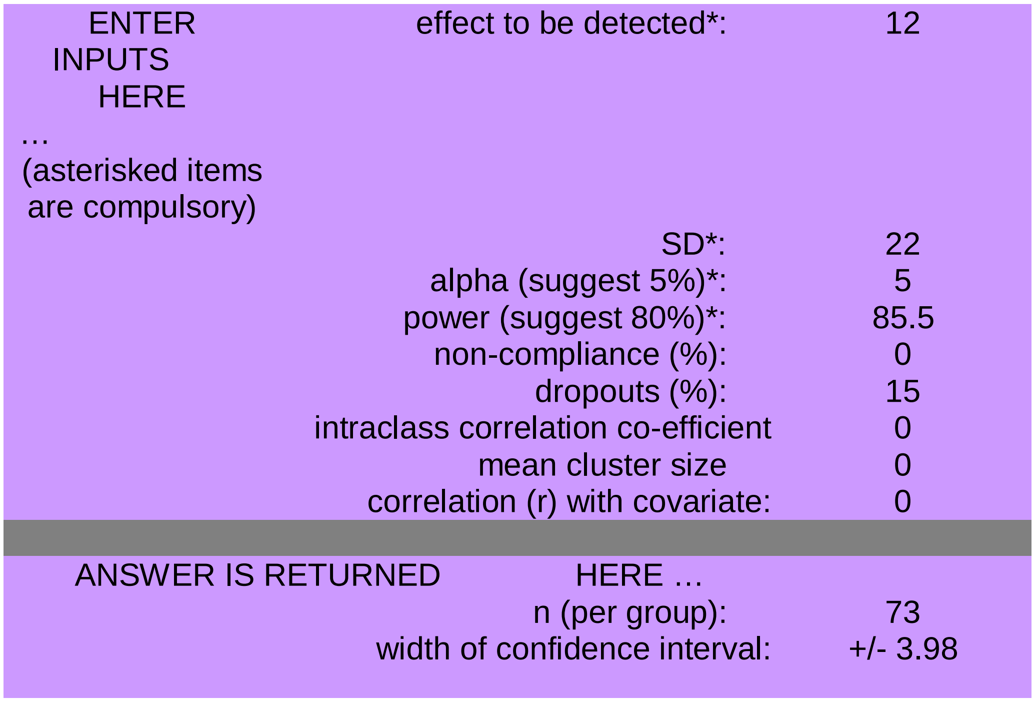
Mina ________________ (igama eligcwele) ngiyavuma ukuba yinxenye yale nxonxo.Ngiyazi ukuthi nginelungelo lokuphuma kulolucwaningo noma yinini,ngokuthanda kwami,futhi ngeke ngikhokhe luthi,ngeke ngijeziswe nokungase ngikuzuze ngeke ngikuthole.

SIGNATURE OF PARTICIPANT:…………………….usuku…………..
Ufakazi (in the case where the participant puts a mark (X))
…………………….Date(Usuku)…………..

Indlela yokuxhumana nabacwaningi

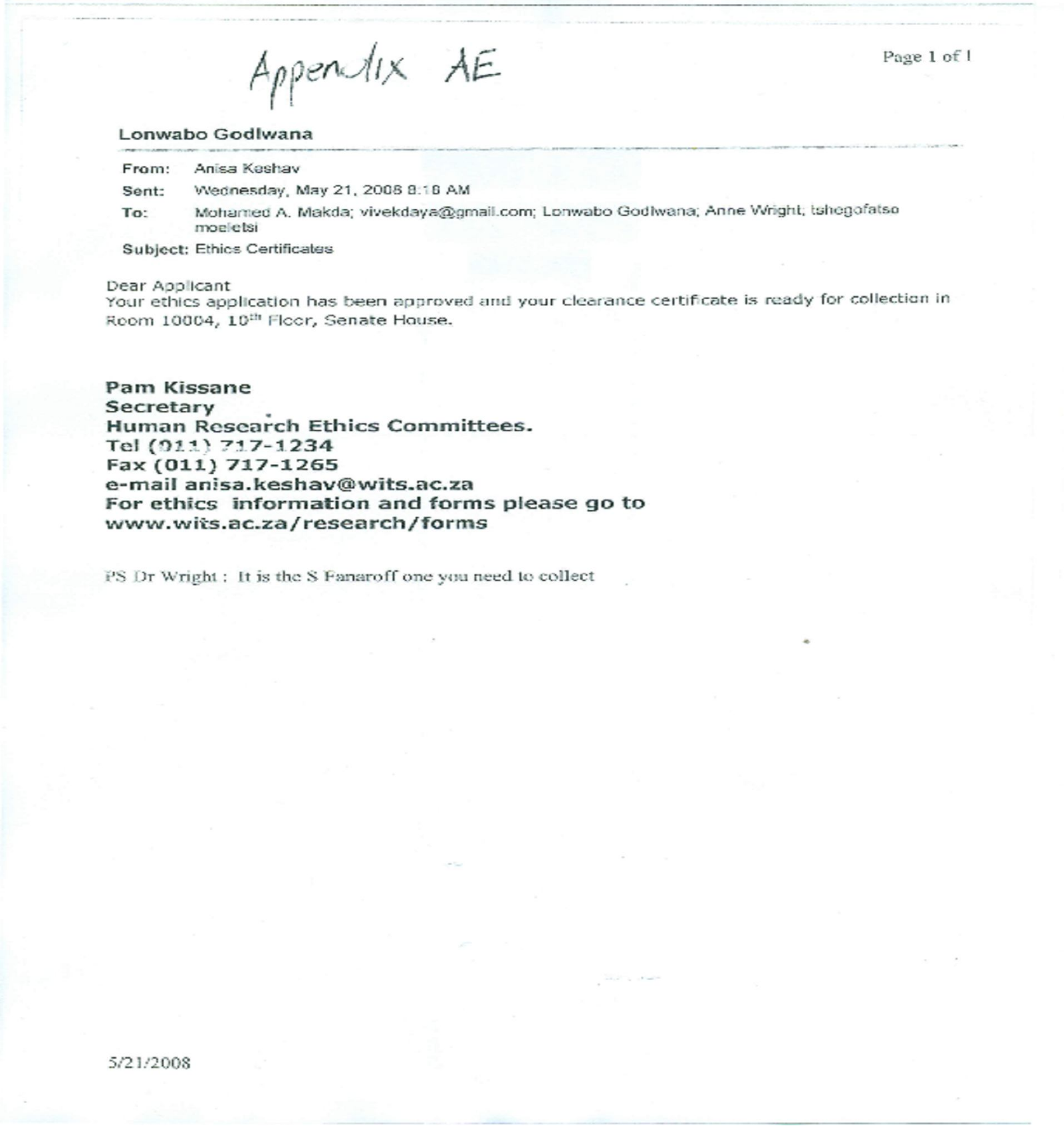
Lonwabo L Godlwana-Umcwaningo Umphathi cwaningo: Prof AV Stewart
inombolo yocingo: 011 717 3707/072 373 2156 inombolo yocingo: 011 717 3718
Inombolo yesikhahlamezi: 011 717 3719
Email:aimee.stewart@wits.ac.za
Email: Lonwabo.Godlwana@wits.ac.za

Appendix AD- Sample size calculation



ENTER INPUTS HERE … (asterisked items are compulsory)	effect to be detected*:	12
	SD*:	22
	alpha (suggest 5%)*:	5
	power (suggest 80%)*:	85.5
	non-compliance (%):	0
	dropouts (%):	15
	intraclass correlation co-efficient	0
	mean cluster size	0
	correlation (r) with covariate:	0
ANSWER IS RETURNED	HERE …	
	n (per group):	73
	width of confidence interval:	+/- 3.98

Appendix AE-Letter from the secretary at Human Research Ethics Committee



Appendix AE

Page 1 of 1

Lonwabo Godlwana

From: Anisa Keshav
Sent: Wednesday, May 21, 2008 8:18 AM
To: Mohamed A. Makda; vivekdaya@gmail.com; Lonwabo Godlwana; Anne Wright; tshegofatso moeletsi
Subject: Ethics Certificates

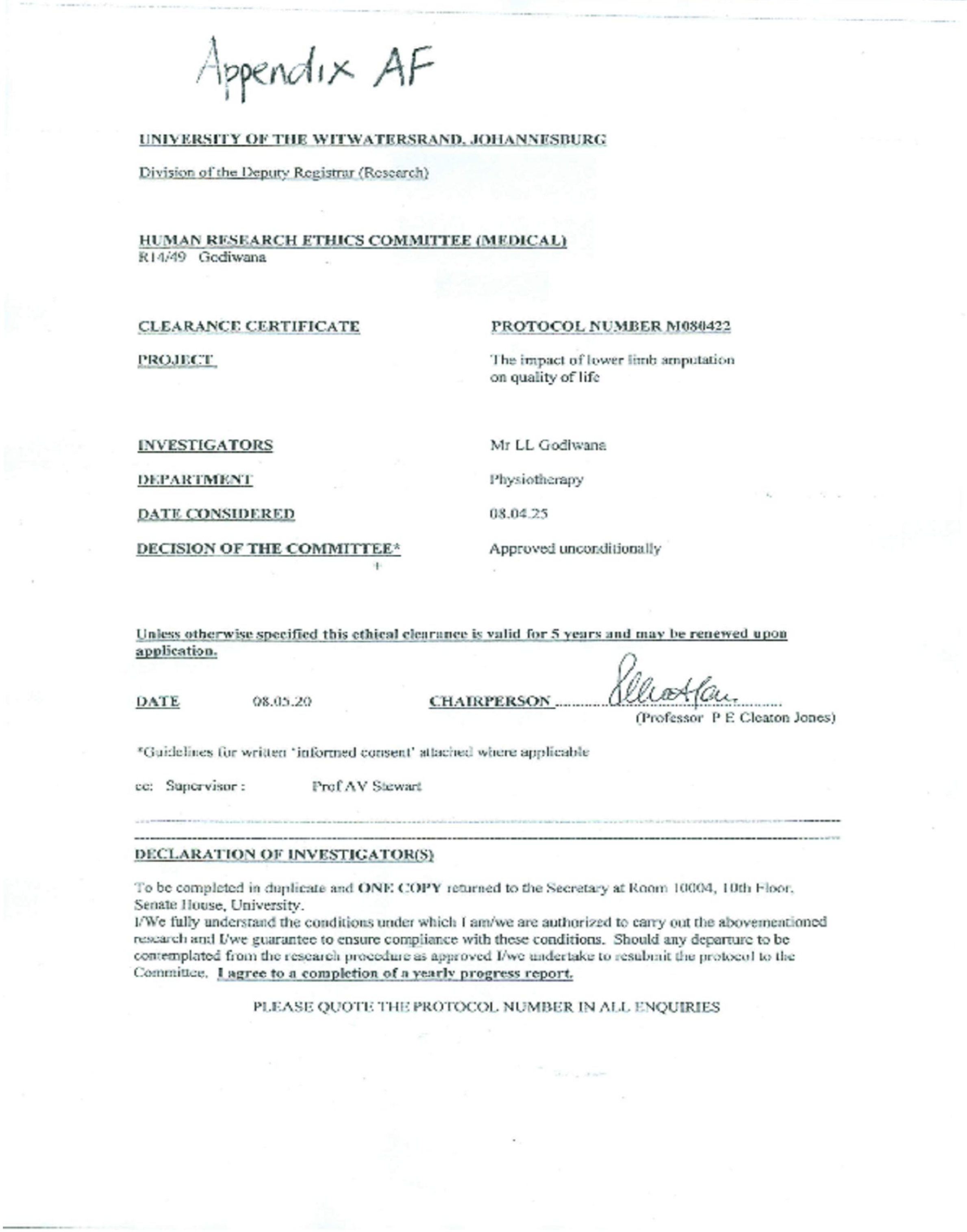
Dear Applicant
Your ethics application has been approved and your clearance certificate is ready for collection in Room 10004, 10th Floor, Senate House.

Pam Kissane
Secretary
Human Research Ethics Committees.
Tel (011) 717-1234
Fax (011) 717-1265
e-mail anisa.keshav@wits.ac.za
For ethics information and forms please go to
www.wits.ac.za/research/forms

PS Dr Wright : It is the S Fanaroff one you need to collect

5/21/2008

Appendix AF- Ethical clearance certificate



Appendix AF

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Godiwana

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER M080422**
PROJECT	The impact of lower limb amputation on quality of life
INVESTIGATORS	Mr LL Godiwana
DEPARTMENT	Physiotherapy
DATE CONSIDERED	08.04.25
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 08.05.20 **CHAIRPERSON** ....
(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

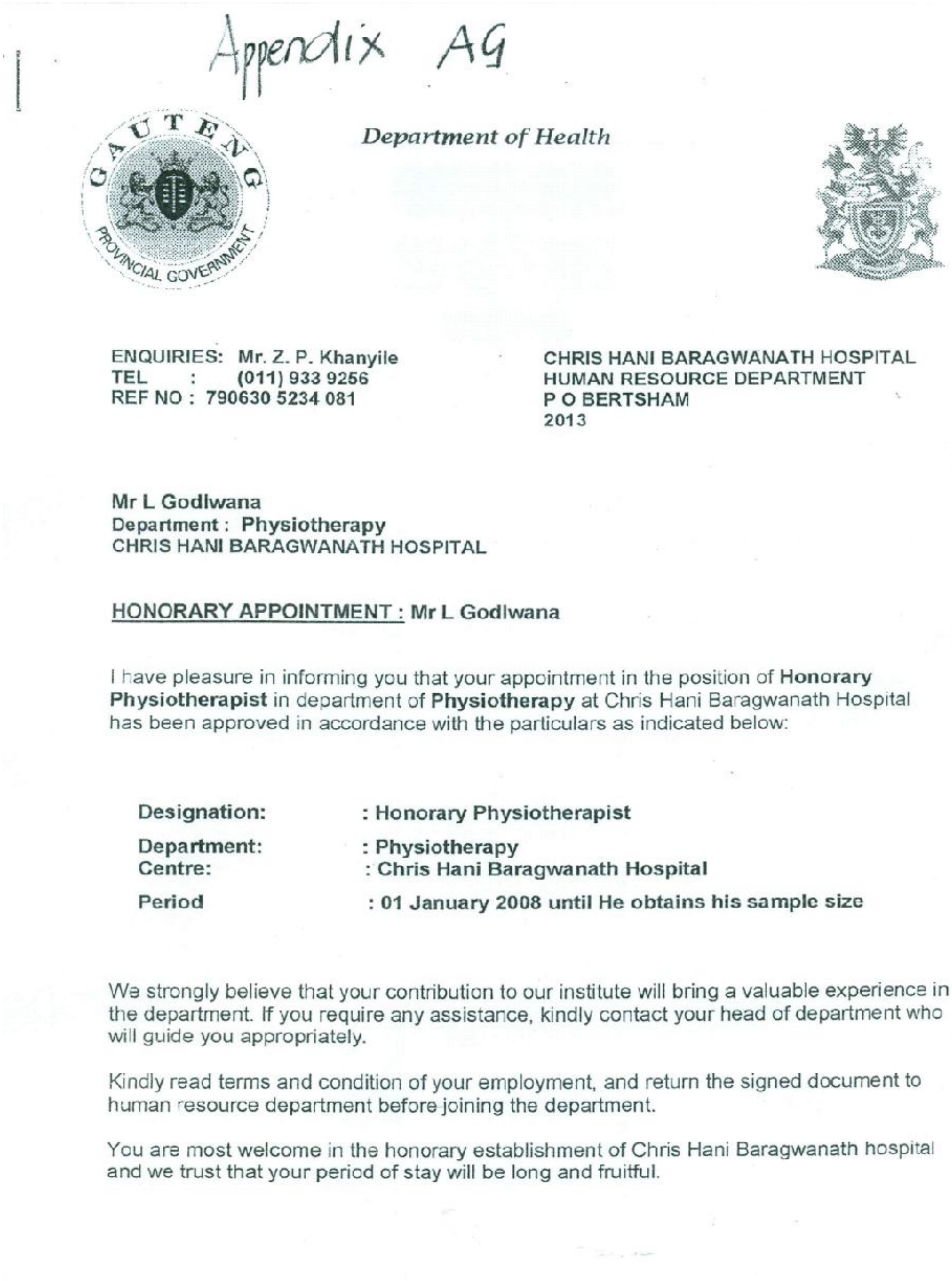
cc: Supervisor : Prof AV Stewart

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix AG- Permission from Chris Hani Baragwanath hospital



Appendix AG

GAUTENG PROVINCIAL GOVERNMENT

Department of Health

ENQUIRIES: Mr. Z. P. Khanyile
TEL : (011) 933 9256
REF NO : 790630 5234 081

CHRIS HANI BARAGWANATH HOSPITAL
HUMAN RESOURCE DEPARTMENT
P O BERTSHAM
2013

Mr L Godlwana
Department : Physiotherapy
CHRIS HANI BARAGWANATH HOSPITAL

HONORARY APPOINTMENT : Mr L Godlwana

I have pleasure in informing you that your appointment in the position of **Honorary Physiotherapist** in department of **Physiotherapy** at Chris Hani Baragwanath Hospital has been approved in accordance with the particulars as indicated below:

Designation:	**: Honorary Physiotherapist**
Department:	**: Physiotherapy**
Centre:	**: Chris Hani Baragwanath Hospital**
Period	**: 01 January 2008 until He obtains his sample size**

We strongly believe that your contribution to our institute will bring a valuable experience in the department. If you require any assistance, kindly contact your head of department who will guide you appropriately.

Kindly read terms and condition of your employment, and return the signed document to human resource department before joining the department.

You are most welcome in the honorary establishment of Chris Hani Baragwanath hospital and we trust that your period of stay will be long and fruitful.

Conditions of employment:

1. You may terminate your services at the hospital at any time (except during critical or ethical duty hours as set by standards of safe practice) by notifying the Chief Executive Officer or his delegate accordingly, in connection with such termination, shall be final.

2. Your services may be summarized/ terminated by the Chief Executive Officer or his delegate and the decision of the Chief Executive Officer or his delegate in connection with such termination, shall be final.

3. You shall subject yourself unconditionally to the rules and regulations of the hospital and the orders of the provincial officers under whose supervision you may work.

4. Should any dispute arise between you and the Chief Executive Officer in respect of any matter not provided in condition, the matter shall be referred to the Director of Health Services in Gauteng, and the Director's decision shall be final.

5. The hospital or department will not accept any responsibility in respect of:
    (a) Your boarding and lodging
    (b) Your public liability
    (c) Finances of your hospital identity card
    (d) Transport

6. Your hospital identity card must be worn at all times whilst on the hospital premises, and returned to Human Resource Department (without refund) on termination of service.

I wish you a happy and successful period of services.

CHIEF EXECUTIVE OFFICE

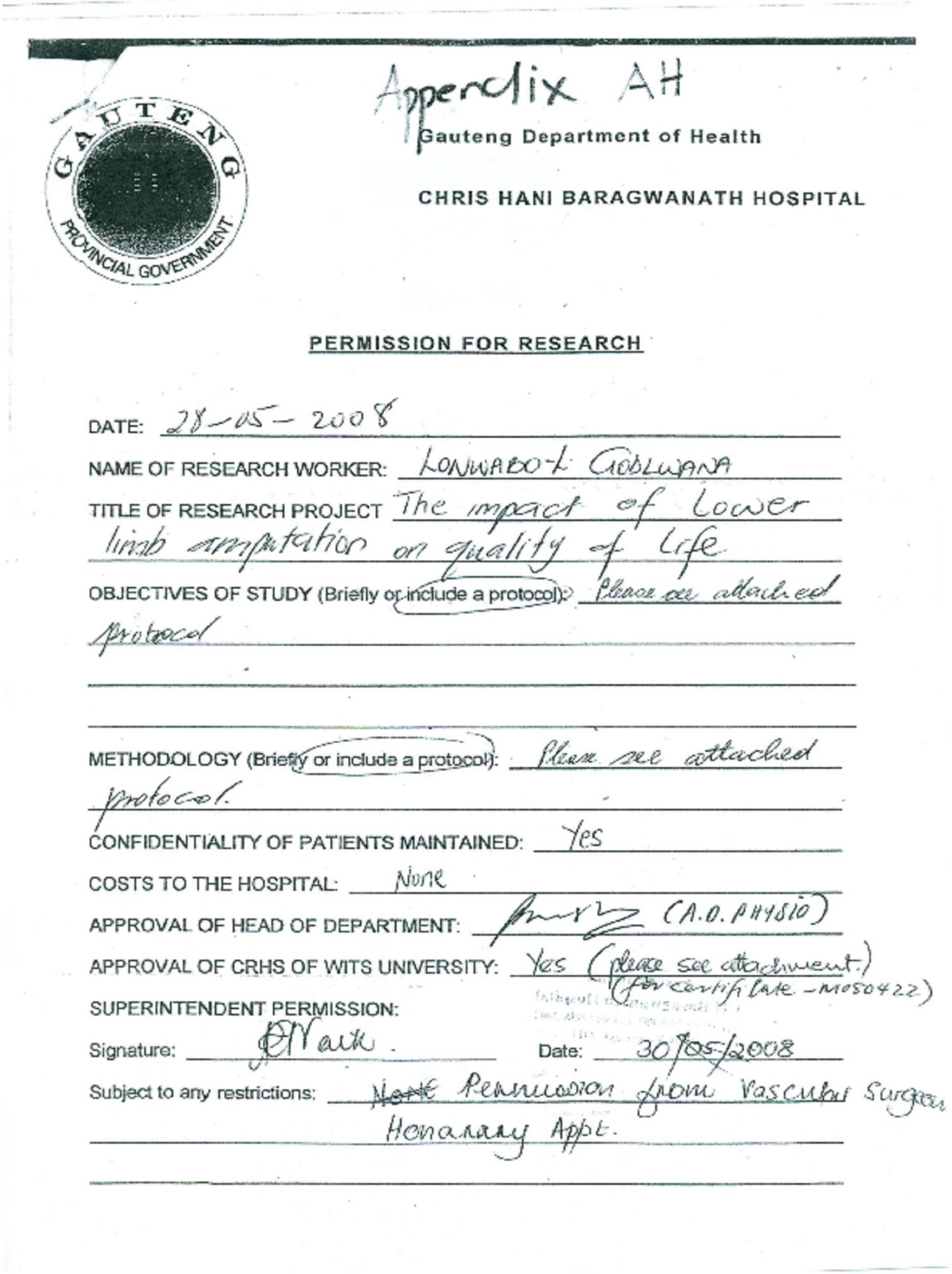
I, Lonwabo L. Godlwana **, Identity Number** 7906305234081

hereby, accept the Honorary Appointment as stipulated and explained to me.

Signed by: ______________________ **Date:** 18-07-08

Distribution
The Head of Physiotherapy Department, Chris Hani Baragwanath Hospital

Appendix AH- Chris Hani Baragwanath hospital permission for research application form



Appendix AH

Gauteng Department of Health

CHRIS HANI BARAGWANATH HOSPITAL

PERMISSION FOR RESEARCH

DATE: 28-05-2008

NAME OF RESEARCH WORKER: LONWABO-L GQOBLWANA

TITLE OF RESEARCH PROJECT The impact of lower limb amputation on quality of life

OBJECTIVES OF STUDY (Briefly or include a protocol): Please see attached protocol

METHODOLOGY (Briefly or include a protocol): Please see attached protocol.

CONFIDENTIALITY OF PATIENTS MAINTAINED: Yes

COSTS TO THE HOSPITAL: None

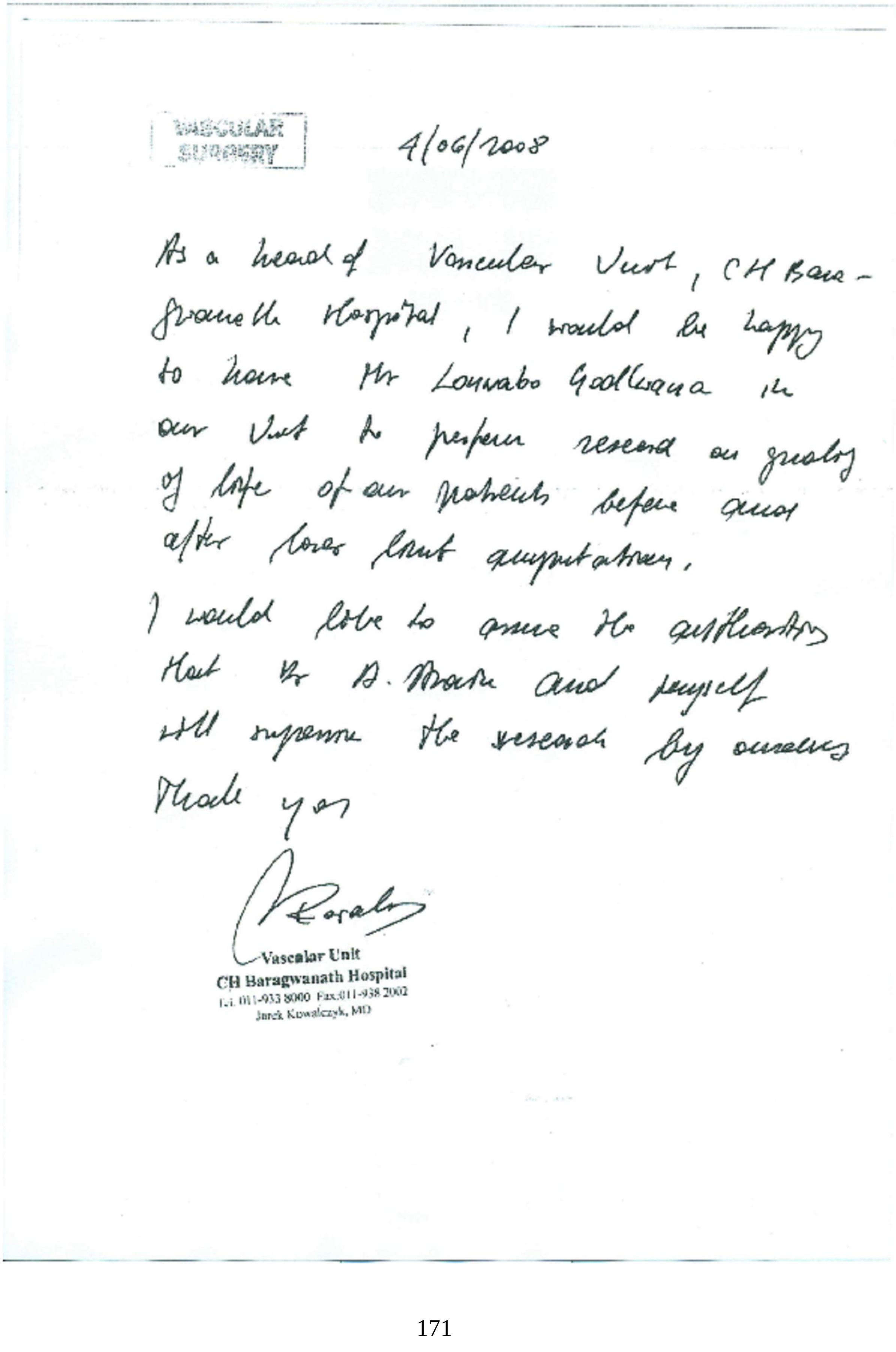
APPROVAL OF HEAD OF DEPARTMENT: (A.O. PHYSIO)

APPROVAL OF CRHS OF WITS UNIVERSITY: Yes (please see attachment.) (for certificate -M050422)

SUPERINTENDENT PERMISSION:

Signature: Naik. Date: 30/05/2008

Subject to any restrictions: ~~None~~ Permission from Vascular Surgeon Honorary Appt.



VASCULAR SURGERY

4/06/2008

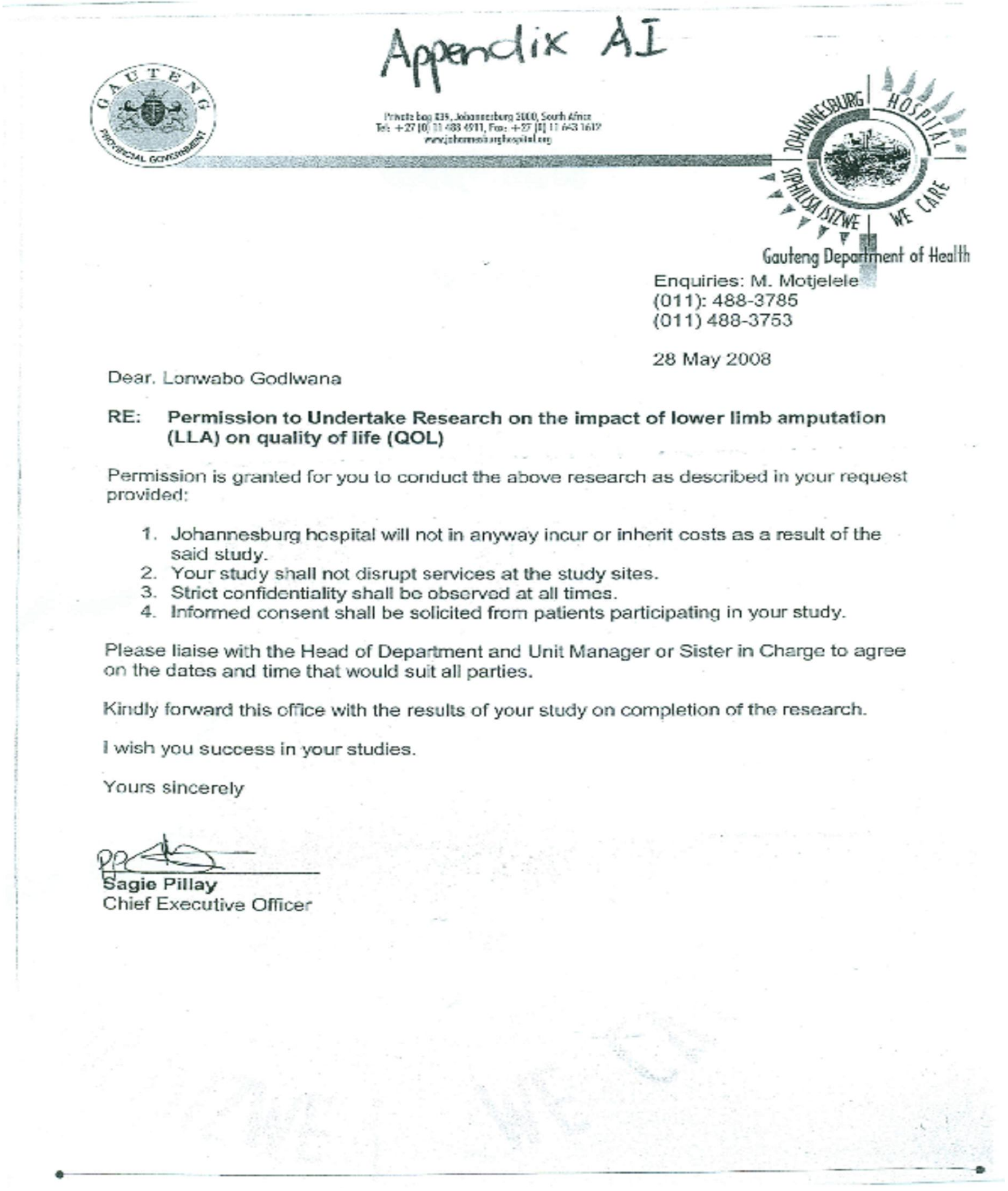
As a head of Vascular Unit, CH Baragwanath Hospital, I would be happy to have Mr Lonwabo Godlwana in our Unit to perform research on quality of life of our patients before and after lower limb amputation.

I would like to assure the authorities that Dr B. Mare and myself will supervise the research by ourselves

Thank you

Vascular Unit
CH Baragwanath Hospital
Tel. 011-933 8000 Fax.011-938 2002
Jarek Kowalczyk, MD

Appendix AI- Permission from Charlotte Maxeke Academic Hospital



Appendix AI

GAUTENG PROVINCIAL GOVERNMENT

Private bag X39, Johannesburg 2000, South Africa
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JOHANNESBURG HOSPITAL
SIPHILISA ISIZWE WE CARE
Gauteng Department of Health

Enquiries: M. Motjelele
(011): 488-3785
(011) 488-3753

28 May 2008

Dear. Lonwabo Godlwana

RE: Permission to Undertake Research on the impact of lower limb amputation (LLA) on quality of life (QOL)

Permission is granted for you to conduct the above research as described in your request provided:

1. Johannesburg hospital will not in anyway incur or inherit costs as a result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.

Please liaise with the Head of Department and Unit Manager or Sister in Charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

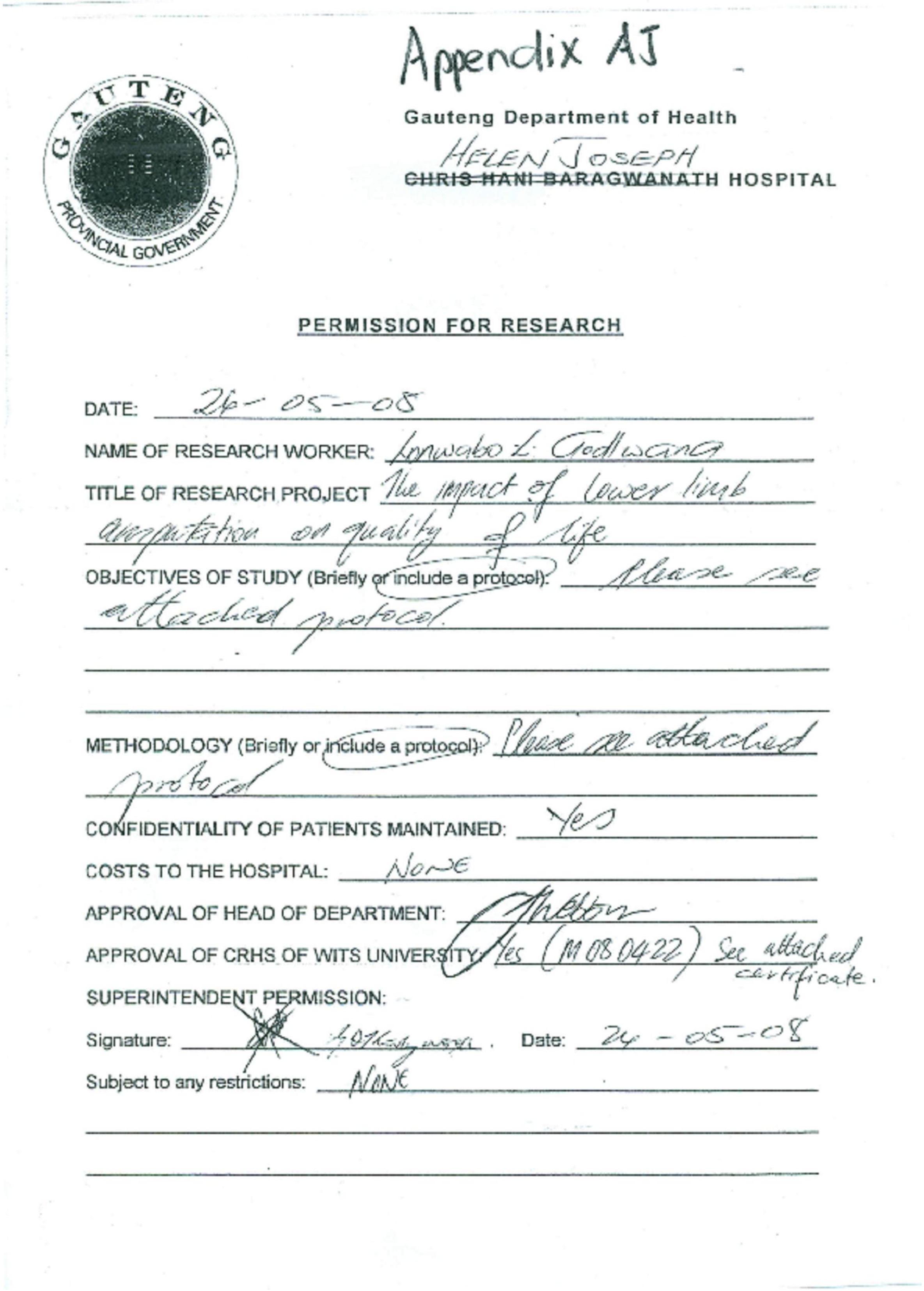
I wish you success in your studies.

Yours sincerely

PP

Sagie Pillay
Chief Executive Officer

Appendix AJ- Permission from Helen Joseph Hospital



Appendix AJ

Gauteng Department of Health

HELEN JOSEPH ~~CHRIS HANI BARAGWANATH~~ HOSPITAL

PERMISSION FOR RESEARCH

DATE: 26-05-08

NAME OF RESEARCH WORKER: Lonwabo L. Godlwana

TITLE OF RESEARCH PROJECT The impact of lower limb amputation on quality of life

OBJECTIVES OF STUDY (Briefly or [✓ include a protocol]): Please see attached protocol.

METHODOLOGY (Briefly or [✓ include a protocol]): Please see attached protocol

CONFIDENTIALITY OF PATIENTS MAINTAINED: Yes

COSTS TO THE HOSPITAL: NONE

APPROVAL OF HEAD OF DEPARTMENT:

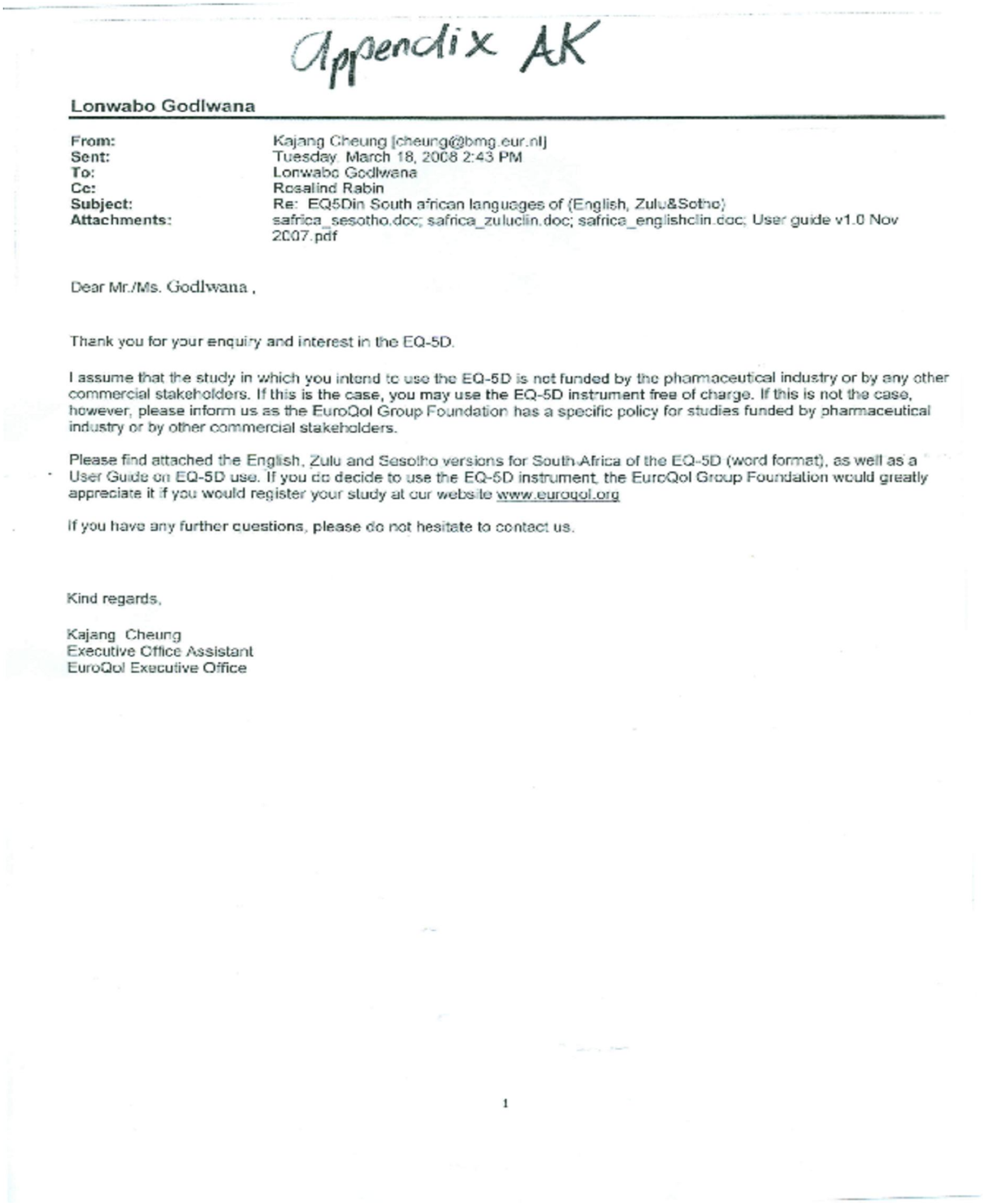
APPROVAL OF CRHS OF WITS UNIVERSITY: Yes (M 08 04 22) See attached certificate.

SUPERINTENDENT PERMISSION:

Signature: Date: 24-05-08

Subject to any restrictions: NONE

Appendix AK- Permission to use the EQ-5D



Appendix AK

Lonwabo Godlwana

From: Kajang Cheung [cheung@bmg.eur.nl]
Sent: Tuesday, March 18, 2008 2:43 PM
To: Lonwabo Godlwana
Cc: Rosalind Rabin
Subject: Re: EQ5Din South african languages of (English, Zulu&Sotho)
Attachments: safrica_sesotho.doc; safrica_zuluclin.doc; safrica_englishclin.doc; User guide v1.0 Nov 2007.pdf

Dear Mr./Ms. Godlwana ,

Thank you for your enquiry and interest in the EQ-5D.

I assume that the study in which you intend to use the EQ-5D is not funded by the pharmaceutical industry or by any other commercial stakeholders. If this is the case, you may use the EQ-5D instrument free of charge. If this is not the case, however, please inform us as the EuroQol Group Foundation has a specific policy for studies funded by pharmaceutical industry or by other commercial stakeholders.

Please find attached the English, Zulu and Sesotho versions for South-Africa of the EQ-5D (word format), as well as a User Guide on EQ-5D use. If you do decide to use the EQ-5D instrument, the EuroQol Group Foundation would greatly appreciate it if you would register your study at our website www.euroqol.org

If you have any further questions, please do not hesitate to contact us.

Kind regards,

Kajang Cheung
Executive Office Assistant
EuroQol Executive Office

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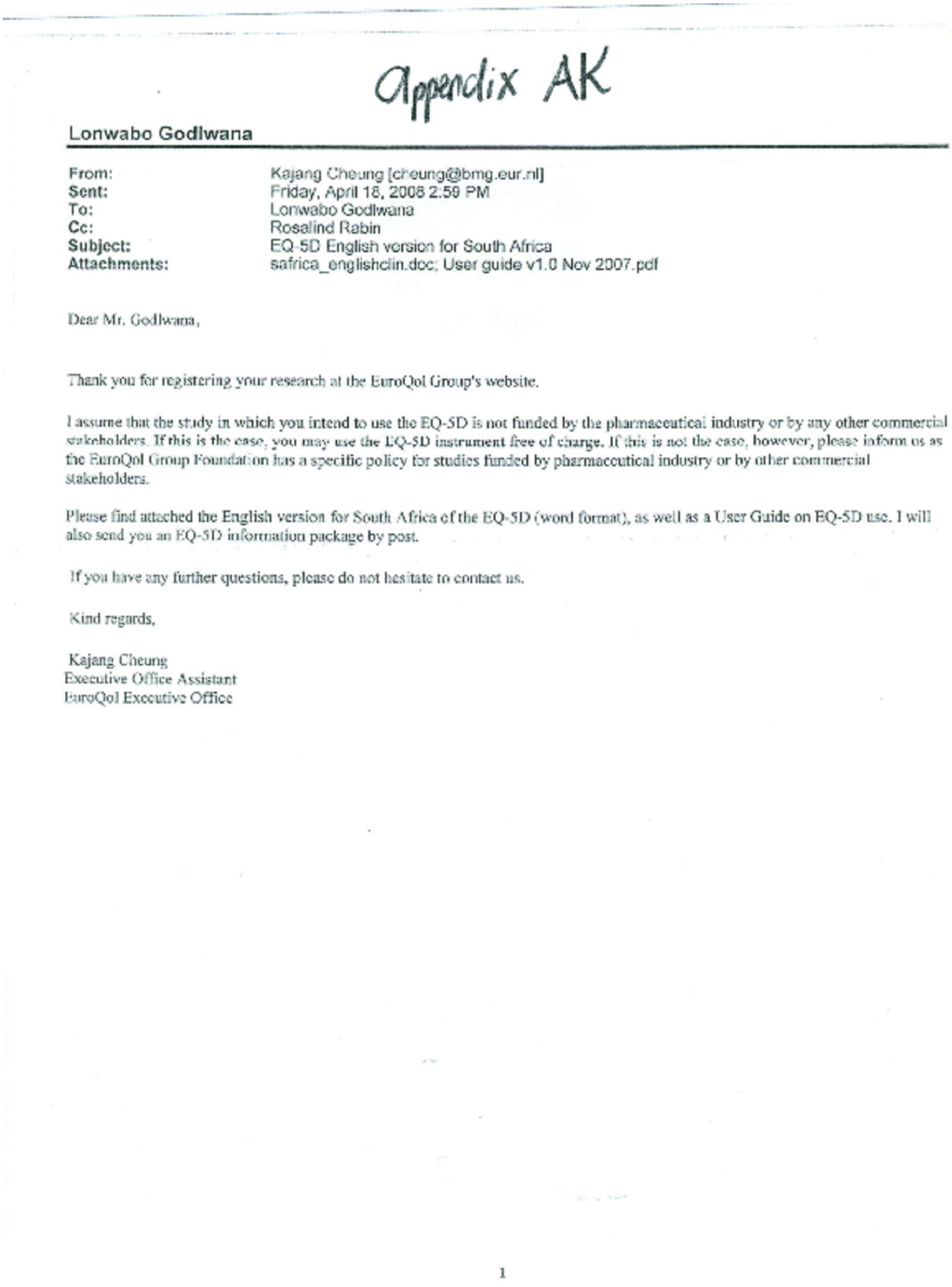


Appendix AK

Lonwabo Godlwana

From:	Kajang Cheung [cheung@bmg.eur.nl]
Sent:	Friday, April 18, 2008 2:59 PM
To:	Lonwabo Godlwana
Cc:	Rosalind Rabin
Subject:	EQ-5D English version for South Africa
Attachments:	safrica_englishclin.doc; User guide v1.0 Nov 2007.pdf

Dear Mr. Godlwana,

Thank you for registering your research at the EuroQol Group's website.

I assume that the study in which you intend to use the EQ-5D is not funded by the pharmaceutical industry or by any other commercial stakeholders. If this is the case, you may use the EQ-5D instrument free of charge. If this is not the case, however, please inform us as the EuroQol Group Foundation has a specific policy for studies funded by pharmaceutical industry or by other commercial stakeholders.

Please find attached the English version for South Africa of the EQ-5D (word format), as well as a User Guide on EQ-5D use. I will also send you an EQ-5D information package by post.

If you have any further questions, please do not hesitate to contact us.

Kind regards,

Kajang Cheung
Executive Office Assistant
EuroQol Executive Office

Appendix AL- In-depth interview with a participant

Chbh130109A

3.1 Ever since I had the amputation, I have been fine, I no longer have that pain that used to traumatize me emotionally. I am facing a couple of challenges out there, in the streets people say a lot of things, some of which hurt me. But I don't care about those as long as I am well. I am still going to live my life. Its not that my mind or hands are injured, its just the leg.

I will apply for an artificial leg and all will be well, things will go back to normal. I will then be able to strive for a better life. Having to face the challenges of life is not a big problem. I wish that I can process my things with the Drs and get the artificial leg. Especially because sometimes there are things I need to do and they need me to be able to balance, just if I can get two legs. Having one leg is a bit disturbing so it would be easy if I get an artificial leg. In that way I will be able to do my things and walk easier.

I used to sell stuff and try by all means to live but now the distances are a challenge to walk. My leg gets tired when I walk. I then end up getting pains from it and I than have to stop there and wait for the pain to subside. Now my things come to a stand still but if I can get the other leg, things would be easier.

Feelings

I feel fine, that is why I said I was happy to have the leg that was traumatizing me amputated. Ever since my amputation, I no longer have that pain I suffered from. With those pains, I couldn't sleep at night, and even during the day I still couldn't sleep. Ever since the amputation, I have been thinking, now I have minor pains and I just need to take tablets, and take care of yourself and stop smoking. You must nurse yourself and deprive yourself the nice time, then you will get better. You must get to a stage where you feel you are getting better and not force matters. You must avoid doing things that do not go hand in hand with your current state of health. Nurse yourself, take is easy you see? So you can have a better life.

3.2 Home

I am facing a lot of challenges, I used to have a lot of friends but now, ever since I got back from the hospital, I have very few friends. The ones I have always been with and sharing things with. Its those things and at times people crack jokes in ways that I don't like and as a person you try disregard them. They didn't cause this and you also didn't cause this. People tend to make joke about your situation and they do not even know you. This seems to fascinate some of them and others empathise with you. Other understand that this is no playing matter. Those are some of the challenges but like I told you, I will be fine after getting the artificial leg.

How do you feel about these jokes?

The way I feel, I've told myself that, life is like that. Its like that, life is like that, I have tried to stop these jokes in the beginning when I had just been back from the hospital. I used to really take them personal, I used to get furious or aggressive. I was not good but somebody set me down and told me that if I listen to all these comments about me I will end up fighting everybody. In one month, how many people are you going to fight with? This person sat me down and told me that I must disregard such things. You must avoid such, and ignore such people, God will sort them out.

3.2 Home and society

At the moment here at home all is well, they nurse me and they help me when I need them to. In the community there are those with their issues but also there are those that treat me like the way I get treated at home. Here at home I have no problem, I have my nieces and sisters. When I have a problem I let them know, much as I train myself so that I am not nuisance to them. So I can be able to do things myself and not keep on complaining.

3.1Qol

I can say that my quality of life at the moment is fine but at times it changes and I don't feel so well. But I have told myself that as a person, I must be brave and even though you are in pain you must not withdraw because of that pain. You must take that pain so that your body can get used to it. You see?

As a person, when you are ill you must not tell yourself that you are ill, take care of yourself, be brave, be brave otherwise its going to be a problem. I can feel it (qol), it tends to control me and that's why I wrote 60% because I know my state of health is not yet back to normal. At the moment its lacking, my state of health is lacking, I wouldn't say its 100% because its not what it used to be. But you must take care of yourself, take your treatment and your tablets all the time, you see?

3.2Home

At the moments its alright, I wouldn't say there are any problems but sometimes there are things that come to mind and you find that you are happy and sometime you are not happy, you see? In my situation, I have told myself that whatever has happened is done, you see? I mustn't worry because if I worry I will always be unhappy, angry at people and irritable. But as a people you must just tell yourself that what has happened is there to stay. That will save you a lot of problems. You shouldn't take a problem that is not yours and put it in your mind, its going to be difficult to deal with as time goes on, you see? I have told myself that I will live with this and its part of my life. I have accepted it, its my life. I don't know, maybe it was a blessing in disguise, you see? So I can't say that I have no problem, I will strive for a better life, so that everything can be just the way I have always wanted it to be.

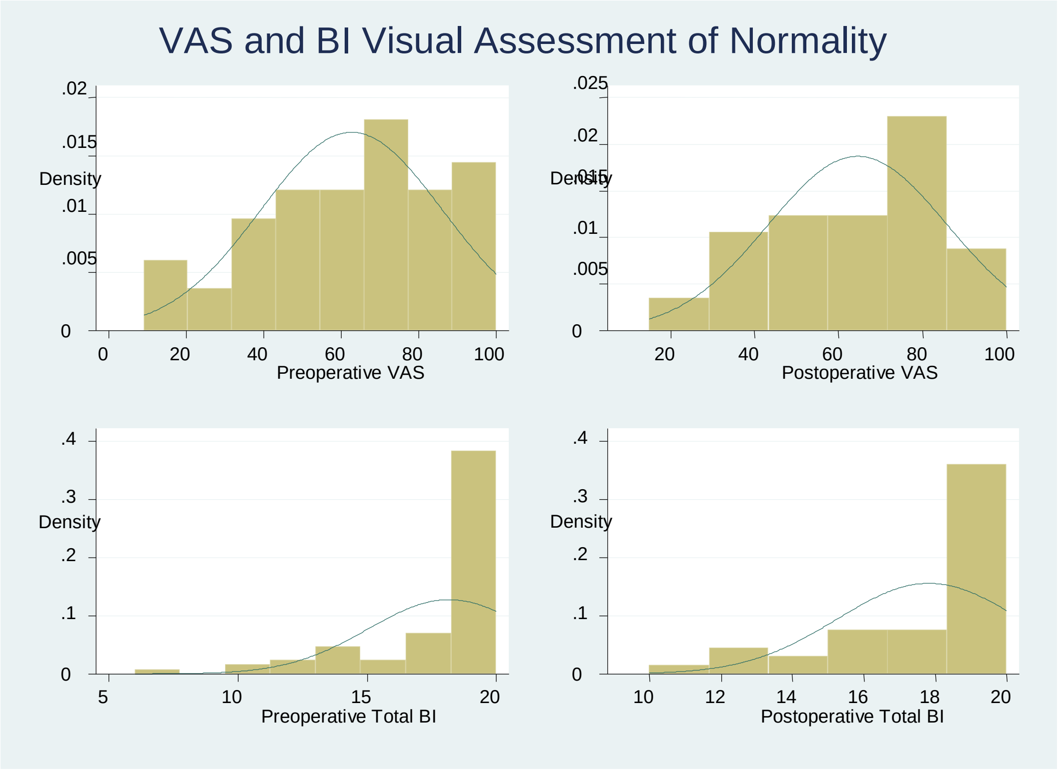
When I say I have accepted I mean I have come to terms with what has happened although I didn't plan it. At the beginning it was the pain, now it's the embarrassment (amahloni). When I was still in the hospital, I used to think, what will the community say? What will my girlfriends say? People close to me? But I told myself that I didn't cause this and they also didn't cause it, you see? I also didn’t know that one day I will be in this situation. So that’s why I am saying I have come in to terms with this. There is no other way.

My leg is gone now and it will never grow again, that’s why I said I have accepted this. Thats why I say if I can just get the artificial leg, my heart would be very thankful and forget about this. Constantly thinking about not having a leg and that I walk with one leg. Even these crutches are bothering me, they take me out of form, that’s why I am striving to get an artificial leg.

3.3 Nothing to add

General observations: Participant generally positive and did not seem stressed. He seemed really willing to face the new situation regardless of the challenges he is facing. At no point did he show any form of extreme negative psychological reaction.

Appendix AM- Distribution of the EQ-5D VAS and BI scores



Distribution of the data

Appendix AN

	Preoperative VAS	Postoperative VAS (n=40)	
Percentile	(n=40)	(n=40)	p-value
25%	50	50	p=0.6
50% (Median)	60	70	
75%	80	80	
Mean (±SD)	64.58 (±21.29)	64.58 (±21.29)	

Data comparing the survivors (n=40) and those who died (n=24)

	Mean (±SD) and percentiles (n=40)	Mean (±SD) and percentiles (n=24)	p-value
Age	Mean 52.9 (±8.61) 47- 25th 52-50th 58.5-75th	Mean 58.54 (±7.27) 52-25th 59-50th 63.5-75th	0.009
Total BI	Mean 19.15 (±2.19) 19.5-25th 20-50th 20-75th	Mean 16.92 (±3.91) 13.5-25th 19-50th 20-75th	0.01
VAS	Mean 62.88 (±22.12) 50-25th 60-50th 80-75th	Mean 67.5 (±24.14) 50-25th 70-50th 85-75th	0.4(NS)

Social habits	**Preoperatively**	**Preoperatively**	
	n=40 (survivors)	**n= 24 (Deaths)**	**p-value**
Use of alcohol Yes No	 n=21(52.5%) n=19(47.5%)	 n= 9 (37.5%) n= 15 (62.5%)	0.02
Smoking Yes No	 n=21(52.5%) n=19(47.5%)	 n= 10 (41.8%) n= 14 (58.3%)	0.03

Appendix AO

	Preoperative BI	Postoperative BI (n=40)	
Percentile	(n=40)	(n=40)	p-value
25%	19.5	17	p<0.001
50% (Median)	20	19	
75%	20	20	
Mean (±SD)	19.15(±2.19)	17.83(±2.56)	