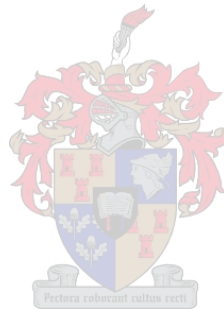


**DESCRIPTION AND EVALUATION OF THE REHABILITATION PROGRAMME FOR
PERSONS WITH LOWER LIMB AMPUTATIONS AT ELANGENI, PAARL, SOUTH AFRICA**

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**Thesis presentation in partial fulfilment of the requirements of the degree of M Phil
Majoring in Rehabilitation at the University of Stellenbosch**



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March 2012

Declaration

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in this entirety or in part submitted it for obtaining any qualification.

Date: March 2012

Abstract

Lower limb amputations cause multiple physical, psychological, environmental and socio-economic barriers. Individuals who have suffered a lower limb amputation require comprehensive rehabilitation to ensure social integration and economic self-sufficiency. In addition, constant monitoring and evaluation is an essential part of human service delivery programmes. However, the amputation rehabilitation programme offered at Elangeni an out-patient rehabilitation centre for clients with physical disabilities in Paarl, Western Cape, South Africa is not monitored, and has not been evaluated since its inception in 2000. Thus, the current study evolved to describe and evaluate the rehabilitation programme for persons with lower limb amputations at Elangeni.

A mixed method descriptive design was implemented. All persons who received rehabilitation, after a major lower limb amputation at Elangeni, between 2000 to 2011, were included in the study population. In addition, the physiotherapist and occupational therapist that provided amputation rehabilitation at Elangeni, at the time of the study, were interviewed. Thirty participants who met the study inclusion criteria were identified. Quantitative data was collected using a researcher designed, structured demographic questionnaire, an International Classification of Function checklist based questionnaire and a participant rehabilitation folder audit form. Two interview schedules one for clients and one for therapists were used for guidance during semi structured interviews. Quantitative data was entered onto a spread sheet and analysed by a statistician using Statistica, version 8. Qualitative data was thematically analysed according to predetermined themes.

No programme vision, mission or objectives could be identified for the amputation rehabilitation programme. Poor record keeping practices and a lack of statistics were found. Rehabilitation was impairment focused with no attention given to social integration. Clients who received prosthetic rehabilitation showed improved functional ability with regard to picking up objects from the floor ($p = 0.031$) getting up from the floor ($p = 0.00069$), getting out of the house ($p = 0.023$), going up and down stairs with a handrail ($p = 0.037$) and moving around in the yard ($p = 0.0069$), climbing stairs without a handrail ($p = 0.037$), going up and down a kerb ($p = 0.0082$) walking or propelling a wheelchair more than 1km (0.0089) and walking in inclement weather (0.017).

A lack of indoor mobility training had a statistically significant negative impact on the participants' ability to lift and carry objects ($p = 0.011$), standing up from sitting ($p = 0.042$), getting around inside the house ($p = 0.00023$), picking up objects from the floor ($p = 0.00068$), getting up from the floor ($p = 0.0072$), getting out of the house ($p = 0.0016$), going up and down stairs with a handrail ($p = 0.019$), moving around in the yard ($p = 0.0013$), going up and down stairs with-out a hand-rail ($p = 0.019$), getting up and down a kerb ($p = 0.0022$), walking or wheeling 1km or more ($p = 0.0032$) and using transport ($p = 0.0034$). Failure to address community mobility during rehabilitation had a statistically significant negative impact on all aspects of community mobility scores except doing transfers and driving.

In conclusion, for the study participants, Elangeni failed to provide rehabilitation according to the social model of disability and Community Based Rehabilitation principles. It is recommended that managers, service providers, and clients re-consider the purpose of Elangeni and develop a vision and objectives for that service. In addition, management should take an active role in service monitoring and evaluation and provide guidance and mentorship to therapists.

Key terms

Lower limb amputation, rehabilitation, program evaluation

Abstrak

Onderste ledemate amputasies impak negatief op 'n persoon se fisiese, sielkundige en sosiale funksionering. Individue wat 'n amputasie ondergaan het benodig omvattende rehabilitasie om sosiale integrasie en ekonomiese onafhanklikheid te verseker. Konstante monitering en evaluasie is 'n essensiële deel van rehabilitasie programme. Nietemin die amputasie rehabilitasie program wat by Elangeni aangebied word, word nie gemoniteer nie en was nog nooit geëvalueer nie. Dus het hierdie studie dit ten doel om die rehabilitasie programme vir persone met onderste ledemate amputasies by Elangeni te beskryf en te evalueer.

Kwantitatiewe en kwalitatiewe navorsingsmetodes is in kombinasie gebruik in die studie. Alle persone wat rehabilitasie by Elangeni ontvang het na 'n onderste ledemaat amputasie, sowel as die terapeute wat by Elangeni werk, het die studie populasie gevorm. In totaal het 32 persone aan die studie deelgeneem. Kwantitatiewe data is met behulp van 'n demografiese vraelys, 'n ICF gebaseerde vraelys, en 'n leer oudit vorm ingesamel. Twee onderhoud skedules, een vir die kliënte en een vir die terapeute, is gebruik as riglyn tydens insameling van kwalitatiewe data. Kwantitatiewe data is statisties ontleed deur 'n statistikus wat gebruik gemaak het van Statistica 8. Voorafbepaalde temas is gebruik tydens tematies ontleding van kwalitatiewe data.

Geen program visie, missie of doelwitte kon geïdentifiseer word nie. Swak rekord houdings praktyke was gevind. Rehabilitasie het gefokus op die fisiese en nie op sosiale integrasie nie. Die kliënte wat prostetiese rehabilitasie ontvang het, het statisties beduidend beter gevaar ten opsigte van optel van voorwerpe van die vloer af ($p = 0.031$), om van die vloer af op te staan ($p = 0.00069$), om uit die huis uit te kom ($p = 0.023$), om trappe met 'n handreling te klim ($p = 0.037$), om op die erf rond te beweeg ($p = 0.0069$), om trappe sonder 'n reling te klim ($p = 0.037$), om by sypaadjies op en af te gaan ($p = 0.0082$), om meer as 'n kilometer te loop of met die rolstoele te ry (0.0089) en om in ongure weer te loop (0.017).

'n Tekort aan heropleiding van mobiliteit binne die huis het 'n statisties beduidende impak gehad op die vermoë om goed te dra ($p = 0.011$), op te staan van sit af ($p = 0.042$), in die huis rond te beweeg ($p = 0.00023$), voorwerpe van die vloer af op te tel ($p = 0.00068$), van die vloer af op te staan ($p = 0.0072$), uit die huis uit te kom ($p = 0.0016$), trappe met 'n handreling

te klim ($p = 0.019$), in die erf rond te beweeg (0.0013), trappe sonder 'n handreling te klim ($p = 0.019$), by 'n sypaadjie op en af te gaan ($p = 0.0022$), meer as 1km te loop of met die rystoel te ry ($p = 0.0032$) en om vervoer te gebruik ($p = 0.0034$). 'n Gebrek aan heropleiding van gemeenskapsmobiliteit het 'n statisties negatiewe impak gehad op alle aspekte van gemeenskapsintegrasie behalwe die doen van oorplasings en bestuur.

Rehabilitasie praktyke was nie gebaseer op die sosiale model van gestremdheid en Gemeenskap Gebaseerde Rehabilitasie beginsels nie. Dit word aanbeveel dat diens verskaffers, kliënte en bestuurders oor die fokus van rehabilitasie by Elangeni moet besin. Daar moet 'n visie en doelwitte vir die diens ontwikkel word. Voorts moet bestuurders van distrik vlak 'n aktiewe rol speel in die monitering en evaluasie van dienste en mentorskap aan terapeute verseker.

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Glossary of terms

Amputation

An amputation is a complete loss in the transverse anatomical plane of any part of a limb for any reason (Godlwana, Nadasan and Puckree, 2008).

Community based rehabilitation

Community based rehabilitation (CBR) is a strategy within community development for the rehabilitation, equalization of opportunities, poverty reduction and social integration of people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities and the appropriate health, education vocational and social services (Joint position paper: ILO, UNESCO, WHO, 2004).

Community integration

Community integration is an advanced rehabilitation outcome where the person with the disability has the ability to function in the community. This includes self-directed management of personal affairs, community mobility, social competency, self-directed health monitoring, the ability to manage one's own finances and participation in recreational activities (Landrum, Schmidt, & Mclean, 1995).

Participation

Participation is the involvement in a life situation (WHO, 2001).

Programme

A programme is a series of steps to be carried out, or goals to be accomplished, or services intended to meet a public need.

<http://www.google.co.za/search?hl=en&defl=en&q=define:program&ei=ArnASezgB>

Programme Effectiveness

Programme effectiveness focus on the outcomes of a programme as illustrated by the results, impacts and accomplishments of the programme (Martin & Kettner 1996).

Programme Efficiency

Programme efficiency focuses on the outputs of a programme and is determined by the amount of services that are provided and the numbers of clients completing the programme in comparison to the inputs e.g. cost involved (Martin & Kettner 1996).

Program Evaluation

A process of measuring to describe, predict and evaluate in order to provide benchmarks and summarize change related to the condition and care of individuals within a programme (Wade, 2004).

Programme Quality

The quality of a programme can be determined by the number of outputs that met a specified quality standard in comparison to inputs (Martin & Kettner 1996).

Rehabilitation

Rehabilitation is a goal-orientated and time-limited process aimed at enabling an impaired person to reach an optimum mental, sensory, intellectual, physical and/or social functional level, to change their lives towards a higher level of independence, through providing the person with the tools to change her or his own life. This can involve measures intended to compensate for a loss of function or a functional limitation (for example by technical aids) and measures intended to facilitate social adjustments or readjustments (Office of the Deputy President, 1997; Department of Health, 2000).

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List of abbreviations

ADL	Activities of Daily Living
CBR	Community Based Rehabilitation
CCRD	Centre for Community Research and Development
CHCC	Community Health Care Centre
CHIEF	Craig Hospital Inventory of Environmental Factors
CVA	Cerebro Vascular Accident
DAS II	Disability Assessment Schedule
DM	Diabetes Mellitus
DOH	Department of Health
HPCSA	Health Professionals Council of South Africa
ICF	International Classification of Function, Disability and Health
ILO	International Labour Organisation
INDS	Integrated National Disability Strategy
LCI	Locomotor Capabilities Index
NRP	National Rehabilitation Policy
PGWC	Provincial Government of the Western Cape
PVD	Peripheral Vascular Disease
SA	South Africa
SANPAD	South Africa Netherlands Research Programme
SCI	Spinal Cord Injury
TAG	Technical Assistance Guidelines
TBI	Traumatic Brain Injury
UK	United Kingdom
UNESCO	United Nations Educational Scientific and Cultural Organisation
WHO	World Health Organisation
WPA	World Programme of Action
WCDoH	Western Cape Department of Health
WCP	Western Cape Province
WCRC	Western Cape Rehabilitation Centre

Chapter 1

Introduction

1.1 Study Outline

In chapter one, information on the background of the study, the study population, the motivation for undertaking the study and the significance of the study is presented. Chapter two consists of a review of the relevant literature. Chapter three describes the research design and methodology. The results of the study are presented in chapter four, which is followed by a discussion of the results in chapter five. The document is brought to a close with chapter six which consists of a discussion of the conclusions drawn from the study and the resulting recommendations.

1.2 Background to the study

Amputations have been with us from the earliest times and it is still sometimes the only option left to surgeons if a limb has been damaged to a point where it has lost viability. Evidence has been found that amputations were carried out as early as the Neolithic period with knives and bone saws (Engstrom & Van de Ven 1999). Amputations become necessary as a result of vascular diseases, diabetes, trauma, tumours, infection and congenital deformities. Of all the foregoing conditions, vascular diseases and diabetes are generally the main reasons for amputations (Pedretti, 2006; Godlwana, Nadasan and Puckree, 2008; Gutacker, Neumann, Santosa, Moysidis & Kröger, 2010).

The impact that the amputation has on the individual's life can be devastating since the amputation of a limb is likely to be accompanied by a profound sense of loss. Amputees have to come to terms with the loss of a limb and their resultant changed body image, discomfort, inconvenience, expenses, loss of function, especially mobility, and restrictions in terms of leisure and productive activities. Socio-culturally, amputees may experience discrimination, stereotyping and adverse reactions to the amputation which can lead to self-hatred and self-deprecation. It is not uncommon for an individual to feel self-pity, anxiety, shock, grief, depression, anger, frustration and a sense of futility in response to an amputation (Pedretti, 2006; Unwin, Kacperek and Clark, 2009; Manderson & Warren 2010).

Therefore, comprehensive rehabilitation is very important not only to retrain physical and functional abilities, but also to assist with psychological and emotional adjustment issues, as well as, social and community integration (Manderson & Warren, 2010). The medical management of amputation clients can be divided into three phases namely; the pre-operative phase, the acute post-operative phase and the rehabilitation phase according to (Manderson & Warren, 2010). The focus of the current study is on the rehabilitation phase as provided at the primary level of health care.

Health care services in the Western Cape Province and the rest of South Africa should be provided along a continuum of care from primary health care to secondary to tertiary levels of service provision (Office of the deputy president, 1997; Western Cape (WC) Health 2007, 2010). Elangeni Physical Rehabilitation Centre (Elangeni), in Paarl, Western Cape, South Africa, the setting of the current study, is situated at the primary health care level. According to South African National Policy, primary level rehabilitation should adhere to the principles of community based rehabilitation (CBR) (National Department of Health (DoH) 2000; Western Cape DoH 2007).

Therefore, in accordance with the above documents, the rehabilitation programmes at Elangeni should be accessible and affordable to all the people within the community that it serves. Furthermore, it should, by empowering clients and families as well as the community, ensure social integration and equal opportunities for all its disabled clients. In order to achieve this, rehabilitation programmes offered at Elangeni should take place both at a community and an individual level (DoH, 2000, Joint position paper: ILO, UNESCO, WHO, 2004). The ultimate aim of individual programmes should be community integration and the productive activity of the client according to the National Rehabilitation Policy (NRP) (DoH, 2000). During this phase measures to assist the client to participate in his/her social roles must be implemented. For persons who have had an amputation this can range from mobility retraining with or without prostheses, to addressing environmental barriers.

Historically, in the Paarl area, rehabilitation services were delivered at Paarl hospital, a secondary referral hospital, and at TC Newman hospital, a primary health care facility. These services focused predominantly on individual therapy and were rendered within the medical model approach. The medical model focused on the correction of impairments and

disabilities (Mackelprang, 2010). Little attention was paid to the role of the environment, and on facilitating social integration. There was also no collaboration with other departments like transport, education and labour (Office of the Deputy President, 1997). As a result, most disabled people living in the Paarl area were socially excluded and had to face barriers like inaccessible buildings, unemployment and discrimination.

Rehabilitation services at Elangeni were initiated ten years ago with a view to addressing these issues, and to ensure inclusion and the equalization of opportunities through the implementation of the social model of rehabilitation and the initiation of CBR programmes (Mr Cupido, Director Health Western Cape, during his speech at the opening of Elangeni in 2000).

An essential part of CBR and other human service programmes is constant programme monitoring and evaluation (DoH, 2000; UN, 2006). One cannot answer questions on the appropriateness, relevance, effectiveness, efficiency and quality of a programme if it is not monitored and evaluated on an ongoing basis. Furthermore, one cannot continuously improve a programme if feedback on its current performance and challenges is unavailable (Martin & Kettner 1996; Velema & Cornielje, 2003). Evaluation is important to maximise programme potential and for guidance during the implementation of similar or new initiatives. The monitoring procedure should provide continuous feedback on how the different resources are being utilised within a programme. In addition, it should highlight problems in planning, implementation and outcomes. To improve current activities and to promote better planning, the lessons learned from evaluation should be utilized by the careful selection of alternatives for future action (DoH, 2000)

1.3 Study problem

It is not clear how successful Elangeni is in the implementation of its ideals since none of the programmes being offered at Elangeni have been described in terms of inputs and processes, and no programme monitoring or assessment is being done at Elangeni. Therefore, the managers and therapists do not know whether the rehabilitation programmes are appropriate, relevant, effective, efficient and of acceptable quality. While Elangeni's objectives apparently focus on issues like the prevention of secondary complications, reintegration into the community and addressing contextual barriers, there is no way to tell if these objectives are being met.

This study aims to initiate a process of programme evaluation at Elangeni by describing the amputee rehabilitation programme at Elangeni and implementing various measuring instruments to determine if programme objectives are being met. Simultaneously, the instruments used in the study will be assessed for suitability for use in future programme evaluation and monitoring at Elangeni.

1.4 Motivation for undertaking the study and possible contribution of the study

The researcher held his first professional placement as rehabilitation therapist at Elangeni and he wanted to use the knowledge and experience that he gained during his time there to give something back to Elangeni and the Paarl community. Thus, this study evolved with the purpose of contributing to the improvement and quality of the programmes that rendered at Elangeni.

The study will provide the management team at Elangeni with a detailed description of the amputee rehabilitation programme. Findings highlight both the strengths and challenges of the programme and serve as an indication of whether money is well spent or not. Furthermore, the findings will assist with future planning and provide a basis for recommendations for strategies or interventions to improve the effectiveness, efficiency and quality of the amputee rehabilitation services rendered. Findings may also assist with motivation for resources and to provide guidance on how to distribute these resources for the optimum benefit of the amputation clients in this setting (Joubert and Ehrlich, 2007).

The results of this study will provide a conceptual framework which rehabilitation managers at Elangeni can apply to describe and evaluate other rehabilitation programmes at Elangeni. Furthermore, this information can be used in the development of a process for continuing the performance management of Elangeni's programmes. Both positive findings and a move to address challenges will be used to win the trust and the support of all the stakeholders involved.

The study will also serve to provide publicity for Elangeni. It will raise awareness of the centre and promote the programmes that are offered there. This will in turn give recognition to the staff and management of Elangeni for the work that is done at the centre and assist in boosting their self-confidence and self-esteem.

In addition, the findings of the study can be used for comparison with other outpatient rehabilitation programmes at similar institutions for example the Bishop Lavis Community Health Centre in Bishop Lavis, Western Cape, South Africa. The programmes at Bishop Lavis will be scrutinised through another research project (SANPAD Proposal, 2008), and an international amputee rehabilitation programme, as described by Mandeson & Warren (2010). These comparisons will enable programme developers at Elangeni to assess which areas of the programme are on par with national and international programmes in the field of amputee rehabilitation and which areas need attention.

At the same time the results of the study will inform programme developers whether the programme adheres to the CBR philosophy and the gold standard for rehabilitation programmes in South Africa as set out by the NRP (DOH, 2000). Does the programme;

- Lead to improved accessibility of rehabilitation services for people who suffer from conditions that can lead to disabilities and those who are living with disabilities;
- Establish mechanisms for intersectional collaboration to implement a comprehensive rehabilitation programme;
- Meet the needs of both the service provider and the consumer

By using this information changes to further improve the programme and align it with CBR and NRP policy can be initiated.

From the literature search it seems as if very few rehabilitation programmes at all levels of health care in South Africa (SA) are being monitored and evaluated. This study will serve to raise awareness regarding the need for monitoring and evaluation of rehabilitation programmes as well as provide some structure on how to go about this type of research.

In addition the WHO Report on Disability (2011) identified a lack of reliable research and calls for research on rehabilitation programmes and policies. This report specifically mentions a need for evidence on the effectiveness of interventions and programmes since evidence based knowledge can guide policy makers in the development of appropriate programmes and assist service providers to choose suitable interventions (WHO, 2011).

Universities can use the findings of the study to teach students about amputee management as well as the importance of programme description, monitoring and evaluation and how to implement these aspects in their own work settings once they are qualified.

1.5 Summary

Individuals who have suffered a lower limb amputation face multiple barriers on various levels such as physical, psychological, emotional and environmental. Therefore, comprehensive rehabilitation services are required. Amputation is one of the impairments being treated during rehabilitation at Elangeni, an outpatient facility with the vision of providing rehabilitation programmes according to CBR and NRP guidelines. However, the amputation rehabilitation programme is not monitored and no information on its effectiveness is available. Thus, the current study evolved in order to measure the performance of this programme with a view to describing it and providing information on possible improvements as well as future monitoring and evaluation processes.

Chapter 2

Review of the relevant literature

2.1 Introduction

The focus of the current study is on a rehabilitation programme for post lower limb amputation. Thus, during the review of the literature, an overview on lower limb amputations with regard to incidence, prevalence and causes is discussed to provide background information against which rehabilitation post amputation will then be presented. This overview is followed by a description from the literature of the aspects to be provided by an amputation rehabilitation programme. These include prevention of secondary complications, mobility preparation and retraining, psychological counselling, community integration and employment. Finally, the researcher will look at rehabilitation services, amputation rehabilitation programmes and programme evaluation in South Africa.

An amputation can be seen as an archetypal impairment since it is visible with a large impact on external appearance and the individual's self-image, emotional status and quality of life (Asano, Rushton, Miller & Deathe, 2008; Manderson & Warren, 2010). The functional ability of the individual is often adversely affected, and it has a negative effect on productivity and social engagement (Manderson & Warren, 2010). Post amputation outcomes are affected by various variables such as age, level of amputation, cause of amputation, level of mobility and rehabilitation services (Kidmas, Nwadiaro, Igun, 2004). The literature (Asano et al, 2008; Basu, Fassidis and McIrvine, 2008) indicated a direct relationship between a person's quality of life and their level of mobility following a lower limb amputation. Other aspects which impacted negatively on personal quality of life post lower limb amputation were depression, lack of social support, presence of co-morbidities, decreased social participation, problems with prostheses and age (Asano et al, 2008). Some factors like age, social support and co-morbidities are not modifiable. However, all the modifiable factors such as mobility, depression, social participation and prosthetic problems should be addressed through a rehabilitation programme (Manderson & Warren, 2010).

2.2 Incidence and prevalence of amputations

The Global Lower Extremity Amputation Study Group that functions over national boundaries provides information on major lower limb amputation rates from countries as diverse as Japan, Taiwan, Spain, Italy, North America and England. The Navajo population, in the United States of America, have at 43.9 per 100,000 people per year incidence, the highest amputation incidence rates in the world. The population from Madrid, Spain has a 2.8 per 100,000 population per year the lowest rate (Global Lower Extremity Amputation Study Group, 2000).

Data from other countries includes figures from Germany where a national survey found that a total of 62 880 amputations affecting the lower extremity were performed in 2006 and 63 005 in 2005 (Gutacker et al, 2010). According to Rommers (2000) an estimated 3300 lower extremity amputations are performed every year in the Netherlands.

The researcher struggled to find any incidence figures for Africa or South Africa (SA). What he could find came from a study done in the nineteen eighties at Tygerberg Hospital, a tertiary hospital in the Western Cape Province. While the researcher presents these figures in lieu of any more recent information readers should be warned to treat the findings with caution since it hails from before the 1994 democratic elections in SA. It is important to keep this in mind since health care services in the country have since been restructured with a focus on primary health care and the decentralisation of many services from tertiary to primary level (Kautzky & Tollman, 2008). However, an amputation represents major surgery and is therefore not performed at primary level with the result that the researcher considers the figures from a tertiary hospital, though dated, still provide useful information. According to this hospital based survey 597 major lower limb amputations were performed over the 3 year period from 1985 – 1987 (Hendry, 1993). The data further indicated an upward trend in the number of amputations performed per year over the three years.

With age, the incidence of amputations increases and the average age of amputees is usually 60 or older (Gutacker et al, 2010; Asano et al, 2008; Ayhan, Reyhan, Metin, Fusun & Yetkin, 2004). However, a study from Nigeria, Africa, found a mean age of 44, 5 (Kidmas et al, 2004) and Bakkes (1999) found a mean age of 48 years in a study on a selected population in the Western Cape Province of South Africa. Both these studies have noted a high incidence of

traumatic amputations which might be the reason for the younger average age (Bakkes, 1999; Kidmas et al, 2004). Participants in the study by Bakkes (1999) all suffered from above knee amputations and were treated as either in or outpatients at the then Centre for Care and Rehabilitation of the Disabled (CCRD), University of Stellenbosch, over a five year period spanning 1993 to 1998 (Bakkes, 1999). In contrast to these two findings from Africa, Hendry (1993) found in the Tygerberg study, mentioned above, a mean age of 60.3 years.

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

In addition the impact of vascular diseases and Diabetes Mellitus (DM) on the body is high and a one year mortality rate of 13.7% was reported in clients who suffered an amputation due to vascular causes (Basu et al, 2008). These diseases also lead to a high incidence of further amputations as 9 – 20% of people suffered a second amputation within one year after the first, while 28 – 51% underwent a second amputation within five years of the first (Gayle & Reiber, 1995).

2.3 Causes of Amputations

According to literature the primary cause of lower limb amputation in industrialised countries is peripheral vascular disease which might or might not be complicated by Diabetes Mellitus (Ray, Valentine, Secnik, Oglesby, Cordony, Gordois and Palmer, 2005; Clark, Kelman and Colagiuri, 2006; Gutacker et al, 2010; Manderson & Warren 2010). On analysis of the clinical records of 1094 clients from Helsinki it was found that all of them underwent major lower limb amputations due to vascular diseases (Gutacker et al, 2010). According to Tate and Forchheimer (2002) in Australia, vascular disease accounts for one third of all amputations of which 40 % is due to DM which is often associated with vascular diseases.

Table 2.1 Causes of amputations in one industrial country and three African settings

	Unwin et al (2009)	Kidmas et al (2004)	Hendry (1993)	Bakkes (1999)**
Setting	UK	Nigeria (Tertiary hospital)	Western Cape (Tertiary Hospital)	Western Cape (Rehabilitation Centre)
PVD & DM	68.7	35.6	82	47
Trauma	18.2	29.9	12	29
Malignancies	3	23	3	6
Infections		7	2	6
Other	9.1	4.5	1	12
	99%*	100%	100%	100%

*Data in the paper referred to add to 99% and no account is given of the missing 1%.

**Only above knee amputees

Table 2.1 shows that in some instances figures from Africa paint a different picture with trauma as cause of amputation increasing (Kidmas et al, 2004). This descriptive study looked at the epidemiology of lower amputations over a five year period, in a tertiary teaching hospital in Nigeria, 94 amputations were performed in the study period, (Kidmas et al, 2004). The authors (Kidmas et al, 2004) ascribe the higher incidence of traumatic amputations in part to gangrene infection in 61% of trauma cases, after they were treated by bone setters for a fracture. Another unusual finding in this study was that malignancies caused 23% of the amputations. Malignancies were often discovered late leading to amputations instead of the use of other treatment modalities (Kidmas et al, 2004).

The only data that the researcher could find for South Africa comes from the study by Hendry (1993) and the study by Bakkes (1999). Findings from Hendry (1993) are more in line with that of industrialised countries than that from Nigeria since 82% of amputations were necessary as a result of vascular disease and 12% as a result of trauma (Hendry, 1993). In 44% of amputations the trauma was caused by pedestrian accidents. Bakkes (1999) found vascular diseases as the most common cause of amputations at 47%. This finding showed a

marked decrease from the findings by Hendry (1993), while trauma showed an increase to 29% (Bakkes, 1999).

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

2.4 Rehabilitation post lower limb amputation

The purpose of rehabilitation is to assist the individual to reintegrate into the community and participate in life roles i.e. to carry on with life as it was before the amputation as far as is possible (Manderson & Warren 2010). This includes the learning of new skills such as caring for ones stump, donning and doffing a prosthesis, and/or wheelchair dexterity and the re-learning of old skills such as walking. Rehabilitation also includes the provision of assistive devices such as prostheses, wheelchairs and crutches, education on health management and the prevention of complications that arise from not maintaining a healthy diet or not taking care of the remaining leg. Finally, rehabilitation should assist the person to regain self-confidence and confidence in their abilities (McColl, Davies, Carlson, Johnston, Minnes, 2001; Schoppen, Boonstra, Groothoff, Van Sonderen, Goeken and Eisma, 2001a; Bruins, Geertzen, Groothof, Schoppen, 2003; Pedretti, 2006; Burger and Marincek, 2007; Manderson & Warren 2010 and WCDoH, 2010).

Successful rehabilitation is dependent on many variables including: comprehensive early post-operative interventions, teamwork, shared goal setting as well as client confidence in the programme and trust in the capability of the rehabilitation professionals (Manderson & Warren 2010; WCDoH, 2010). Rehabilitation goals focus typically on wellness, mobility and independence (Manderson & Warren 2010).

The core professional members of the team include the surgeon, nurse, physiotherapist, occupational therapist, social worker and prosthetist (Visagie 2004; Godlwana et al, 2008; Manderson & Warren 2010 and WC DoH, 2010). Of all these professionals the prosthetist is central in cases where the person will use a prosthetic leg for mobility. The prosthetist must develop a trusting relationship with the client in order for the client to trust the prosthesis. This

relationship is ongoing during the client's lifetime as prostheses require re-fitting, repair and replacement from time to time (Manderson & Warren 2010).

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

2.4.1 Stump care

New amputees may be reluctant to handle their stumps and this must be overcome by a process of familiarisation where the health professionals handles the stump intentionally and continuously for examination, wound care, washing, coning and fitting the prosthesis. Simultaneously, clients are encouraged to touch their stumps by putting on moisturiser, for instance (Manderson & Warren 2010).

Stump care during the rehabilitative phase is recommended as part of prosthetic preparation and to prevent stump infections and wounds. Clients are taught to wash the stump daily with mild soap and water and to dry it thoroughly with a towel, as well as to do stump bandaging in order to reduce oedema, improve venous return, tone flabby tissue and shape the stump conical for future prosthetic fit (Manderson & Warren 2010). Once the clients have received the prosthesis they are also taught to assess the stump on a daily basis for signs of chafing, skin breakdown or blisters (Manderson and Warren, 2010). Should they experience any of these problems they must not wear the prosthesis and should seek immediate medical advice. In most cases the nursing staff is responsible for stump care education, but any of the other team members can also do it (Humm 1997; Engstrom & Van de Ven, 1999; Visagie 2004).

2.4.2 Personal health management and prevention of secondary complications

An essential part of rehabilitation is to ensure that clients understand how to manage their own health and prevent complications that can lead to delayed healing in the stump or cause a need for further medical intervention or even further amputations, a real risk as indicated in 2.2 above (Manderson & Warren 2010).

According to Pedretti (2006) complications most commonly experienced by amputees include stump pain, contractures, soft tissue adhesions, stump wounds, oedema, neuroma and phantom sensations. Further amputations are common in clients with vascular amputations and must be prevented as far as possible (Pedretti, 1996; Godlwana et al 2008). The basis for preventing most of these secondary complications and further amputations is client education. Education includes information for a healthy lifestyle i.e. the risks related to smoking and substance abuse, the importance of a healthy diet and what that entails, the importance of adhering to special dietary guidelines where necessary and of taking medication as prescribed, the importance of regular exercise, how to prevent contractures and wounds as well as to seek medical advice should this happen, how to clean the socket and stump sock if relevant and the importance of proper care of the remaining limb (Visagie 2004; Manderson & Warren 2010). All health care workers are responsible for ensuring that clients have the adequate knowledge and understanding to prevent secondary complications.

Maintaining full range of motion in the stump, especially extension and adduction of the hip joint and extension of the knee when present, is crucial for prosthetic walking (Engstrom & Van de Ven, 1999). The stump range of motion is maintained through active range of motion exercises and the correct positioning of the stump. The client must be taught by the physiotherapist to maintain this independently (Engstrom & Van de Ven, 1999; Visagie 2004; WCDoH, 2010).

According to (Galley, 2004) prosthetic use over a long period of time can bring on its own set of secondary medical problems in the joints of the lower limbs and the spine. On comparing a non-amputee population to an amputee population that uses prostheses, it was found that osteoarthritis or degenerative joint diseases were two to three times more likely in the amputee population. Another secondary problem experienced by the amputee population was

lower back pain. (Gailey, 2004) recommends the following precautions to prevent the above complications:

- The prosthesis should fit correctly at all times
- The prosthetic leg and sound leg should be of an equal height
- The sound leg should not be favoured during walking
- Avoid excessive hopping on the sound leg. In the event that the prosthesis is not being worn the person should make use of crutches
- Always maintain good sitting and standing posture
- A cane can be used to reduce excessive stress on the knee or back if pain is present
- Retain an optimal body weight through a nutritious diet
- Do regular exercises and incorporate cardiovascular endurance, stretching and strengthening in the exercise programme
- Maintain a regular appointment schedule with the doctor, prosthetist and the physiotherapist.

2.4.3 Preparation for mobility retraining

Muscle strength and endurance

For prosthetic walking it is important that all stump muscles are fully innervated and of maximum strength (WCDoH, 2010). The most important muscle groups that need to be strengthened are the hip extensor and abductor muscles as well as the abdominal muscles for core stability. These muscles will in time be taught how to control the prosthesis. Clients require a therapeutic exercise programme, usually provided by the physiotherapist, to regain their muscle strength and endurance (Engstrom & Van de Ven, 1999; Visagie 2004; Manderson & Warren 2010). According to Manderson and Warren (2010) one of the main roles of the physiotherapist is to see that clients with lower limb amputations have adequate balance, muscle strength and physical endurance to enable them to use their prostheses and to perform their daily routines. Donachy, Brannon, Hughes, Seahorn, Crutcher and Christian, (2004) raised the concern that in most instances intensive endurance and resistance weight training is not being made available for clients with lower limb amputations since most of the standard resistance weight machines require bilateral use of the lower limbs.

The strength of the thigh muscles in the transtibial amputees were investigated by several authors in the past according to Moreinfeld, Ayalon, Ben-Sira, Isakov (2000) and Ryser, Erikson, Cahalan (1988). In addition, one study could be found which focused on hip abductor strength in transfemoral amputees (Ryser et al, 1988). It was found in all these studies that compared to the sound limb, the strength was significantly lower in the amputated limb.

Stump muscle strength is influenced by the length of the stump (Isakov, Burger, Gregoric, Marincek, 1996). Isakov et al (1996) found the muscles in shorter below knee stumps (<15.1cm) to be significantly weaker than in subjects with a longer stumps. No difference in strength was found when the amputees were separated into two groups - one who had the amputation seven or more years ago and the other who had the amputation less than seven years ago (Isakov et al, 1996).

Cardio vascular fitness

Exercises to improve cardio vascular fitness and to condition the cardiovascular system for prosthetic walking are essential since the use of a prosthesis puts high cardio-vascular demands on the body (Visagie, 2004; Manderson & Warren 2010; WCDoH, 2010). The increase in energy expenditure during prosthetic walking may result in a decrease of activities in individuals with lower limb amputations (Huang, Chou, Su, 2000).

Chin, Sawamura, Fujita et al, (2002) conducted a comparative study on cardio respiratory fitness with participants between the age of 10 and 30 years who had a traumatic lower limb amputation and able bodied participants who did not participate in a regular exercise programme.

They found that the able bodied subjects' fitness level was higher than the individuals who had a traumatic lower limb amputation. The positive news was that after endurance training, the individuals who had lower limb amputations, fitness level status recovered to a level that was more or less the same status as the able-bodied subjects. In this study, traumatic amputees improved their fitness level through exercising on a one-leg cycle and the researchers found a significant increase in maximum oxygen uptake and anaerobic threshold (Chin, et al, 2002). To enhance endurance it is preferred that the major muscle groups are

used by doing sustained aerobic exercises, according to the guidelines that were established by the American College of Sport Medicine (Pollock, Gaesser, Buther, Despres, Dishman, Franklin and Garber, 1998). However, amputees experience challenges in this respect since aerobic exercise machines usually require the use of both lower limbs (Donachy et al, 2004).

In addition to the energy requirements for prosthetic walking one has to keep in mind that heart disease is an important factor that needs to be considered in the care of the client with a vascular amputation (Roth, Park & Sullivan, 1998). Cardiac testing should be considered, because cardiac evaluation can identify individuals who might be at high risk for complications during the rehabilitation process. To improve cardiac conditioning and enhance quality of life and participation in clients with vascular amputations techniques such as standard ambulation training, arm ergometry, and treadmill walking can be utilised.

Stump desensitization

Desensitization can be described as a form of treatment for hypersensitivity that aims to elicit habituation and thus decrease hypersensitivity of the residual limb after surgery, to improve function (Pedretti, 2006). When a hypersensitive area is over stimulated, with stimuli that does not cause harm, it minimizes the response to stimuli. The central nervous system learns to accept these stimuli as non-harmful (Manderson & Warren, 2010). Stump desensitization includes activities like handling and massaging the stump daily, rubbing, and tapping, applying pressure and heat or cold to the stump. In terms of stump desensitization it is important that the therapist teaches these techniques to the clients as well as to the caregivers so that they can apply it at home (Manderson & Warren, 2010).

2.4.4 Mobility Training

Bed mobility

Clients should be educated how to move independently in different directions on the bed, roll and sit and stand up. In most cases this is the responsibility of the physiotherapist (Pedretti, 2006; Manderson & Warren 2010; WCDoH, 2010).

Balance retraining

Physiotherapists assist the clients to re-train their sense of balance through standing, hopping on one foot, doing transfers and crutch walking (Manderson & Warren 2010; WCDoH, 2010).

Crutch/frame walking

Crutch and frame walking requires that clients are educated about how to walk with crutches or with a walking frame. Furthermore, clients are taught to get up from sitting to a standing position, how to go up and down steps, how to negotiate uneven terrain, slopes, busy streets and escalators and how to get in and out of cars, busses or trains as applicable. Elbow crutches are preferred since their use promotes a more natural posture which eases future prosthetic walking. A walking frame or axilla crutches are used only where a client needs the added stability. The physiotherapist is responsible for this duty (Visagie 2004, WCDoH, 2010).

Prosthetic fitting and walking

The prosthesis plays a very important role in the life of those persons with amputations who use prostheses for ambulation. Asano et al (2008) found prosthetic problems to be a significant predictor of poor quality of life outcomes for amputees.

According to Manderson and Warren (2010) there is a debate around the appropriate time between amputation and the fitting of prosthesis and timing varies between hospitals according to their institutional cultures. However, the sooner the person receives a prosthesis the better prosthetic outcomes will be (Gauthier – Gagnon, Grise & Potvin 1998). No recent figures on prosthetic waiting periods in the Western Cape could be found, but in 1993 amputees waited on average five months for their prostheses (Hendry, 1993). This figure increased to an average of 10 months for clients dependent on state services in 1999 (Bakkes, 1999; Groenewald, 1999). According to Bakkes (1999) the waiting period was shorter in the private sector in the Western Cape Province. She found a waiting period of six months for this sector. In instances where long prosthetic waiting periods are a reality, home exercise programmes were essential since this shortened the prosthetic rehabilitation time

significantly. Individuals who received home exercise programmes wore their prostheses for significantly longer hours per week (Groenewald, 1999).

Completion times for prostheses are put at two to five days internationally (Manderson & Warren 2010). In the Western Cape clients had to wait longer for their prosthesis because extended waiting times for completion of the prosthesis was found. One study found that the length of the rehabilitation period was increased for 41% of amputees, because of waiting for fit and alignment changes to the prosthesis (Groenewald, 1999).

Prostheses are kept as light as possible. The prosthesis feels heavier to the user because there are no muscles to move and stabilise the joints. The weight of the prosthesis depends on the material used (Manderson & Warren 2010).

Prosthetic manufacturing, fit and alignment is primarily the responsibility of the prosthetist (Visagie 2004; Manderson & Warren 2010). Temporary check sockets may be used to ensure a better fit in the final socket (Manderson & Warren 2010). The prosthesis must fit correctly; no pinching or chaffing should occur and fit as well as alignment should be checked carefully (Manderson & Warren 2010).

Once the fit and alignment are correct the physiotherapist and client commence with re-education of walking (Manderson & Warren 2010). During prosthetic rehabilitation the client must learn to trust the body and the prosthesis. Clients must gain confidence in its durability, strength and stability (Manderson & Warren 2010). The prosthetist and physiotherapist often work in tandem to ensure the best results (Manderson & Warren 2010). Retraining of walking often starts in the parallel bars and progresses through the gymnasium to outside terrain. The full spectrum is covered from donning and doffing of the prosthesis, through walking on flat indoor terrain to uneven outside terrain, stairs, and slopes and getting into or out of a vehicle (Manderson & Warren 2010).

Wheelchair mobility

Many people who underwent lower limb amputations never learn to walk again or manage to walk only short distances because of physical or prosthetic problems. This leaves them dependent on a wheelchair for mobility with the environmental barriers inherent to wheelchair

use such as stairs, narrow doors, turnstiles and rough terrain limiting their mobility (Rommeers, Vos, Groothoff and Eisma, 2001; Manderson & Warren 2010).

Clients who require a wheelchair for all or part of their mobility needs must be issued an appropriate wheelchair (WHO, 2008). They must also be orientated on how to use the wheelchair. Clients are taught how to push themselves forward and backwards, how to turn, how to use the brakes, how to balance on the rear wheels, cover uneven terrain and go up and down kerbs. Furthermore, clients must be taught how to transfer to and from the wheelchair and/or the bed, floor, toilet, bath, shower, a chair and car according to the demands of their respective lifestyles. Where clients are unable to perform these activities on their own, a caregiver must be taught how to assist them with the activities (Provincial Government of the Western Cape (PGWC), 2009). An important aspect with regards to wheelchair use in clients who suffer amputations is the altered sense of balance especially with bilateral above knee amputations which can cause the wheelchair to tip over backwards easily. The physiotherapist and or occupational therapist are responsible for wheelchair mobility (Visagie 2004; WCDoH, 2010).

Community mobility

Community mobility according to Pedretti (2006) refers to the general public making use of both public and private transport in a community. One of the objectives of “The Americans with disabilities Acts of 1990” is that disabled people in America should have equal access to public transport such as buses, trains, ships, and other means of transport. With the introduction of this act, adjustments were made to the public transport services to accommodate the disabled clients. In South Africa public transport is notoriously inaccessible (Emmet, 2006). Although Dial-a-Ride, a shuttle services that assist people with disabilities with transport, exists in Cape Town this services is limited to certain areas and not able to address the need. Where the client does not achieve independent community mobility, caregivers should be trained and educated on how to assist the amputation client in this area (Pedretti, 1996; Engstrom & Van de Ven 1999).

2.4.5 Psychological counselling

It is essential that rehabilitation programmes incorporate a psychosocial component in addition to the physical, as a significant proportion of persons with amputations experience symptoms of depression (Asano et al, 2008). Therefore, it is important that people who have undergone amputations receive counselling to address depression, anger, denial, coping and accepting (Predetti, 2006). Psychosocial counselling should commence pre-operatively to facilitate the process of adapting to limb loss (Penington, Warmington, Hull, Freijah, 1992), so that clients can be able to make psychological adjustments after a lower limb amputation (Horgan and, MacLachlan, 2004; Unwin et al, 2009). This psychological preparation provides the time to ask questions and it discourages unrealistic expectations of post-operative function. At this stage information leaflets and booklets can also be provided to the clients (Ham & Kerfoot 1986). Challenges that clients have to face, which may have psychological and social effects on their lives include: communication with providers, participating in their own care and negotiating health care systems (Ciehanowski and Katon, 2006).

Counselling can be provided by a social worker or occupational therapist (WCDoH, 2010), but some clients may need to be referred to a psychologist or psychiatrist (Predetti, 2006). One can say that the need exists for the services of a clinical psychologist for amputees. According to Delehanty and Trachsel, 1995, the role of the psychologist can be seen to oversee appropriate protocols for the screening of amputees, to be a consultant and to supervise relationships to assist amputees with adjustments. The psychologist is in the position to do specific assessments as well as to provide psychotherapeutic interventions with the amputees based on evidence.

Post-operative counselling can take place on an individual basis or in group sessions, depending on what the client prefers. The purpose of counselling is to assist the client and his/her social network with social and psychological issues and to assist with the acceptance of and adaptation to the amputation.

2.4.6 Community integration

According to Maart, Eide, Jelsma, Loeb & Ka Toni (2007) the impact of the environment is a major cause of disability in South Africa and more research should be done to explore the

impact of the environment on persons with disabilities. Community integration is about assisting the person with a lower limb amputation to resume his/her life roles previous to the amputation and focus on ordinary activities and everyday tasks like driving, household chores, sport and recreation, religious activities and managing finances. To integrate successfully into the community the client should be able to handle or direct his own personal affairs i.e. financial management and handling of personal documentation, do or direct his/her own shopping, be mobile in the community and access community services and organisations like churches, sport clubs, post office, banks, clinics, hospitals and libraries of his/her choice. The client should have the ability to make use of public and private transport. In addition, the client should also be able to do self-directed health monitoring i.e. know how to administer his/her medication, be able to attend his/her medical or doctors' appointments and maintain a healthy life style. In terms of recreational activities, ideally the client should be able to participate in different recreational activities of his/her choice (Predetti, 2006; Manderson & Warren 2010).

According to Manderson and Warren (2010) it is important that clients are encouraged to resume with their everyday tasks. Aspects that should be attended to are determined by previous life roles, safety needs and mobility. The social worker and occupational therapist needs to address these issues. Part of the occupational therapist's role to reintegrate clients into the community is to do a home visit to assist if modifications need to be done, and also to determine the need for rails and ramps. Other activities might involve excursions to shops and crowded areas. The Occupational therapist should also work with partners and significant others to help smooth the path for them as well (Manderson & Warren 2010; WCDoH, 2010).

According to Predetti (2006), it is important that individuals who have prostheses to incorporate them into their lifestyle, including social activities. People who wear prostheses should be encouraged to use them in activities like shopping or going for a walk, so that they don't become uncomfortable when wearing their prostheses.

2.4.7 Employment

The focus of amputee rehabilitation should be reintegration of the individual into the community as an independent and productive member of society (McColl et al, 2001).

However, this is a challenging area of rehabilitation. Findings by Nissen & Newman (1992) indicate that together with recreation and community mobility, employment is one of the areas where persons with lower extremity amputations experience poor success. Schoppen et al, (2001a, p. 1427) defines successful job integration as “*successfully reintegrated with respect to work if they were still working or had stopped working for reasons that were not related to the amputation (other diseases or handicap, marriage or children, removal, retirement, dismissal). Amputees were not successfully reintegrated if they had stopped working because of consequences of the amputations*”. The client should ideally be able to return to his/her previous work with adjustment or adaptations if required.

Before amputees return to their place of work, it is advisable that the occupational therapist does a work visit to assess the need for reasonable accommodations i.e. assistance or adaptations to the working environment so that the amputee can return to a safe environment (Pedretti, 2006; WCDoH, 2010). Pedretti (2006) also pointed out that there should in some cases be a restriction on the workload of the amputee, for instance, restricting the amount of weight that the client lifts and carries or restricting work on ladders. The employer needs to be educated about the condition of the client, so that the employer can have intellectual insight in the impairment. McColl et al (2001) advise that amputees should rather change jobs to enhance their chances of successful reintegration instead of adapting their former work.

Return to work is negatively influenced by stump and wound healing problems (85%), by reintegration of the job process problems experienced (46%), and with mental problems that were experienced (23%) (Bruins et al, 2003). According to (Schoppen et al, 2001a) the return to work can be influenced by the factors that are related to impairments and disabilities due to the amputation and work related policies. The other common general factors that can also influence the return to work are age, gender and the educational level of the amputees.

In a study of 652 amputees in the Netherlands, it seems that of the lower limb amputation, participation in job activities were good in comparison to the general Dutch population. A decline was shown in job participation of clients who were older than 40 years. It was also found that there is a long delay for amputees before they return to work. Other problems that clients have experienced at work were fewer promotion possibilities and challenges with regards to making modifications to their workplace (Schoppen et al, 2001a).

To conclude, people who had amputations of the lower limbs do experience problems when it comes to return to work. The tendency is amputees change to other work or prefer to work only as part time workers and in most instances modifications of the workstation are needed (Burger & Marincek, 2007). Burger & Marincek (2007) recommended that counselling should be part of the vocational rehabilitation process.

From the above it is clear that rehabilitation services and policies in individual countries play an important role in the ultimate outcome of amputees. Therefore this discussion now turns to rehabilitation and more specific amputee rehabilitation services in Africa and South Africa.

2.5 Amputee rehabilitation services in Africa

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

2.6 Rehabilitation services in South Africa

2.6.1 National policy

According to the philosophy of primary health care on which health care provision in South Africa is based rehabilitation is one of the pillars of primary health care (Kautzky & Tollman 2008). South Africa's policy framework for disability and rehabilitation, the White Paper on an Integrated National Disability Strategy (Office of the Deputy President, 1997) and the National rehabilitation policy (DoH, 2000), describes appropriate rehabilitation as a goal oriented, time limited process that assists people with disabilities to become fully participating members of society and states that rehabilitation at primary health care level in South Africa should be delivered on community based rehabilitation principles. Community based rehabilitation has

two main objectives one focusing on the individual and one on the community. These objectives are:

1. Ensuring that people with disabilities can maximize “*their physical and mental abilities, can access services and opportunities and become active contributors to society.*” (International Labour Organisation, United Nations Educational, Scientific and Cultural Organisation, WHO, 2004, p2).
2. Activating communities into promoting and protecting human rights of people with disabilities through changes in the community, for e.g. by removing environmental barriers (International Labour Organisation, United Nations Educational, Scientific and Cultural Organisation, WHO, 2004).

Community based rehabilitation is people-centred and people-driven. It “*focuses on mutual transfer of skills, knowledge and resources between the community, people with disabilities and service providers*” (DOH, 2000 p7). These are then the broad principles one would like to see in all rehabilitation programmes in South Africa including the one currently under study.

2.6.2 Rehabilitation service delivery

Literature on the provision of rehabilitation services in South Africa is scarce and the only national figures that could be found dated back to 1999 where the Community Agency for Social Enquiry survey found that 39% of persons in South Africa who needed rehabilitation received it (Case, 1999). A more recent report on health care access in South Africa by the South African Human Rights Commission (2009) stated that access to rehabilitation is poor, but provided no further explanatory information or figures.

Localised studies from various South African settings further point to limited rehabilitation services, especially at primary level (Saloojee, Phohole, Saloojee & IJsselmuiden, 2007; Rhoda, Mpofu & De Weerd, 2009; Wasserman, DeVilliers & Bryer 2009; Equitable, 2011).

Saloojee et al (2007) studied children with disabilities in Orange farm, a peri urban settlement in Gauteng. They found that 26% of children who needed rehabilitation services received it and that 233 children needed assistive devices of which 28% were either ordered or issued. Couper (2002) found similar results in KwaZulu Natal where one third of children who needed

rehabilitation received it. Wasserman et al, (2009) did a multi-centre longitudinal cohort study in rural KwaZulu Natal, with the aim to assess the discharge planning of stroke clients and to evaluate integration and continuity of stroke care between hospital and the community. They found that there were no rehabilitation services available to clients after discharge.

Rehabilitation services at medical institutions such as community health care centres (CHCC) and hospitals are usually offered by therapists. It is true that the presence of a therapist does not automatically lead to the provision of comprehensive rehabilitation as findings by Henn (2009) and De Wit, Putman, De Jaeger, Baert, Berman, Bogaerts et al (2005) indicate. The structure and content of the sessions should be taken into consideration to determine whether therapy or rehabilitation is offered. However, one can assume the presence of a therapist to be the minimum requirement for rehabilitation at CHCC level. Rhoda et al (2009) found that only 20 of the 39 Community Health Care Centres in the Western Cape Metro Health District offered therapy services. Of these, all 20 have physiotherapists, 10 offered occupational therapy services and at 2, students were providing speech therapy. Thus, a large percentage of people living in this geographic area do not have access to therapy services and thus by extension, to rehabilitation services at the primary level of care. It was also pointed out that services at the Community Health Centres were poorly coordinated which further impacts negatively on effective rehabilitation (Rhoda et al, 2009).

Finally, data from a study on health care access at primary level indicate that while some therapy services are provided at primary level in the Northern Cape Province of South Africa none of the therapy provided adhered to the principles of rehabilitation as discussed above (Work package 3 report, Fraserburg, 2011).

One South African study which specifically evaluated a rehabilitation programme could be found in the literature (Henn, 2009). In this study the rehabilitation programme for persons with complete paraplegia at Netcare Rehabilitation Hospital was evaluated. It was found that the rehabilitation programme was effective in terms of addressing the needs for physical independence. Another positive finding of the study was that 80% of the population indicated that they had gained knowledge about their wheelchair and equipment and the maintenance thereof (Henn, 2009).

On the other hand, it was found that not all of the broad rehabilitation principles were included in the rehabilitation programme. In terms of preparation for community integration, a vital part of rehabilitation, 31% of the clients scored themselves below 70%. Another crucial area was returning to work, where 44% of participants indicated that there was a possibility of their returning to their previous work, but reasonable accommodations were needed. However, no work visits were done during rehabilitation and the rehabilitation team did not offer any support with regard to assisting them to facilitate these accommodations. It was further found that 75% of the clients scored themselves lower than 70% in terms of assistance by the rehabilitation team with regard to adaptations to their houses. Thirty seven point five per cent of participants indicated that no home visits were done. In addition, study participants had no knowledge of where to seek medical assistance after discharge (Henn, 2009). One cannot extrapolate this data to all rehabilitation services in SA since the study was done on a homogenous population in a very specific setting. However, the findings raise concerns that should be further explored and leaves one with serious questions about the extent to which rehabilitation services in SA adhere to the objectives of the NRP.

2.6.3 Amputation rehabilitation services in the Western Cape

In 2010 the Western Cape Department of health published clinical guidelines on rehabilitation and prosthetic prescription for lower limb amputees (WCDoH, 2010). The purpose of the guidelines is to ensure that persons who underwent lower limb amputations in Western Cape Department of Health facilities are optimally rehabilitated and that appropriate candidates are referred for prosthetic rehabilitation. The objectives of the guidelines are to:

1. *“Provide clinical guidelines for the immediate post-operative management of amputees irrespective of their potential to receive a prosthesis.”*
2. *“Provide guidelines for the appropriate referral to community and sub-acute resources in the Western Cape to ensure continuity of these early management plans.”*
3. *“Provide general assessment guidelines as to the suitability of candidates for prostheses” (WCDoH, 2010 p1).*

According to these guidelines amputation rehabilitation in the Western Cape should be initiated during acute care since comprehensive, early intervention leads to improved long term outcomes. Acute care intervention should be provided through a multi-disciplinary

team. The team should ideally consist of doctors, nursing staff, occupational therapists, physiotherapists and social workers. In instances where members of a professional group are not available, other professionals should step in and ensure that the necessary interventions are performed. The focus of treatment during this phase should be on managing co morbidities, wound care, stump bandaging, prevention of contractures, independent self-care, bed mobility, crutch or frame walking, wheelchair mobility if appropriate, ordering appropriate assistive devices, home and work assessment, grief counselling, financial advice and carer training. Finally, this team should establish a rehabilitation and discharge plan for future holistic health and functional status management (WCDoH, 2010).

Various rehabilitation and discharge management plans are presented in the guidelines. The most suitable one must be chosen for each client, “...*depending on the patient’s needs for wound care, assistance with self-care, ability and potential to mobilise and availability of resources*” (WCDoH, 2010 p 4). For client’s independent in self-care and with good mobility, referral for prosthetic rehabilitation should be considered. During the prosthetic rehabilitation phase different management strategies are again provided. In this instance they are based on the level of amputation since the kind of prosthesis which is provided and the potential to walk, differ according to the level of amputation (WCDoH, 2010).

The clinician or client can request an assessment for prosthesis fitting. The assessment should be done by a physiotherapist, doctor and prosthetist. Where a prosthesis can improve the function of the client it should be considered. However, many factors impact on prosthetic functioning. These include; cardio-respiratory status and fitness, neurological co-morbidities, viability of the remaining limb as well as range of movement, strength, length, shape, soft tissue that might affect fit and stability of the prosthesis, bone end, wound healing, scar mobility, pain, and skin condition of the amputation stump. Other factors that are considered include the client’s compliance with treatment such as risk factor modification and pre-morbid level of function (Bakkes, 1999; WCDoH, 2010).

Where it is deemed that these factors will prevent a client from being able to use a prosthesis the client should be referred back to the relevant therapist who must attempt to address the problems through rehabilitation. This involves an amputation exercise programme to improve

endurance, mobility, balance and stump care, in order to optimise self-care, mobility and community integration (WCDoH, 2010).

On the other hand, if the client meets the requirements for prosthetic rehabilitation stump maturation needs to be finalised with appropriate compression bandaging and the prosthesis must be ordered. Prosthetic applications can be made via the Orthopaedic Aftercare clinics at the clients local Community Health Centre or the Orthotic and Prosthetic Centre. It is preferable that pre-prosthetic preparation as well as uncomplicated below and through knee prosthetic rehabilitation is completed on an out-patient basis (WCDoH, 2010). In instances where clients insist on having prostheses for cosmetic reasons when it is not functionally indicated, psychological counselling must be provided (WCDoH, 2010).

There are thus clear guidelines available in the Western Cape with regard to amputee and prosthetic rehabilitation. However, only evaluation of existing amputation rehabilitation programmes in this province will tell us to what extent these guidelines are adhered to.

2.7 Programme evaluation

In order to assess whether rehabilitation interventions are successful and if rehabilitation programmes are achieving their objectives it is necessary to perform continuous monitoring and evaluation of the programme through outcomes measurement. According to Kettner, Moroney & Martin (1999) the word “monitoring” comes from the Latin word *monere* that means “to warn”. Monitoring of the programme will provide feedback to the programme administrator and literally warns him/her when the programme is starting to deviate from its original design, so that corrective action can be taken to bring the programme back into line when necessary.

Thus every social programme, including rehabilitation programmes, should be monitored and evaluated by one, or more outcome measures (Kettner et al, 1999; DoH, 2000; UN, 2006, Velema & Cornielje, 2003). In order to effectively implement outcome measures, the programme should have measurable objectives (Kettner et al, 1999).

Information gathered on the strengths and weaknesses of the programme through measurement is an integral part of the future planning process (Kettner et al, 1999).

Ultimately, outcome measures should provide service developers with information on client progress as well as programme efficiency, effectiveness and quality. For the purpose of this study the focus of the outcome measures used should focus on the programme more than on the progress of the individual client. Thus, the systems model (figure 2.1) as described by Kettner et al (1999) was identified as a suitable framework for the study.

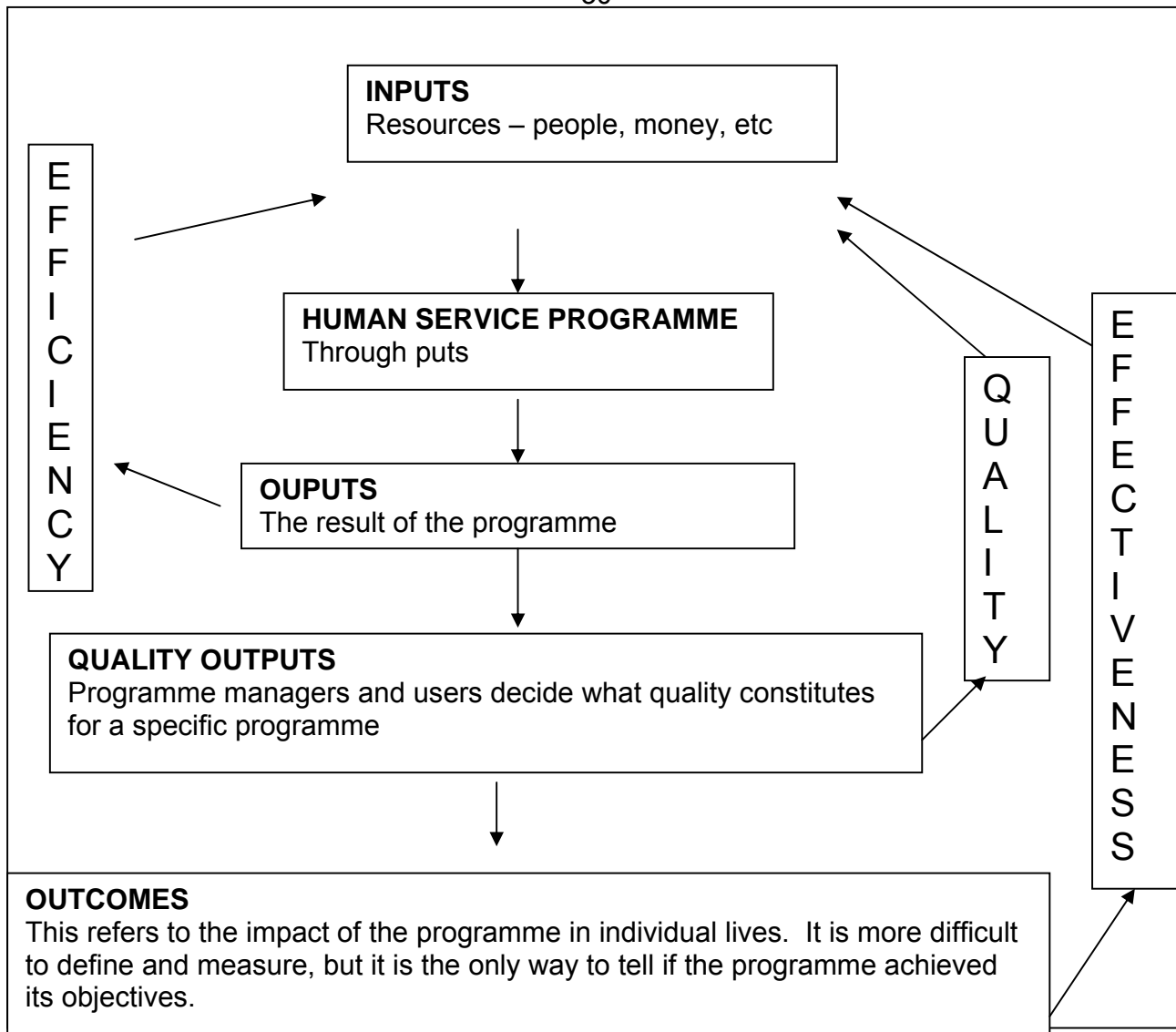


Figure 2.1: Systems framework for performance measurement according to Kettner, Moroney and Martin (1999)

As shown in figure 2.1 the elements in the systems model consist of programme inputs, programme throughputs, programme outputs and programme outcomes (Kettner, Moroney and Martin, 1999).

Programme inputs include all resources and raw materials, like funding, staff, facilities and equipment, utilised in the programme. The process or throughputs refer to the actual implementation of the programme i.e. the actual treatment or service delivery during which the inputs are consumed and translated into outputs. Programme outputs are the number of clients treated, or number of services delivered in a certain period of time and high output will

indicate that a service is efficient; i.e. that the ratio of output over input is good. However, it does not imply that the outputs adhere to a certain minimum standard or are of a certain quality. Therefore benchmarks need to be set against which outputs can be measured to determine if they are of an acceptable quality. Finally, outcomes must be considered. Outcomes refer to the difference that the programme is making in the lives of its clients and if the programme is achieving its objectives, thus including such aspects as the impact of the programme on quality of life (Kettner et al, 1999).

Constant monitoring of outputs, quality outputs and outcomes are translated into feedback that is reintroduced into the system as an input in order to constantly improve the service (Martin & Kettner 1996). This type of on-going assessment is extremely important in human service programmes. If there is no performance measurement, a service can continue for years and years without anyone knowing whether its objectives have been achieved. In order to implement performance measurement, one needs measurement tools.

2.8 Measurement tools

Measurement tools are used to assess the benefits of rehabilitation and changes in functional ability of clients over time (WHO, 2011). Ways of measuring can include impairment measures which focus on one area only, like the Oxford Scale for Muscle Strength, range of motion tests or more advanced activity measures like the Locomotor Capabilities Index (Gauthier-Gagnon, Grise & Lepage, 1998), activity measures such as the Functional Independence Measure (FIM User Manual, 2003) and/or participation measures like the Reintegration to Normal Living Index (May and Warren, 2002) or measures that combine these aspects like the International Classification for Function, Disability and Health (ICF) checklist (WHO 2001). Historically, rehabilitation measures focused mostly on impairments (WHO, 2011). As a result, a study on the use of outcome measures by South African physiotherapists showed that while 84% of them used outcome measures regularly, the type of measures most frequently used were impairment measures. Quality of life and participation measures were used least frequently (Inglis, Faure and Frieg, 2008).

However, there is a move towards including activity and participation outcomes (WHO, 2011). These might focus on individual clients and measures aspects such as mobility, self-care, employment and quality of life or might focus on programme outcomes such as percentage of

persons discharged to their homes and re-integration into employment rates (WHO, 2011). The only study on rehabilitation programme measurement in South Africa, which could be found in the literature, was the study by Henn (2009) which was previously described in this literature review. She used an activity measure, the Functional Independence Measure (FIM) and an activity and client needs assessment measure, the Needs Assessment Checklist (NAC) as measuring instruments.

When using performance measurement tools one has to take into account the following criteria: utility, validity, reliability, precision, feasibility and cost (Kettner et al, 1999, Kuechler, Velasquez and White, 1988, Millar and Millar, 1981, Nurius and Hudson, 1993, Rossi and Freeman, 1993, Tatara, 1980).

Utility is the most important of the seven criteria and refers to the tools ability to generate relevant and useful information. If information gathered is not relevant and useful it will be ignored by stakeholders, (Kuechler et al, 1988; Millar and Millar, 1981; Martin & Kettner 1996; Nurius and Hudson, 1993).

Rossi and Freeman (1993) explain validity as the extent to which any measurement tool measures what it is supposed to measure. For instance, in the case of programmes, it must measure the actual results, impacts and accomplishments of the specific programme (Martin & Kettner 1996).

A reliable measure produces the same results repeatedly. According to the general rule, reliability will be higher the more standardised the outcome measure (Martin & Kettner 1996).

Precision refers to the tools' ability to capture incremental changes (Martin & Kettner 1996).

According to Millar and Millar (1981) feasibility is about the practicality of the tool. This can be influenced by political, ethical, administrative and personnel factors as well as aspects of the tools itself such as length of time it takes to complete (Martin & Kettner 1996).

Cost refers to how expensive it is to use a tool. This includes start up and maintenance cost and can refer to aspects such as having to buy copyright to use a tool or having to train personnel in its use (Millar & Millar, 1981; Martin & Kettner 1996).

The last quality of a good measurement tool is that it should be multi – disciplinary so that the tool and data gathered with it can be used by all the team members (Martin & Kettner, 1996).

The best suited selection of the type of outcome performance measures to use in an individual human service programme does not involve only an individual assessment of all seven criteria but also assessment of trade-offs between criteria.

According to Kuechler et al (1988) and Martin (1988), outcome measurements can be placed into one of four categories namely numerical counts, standardized measures, level of functioning scales and client satisfaction measures.

Kettner et al (1999) describe numeric counts as a nominal measure relating to client flow. Numeric counts are relatively easy to define and to interpret and these data are often collected by many programmes which allows for comparison between programmes. The disadvantages of numeric counts are that they are less precise and valid compared to other types of outcome measures (Martin & Kettner, 1996; Kettner et al, 1999).

Standardized measures are used to assess quality of life changes in clients before and after tests. They are widely used by practitioners and are objective instruments that are usually valid and reliable (Kettner, Moroney, Martin, 2008). One of the disadvantages is that standardized measures often come with a price, since they are copyrighted and can only be used with the permission of the copyright owner (Martin and Kettner, 1996).

Level of functioning scales capture changes in clients functioning before and after treatment (Martin & Kettner, 1996). The benefit of the level of functioning scale is that it can assist case managers to determine priorities and allows progress tracking throughout the process (Kettner et al, 1999).

In client satisfaction measures, clients are asked to report on various aspects of the programme such as timeliness, appropriateness, impact on their lives as well as staff attitude and behaviour (Martin & Kettner, 1996). While client satisfaction measures might seem to be the easiest way to collect information, programme planners should be cautious about overusing it or having unrealistically high expectations for this measure (Kettner et al, 1996). Programme planners should be cautious of having unrealistically high expectations of client

satisfaction measurement, because clients might not give an accurate assessment in the changes of their quality of life and in most cases the reports that they give are subjective. According to (Kettner et al, 1996) the nature of client self-reporting is not precise.

The current study incorporated a variation of outcome measures types including numeric counts (in the questionnaire on demographic details, the rehabilitation programme, client satisfaction with the programme and secondary complications, in the folder audit form and in the data coding form of programme statistics), level of functioning scales (in the ICF based questionnaire on activities, participation and environmental factors) and client satisfaction measures (in the questionnaire on demographic details, the rehabilitation programme, client satisfaction with the programme and secondary complications). A limitation was that the level of functioning scales was only administered once thus no baseline scores to compare against were available.

2.9 Summary

Chapter two provided a review of the literature relevant to the study; it explained the impact that an amputation has on functional abilities, productivity and social engagement. There was a direct relationship between a person's quality of life and their level of mobility following a lower limb amputation and individual quality of life could be further negatively affected by emotional and psychological challenges such as depression.

Epidemiologically amputation was found in a younger population in Africa than in developing nations, men were affected more frequently than women and vascular diseases were the main cause with trauma emerging as a more and more common cause in Africa.

Rehabilitation post amputation was essential and the rehabilitation process should include prevention of secondary complications, mobility preparation and retraining, psychological counselling, community integration and employment. However, the literature pointed to a lack of rehabilitation services in South Africa. Thus while guidelines of the amputation rehabilitation services in the Western Cape were published it was unsure to what extent these were implemented. The chapter concluded with a discussion on the importance of programme evaluations and the use of measurement tools.

Chapter 3

Study methodology

3.1 Introduction

Chapter three provides the study aim and objectives. The chapter also explains the study design and introduces the reader to the study setting; Elangeni Physical Rehabilitation Centre (Elangeni). The study design and identification of study participants are described. This is followed by a description of the data collection instruments, pilot study data collection and analysis procedures. Finally, the chapter describes the process of verification and trustworthiness of the data that was followed and the ethical considerations that were applied in the study.

3.2 Study aim

To describe the rehabilitation programme for persons with lower limb amputations at Elangeni Physical Rehabilitation Centre, in terms of programme inputs, the process of rehabilitation, outputs, client satisfaction and programme outcomes.

3.3 Study objectives

- To describe the demographic profile of the study participants,
- To describe the amputation history of the study participants,
- To describe the inputs and process of the amputation rehabilitation programme offered at Elangeni,
- To determine the efficiency (outputs) of the programme,
- To determine client satisfaction with this programme,
- To determine programme effectiveness (outcomes) with regard to:
 - The presence of secondary complications in the study participants,
 - The functional outcome of study participants,
 - The participants' level of community integration and participation,
 - The impact of environmental factors on participants' community integration/participation.
- To make recommendations towards improving the programme.

3.4 Study design

A descriptive study was conducted to evaluate the amputee rehabilitation programme at Elangeni. A mixed-method design was used with a quantitative phase followed by a qualitative phase (Creswell, Clark P, Gutmann and Hanson, 2003). Using mixed-method designs, the complementary nature of qualitative and quantitative methods of the research is emphasized and for joint research objectives, the results can be used for their practical application (Kroll, Neri, Miller, 2005).

Since qualitative data is in the form of words and is more information-rich than quantitative data, which is in the form of numbers, qualitative data was used to enhance the quantitative findings in this study (De Vos, Strydom, Fouché, Delpont, 2005). Qualitative data can provide subtle descriptions and multiple perspectives, in addition, to the factual evidence gathered through the quantitative data, and thus assist the reader to gain a sense of the subjective world of the respondents (De Vos et al, 2005). Therefore, in the case of this study, numerical counts and level of function scales were used to quantify participation restrictions and the magnitude of environmental barriers, for instance, while the reasons for scores and related experiences were explored and underscored through data gathered from semi-structured interviews.

3.5 Study setting

The study was performed at Elangeni Physical Rehabilitation Centre (Elangeni). Elangeni is located in the town of Paarl in the Western Cape Province, South Africa. The Paarl area is a peri urban area. The Paarl area has a variety of places of interest, such as the Paarl Mountain with the historical “Taalmuseum”¹, the Bergriver where the yearly Berg river canoe marathon takes place, the Paarl Mall which also accommodates disabled persons, businesses, farms and sport facilities for the members of the community. Paarl has a very good infrastructure in terms of roads and railways. Elangeni is the only free standing outpatient rehabilitation facility for persons with physical disabilities, in the Western Cape Province, outside of the Western Cape Metropole. Elangeni is funded by the government and clients are generally people lower socio-economic standing.

¹The “Taalmuseum” is the Afrikaans Language Museum.

Elangeni is a relatively recent service and opened its doors in September 2000. The purpose of Elangeni is to render a dynamic, comprehensive, physical, outpatient rehabilitation service of high quality to clients of the West Coast Winelands region, where Elangeni is situated. Elangeni also strives to play a vital role in the establishment of a rehabilitation network in the West Coast Winelands region (Telephonic conversations with the senior physiotherapist at Elangeni, Faeka Toffar, February, 2009). Facilities include; a gymnasium where most of the rehabilitation services take place, three consultation rooms, an open plan office for staff members, two waiting rooms, a kitchen and two toilets that are wheelchair accessible.

An inter-disciplinary teamwork approach is followed. The core staff members comprise of a physiotherapist, a physiotherapy assistant, two occupational therapists, a speech therapist, an administration clerk and a general worker. Other session services that are provided by; physiotherapy students, speech therapy students and medical students from the University of Stellenbosch. Should a client require additional medical input s/he is referred to Paarl hospital, a secondary hospital in the area.

Clients are referred to Elangeni from the surrounding hospitals like TC Newman, Paarl Hospital and various clinics in the Paarl and surrounding areas. The clients suffer from conditions like head injuries, cerebro vascular accidents, cerebral palsy, spinal cord injuries, hip and knee replacements, amputations and hand injuries. Furthermore, a variety of orthopaedic diagnoses are also managed at Elangeni. Rehabilitation programmes include home and work visits. Advice is given to the family or employer about how adaptations can be made to the environment. Although home and work visits are part of the rehabilitation programmes, these are done only when the therapist thinks that there is a need, and not all clients receive these visits. Other programmes that are offered by the centre are; back classes, training of home based caregivers as well as outreach services to different clinics. The average number of clients that are seen per day varies from 15 to 25.

No formal measuring instruments are utilized to measure client outcomes. The current procedure is to document clients' progress in folders. When the client is discharged a short multi-disciplinary report is written on the client's progress during rehabilitation.

No transport is offered by Elangeni hence clients need to make provision for their own in order to reach the centre. Clients who do make use of public transport will in most cases use

taxi. Busses are not available; the train station is situated far from the centre (approximately 30 minutes' walk).

3.6 Study population

Primary population

All persons who received rehabilitation after a major lower limb amputation at Elangeni during the period 1 September 2000 (opening date) to 31 December 2010 formed the study population.

Secondary population

This consisted of the physiotherapist and occupational therapist that provided rehabilitation to amputation clients at Elangeni in July 2010 when data collection for this study was done.

3.6.1 Inclusion criteria

- Clients who had a major lower limb amputation, i.e. an amputation through or proximal to the ankle joint (Godlwana et al 2008).
- Clients who were cognitively able to understand the study and give informed consent.
- Clients who had not completed the programme were also included.
- Clients of all ages were included in the study.

3.6.2 Exclusion criteria

- Those with congenital deformity (limb not amputated).
- Clients who had minor lower limb amputations, i.e. amputations distal to the ankle joint (Godlwana et al 2008).
- Clients who have suffered a further amputation or other major trauma to the body, since discharge from the rehabilitation programme, which may have an effect on outcomes. Although, further amputations and the causes of these amputations were documented as these can provide some information on client education and preventative strategies.

- Clients with cerebro-vascular accidents, spinal cord injuries or head injuries, in addition to the amputation, since the additional impairments caused by these conditions will influence the outcome of the amputation rehabilitation programme.
- Clients who received further amputation rehabilitation at another facility since their discharge from Elangeni, although the reasons for this were explored.

3.6.3 Study participants

The researcher originally planned to examine the daily treatment registers or admission records of therapists to obtain the names and folder numbers of potential study participants. However, on accessing Elangeni it became clear that hard copies of such records were not being kept. Records had been kept electronically, but, according to the clerk their computers had been stolen three times in 2007, 2008 and in 2009, and no backups of electronic information were made. Consequently all client information such as personal details, diagnoses and folder numbers were lost. Thus the researcher had to explore other avenues to identify participants. These are explained below, and presented in table 3.1.

The researcher was referred by the therapists to the clerk working at the centre to try and find names of possible participants and relevant folders. According to him, folders older than five years were not kept at Elangeni but were sent to TC Newman hospital. The clerk at Elangeni indicated that it would be very difficult to access those folders. He was, however, willing to assist the researcher to try to find what records they could. This led to a search at Elangeni on a Saturday during which a folder containing information on contact details (phone numbers with addresses) and diagnoses of clients was found in one of the cupboards. This information assisted the researcher to identify six potential study participants, of whom two did not have contact details. Four of the six were included for the study.

Since the researcher was not sure that this list was extensive he explored other avenues to identify potential study participants. He perused the records from the Orthotic and Prosthetic Centre in the Western Cape. At the Orthotic and Prosthetic Centre thirty potential participants were identified. Of these four had passed away, four of the names on the list were also found at Elangeni and nine had no contact details. Thus thirteen could be included in the study.

Secondly, the researcher contacted the theatre department at Paarl Hospital, where most of the amputations would have occurred and asked for a list of names of all persons who had, had an amputation at the hospital in the past ten years. They had records only for the past three years which were given to the researcher. It was also brought to the attention of the researcher that Elangeni was also provided with this list. The list contained 103 potential participants, of whom sixteen had passed away, thirty had minor amputations and 43 had no contact details. Ten could be included in the study.

Finally members of the community became aware of the research through word of mouth, and referred three potential participants to the researcher. Out of a total 142 potential participants, 112 participants had to be excluded and thirty participants were identified for the study.

Table 3.1: Identifying the study population and study participants

Identified from	Number identified	Number Excluded and reasons for exclusion		Number Included
Folder at Elangeni	6	Clients who died		4
		Clients who had minor amputations		
		Clients with CVA, SCI or TBI		
		Clients with no contact details	2	
Paarl hospital theatre	103	Clients who died	16	10
		Clients who had minor amputations	30	
		Clients that were on list at Elangeni	4	
		Clients with no contact details	43	
Orthotic and prosthetic centre	30	Clients who died	4	13
		Clients who had minor amputations		
		Clients with CVA, SCI or TBI Clients with	4	
		Clients with no contact details	9	
From community	3			3
Total	142	112		30

Due to the fact that the identified population was a small group no further sampling was done. All quantitative and qualitative data collection tools, except the folder audit, were completed with all 30 participants.

With regards to the folder audit the researcher experienced challenges with accessing the folders because they were kept at different venues and could, in some instances, not be found. Finally, the researcher audited the six folders which could be found. Data from the various folders was very similar and pointed toward a fixed routine being followed during the rehabilitation of amputation clients at Elangeni. The data become repetitious and led the researcher to argue that data from the audited folders could be seen as representative of the larger study population and he desisted from trying to find anymore folders.

3.7 Data collection instruments

3.7.1 Instruments to collect quantitative data

3.7.1.1 Structured questionnaire on demographic details, the rehabilitation programme, client satisfaction with the programme, and secondary complications (Appendix 2)

The researcher developed a structured questionnaire to collect the relevant data on client demographics, the amputation, rehabilitation received, secondary complications and satisfaction with the rehabilitation programme. This form was developed since none could be found in the literature that addressed all the issues necessary to respond to the objectives of the study. Assistance was sought from a statistician as well as from an expert with clinical and research experience in the field of amputations. Furthermore, literature on questionnaire design and development was consulted (Boynton and Greenhalgh, 2004).

3.7.1.2 ICF based questionnaire on activities, participation and environmental factors (Appendix 3)

This questionnaire was developed through combining the World Health organisation's (WHO) International classification on function, disability and health (ICF) checklist of activities, participation and contextual factors (WHO 2001), the WHO Disability assessment Schedule II (DAS II, 1981) and adding some detail from the Locomotor Capabilities Index (LCI) (Gauthier-

Gagnon et al 1998), and the Craig Hospital Inventory of Environmental factors (CHIEF) (Whiteneck, Harrison-Felix, Mellick, Brooks, Charlifue and Gerhardt 2004).

The questionnaires were combined and a new format developed for various reasons. Firstly, the disability assessment schedule does not include all areas of concern, for e.g. acknowledging wheelchair use as a form of mobility, toileting, lifting and carrying objects. Secondly, in some instances the ICF did not include some important issues for an amputee population like; standing up from sitting, going up and down stairs and walking in poor weather – details which are covered in the LCI. Thirdly, questions on contextual factors from the DAS II such as; “How much of a problem did you have because of barriers or hindrances?” were removed as they are covered in greater detail in the ICF checklist on contextual factors. Further contextual factors from the CHIEF were added. These included; crowds, terrain and availability of information. Many aspects from both the DAS and the ICF were removed as it was felt that these were not directly related to the impairment of a lower limb amputation. These included; questions on learning and applying knowledge, as well as communication. Finally, examples were expanded upon to make them more relevant to the South African context.

3.7.1.3 Data coding form for relevant programme statistics (Appendix 4)

This form was also developed by the researcher to gather information such as; the number of clients treated in a year, the average length of treatment periods, the number of sessions per client, the length of sessions, the use of group sessions, the running costs of Elangeni and other inputs into the programme, in order to describe the programme and determine programme efficiency.

3.7.1.4 Folder audit form (Appendix 5)

This form was developed by the researcher to gather data from folders of persons who received amputee rehabilitation at Elangeni. The purpose of this was to determine from the folders what rehabilitation interventions clients received in order to gain a further understanding of the programme and to be able to triangulate information from various sources (Domholt, 2005).

3.7.2 Instruments to collect qualitative data

3.7.2.1 Interview schedule for occupational therapist and physiotherapist (Appendix 6)

This interview schedule was developed by the researcher and was used as a guideline during the semi-structured discussion with the occupational and physiotherapist on the lower limb amputee rehabilitation programme that was offered at Elangeni. The purpose of this was to gather an understanding of the programme from their point of view.

3.7.2.2 Interview schedule for clients (Appendix 7)

The researcher developed this interview schedule that was used as a guideline during the semi-structured interviews with clients to gather an in depth understanding regarding the amputee rehabilitation programme as it is offered at Elangeni, from their perspective.

3.8 Pilot study

It is important to do a pilot study because questionnaires might fail due to the fact that participants did not understand them, were unable to complete them, got bored or felt offended by the questions (Boynton, 2004). A pilot study was done to raise the researcher's awareness of any of the above problems in order to address them.

The researcher further used the pilot study to ensure that the gathered data was sufficient to answer the research question, aims and objectives (Leedy & Ormrod, 2005). He also determined how long it took to complete the instruments in order that this information could be provided to prospective participants and also to assist the researcher with the planning of the data collection phase of the study.

Before the pilot study was performed the researcher asked a colleague who was knowledgeable in the field of amputee rehabilitation to critically review the data collection tools and to indicate which of the questions were unclear, vague or repetitive or if any aspects relevant to the study were not covered by the questions. After the suggested changes had been implemented the measuring instruments were piloted by the researcher. Three clients who had undergone amputation rehabilitation at Bishop Lavis rehabilitation centre, another

primary health care institution in the Western Cape Province, and one therapist from this institution were asked to participate in the pilot study.

The feedback from the participants of the pilot study indicated that none of the questions were unclear. The pilot data was analysed and the data was found to be sufficient to realise the study aim and objectives. No questions were found to be redundant. Thus no changes were made to questionnaires.

3.9 Data collection

3.9.1 Data collection from client participants

All data was collected by the researcher himself. He began the process of data collection by making telephonic or personal contact with the participants at their homes. The purpose of this contact was to explain the study to the participant, request provisional consent and set a date, time and venue convenient to the client for a meeting to complete the quantitative data collection tools. Furthermore, the client's language of preference was determined. All clients indicated that they wished to speak Afrikaans during the data collection process.

On meeting those participants who agreed verbally to participate in the study, the information and the contents of the consent form were clarified in the language of their choice. Although the researcher is fluent in English and a Xhosa translator was available, all 30 of the participants preferred the interview to be in Afrikaans. The informed consent forms were only available in English, but the content of the informed forms was explained in detail to the clients in Afrikaans. When they had indicated that they understood the contents of the information and consent form and that they were willing to participate in the study, they were requested to sign it. Quantitative and qualitative data were collected simultaneously. The researcher started with the structured questionnaires (data coding form and ICF based questionnaire) in order to gather quantitative data. On completion of these, the client was asked to indicate whether she / he were agreeable to participate in a further interview on the subject. If they consented to this, permission was requested for the use of a tape recorder to record the interview after which the researcher proceeded. It took between one and a half to two hours to complete data collection with clients.

Additional data was obtained by means of field notes that focused on aspects such as, communication patterns, dynamics and non-verbal communication (De Vos, Strydom, Fouchè and Delport, 2002), to add to the transcripts in order to complete the data collection.

The researcher had originally proposed to use the findings from the quantitative data as well as the researcher's experiences of participants during the data collection process to purposively select information rich clients to participate in the qualitative phase of the study. However, in the end the researcher interviewed all the participants. The reason for this change was that the research population was not as big as it was initially thought it would be.

3.9.2 Data collection from records at Elangeni

As already indicated above, client medical records were difficult to obtain. However, an appointment was made with the physiotherapist and occupational therapist at Elangeni to collect data to complete the folder audit forms from those folders which were available. The researcher and the clerk searched for folders at the centre. They were able to find six folders in a cupboard. Clinical notes from these folders were used to complete the folder audit forms.

The researcher was unable to get any information like yearly reports or financial records or any other relevant programme statistics from Elangeni and was unable to complete Appendix 4.

3.9.3 Data collection from therapists at Elangeni

An appointment was made with the therapists on a date that suited them. The interviews took place at Elangeni in one of the consulting rooms that ensured privacy. Only the researcher and the therapist were in the consulting room during the interview. Before the interview started the purpose of the study was explained to the therapist, after which written consent was obtained from the therapist. The researcher also informed the therapist that the interview was to be tape recorded and obtained consent for this. When the therapist agreed to continue with the interview, the researcher pressed the start button of the tape recorder and commenced with the interview. The physiotherapist refused consent for the interview to be recorded, hence, the interview questions were asked and the researcher had to write down

the answers. While the researcher acknowledged that some detail might have been lost in this process it was preferable to not interviewing the physiotherapist at all.

After the interviews the researcher thanked the therapists for their participation.

3.10 Data Analysis

3.10.1 Quantitative data

Quantitative data was entered onto a prepared Excel spread sheet with all the variables listed as columns. The top row contained the titles of these variables. The responses from the different respondents were entered as rows. To analyse the data the researcher made use of Statistica (data analysis software system), Version 8 together with the assistance of a statistician. Spearman rank order correlations and Mann-Whitney U tests were used to determine whether a correlation between variables exists. A rank score of less than -0.04 was seen as indicative of an inverse relationship between variables, while a rank score of more than $+0.04$ were seen as indicative of a positive relationship. A P value of < 0.05 was seen as statistically significant.

Data are presented graphically in tables and graphs where relevant, to enable the reader to see the nature of the distribution of the particular variable.

3.10.2 Qualitative data

All interviews except the one with the physiotherapist were audio recorded. The researcher listened to these recordings a number of times to familiarise himself with the data. Audio-recordings of interviews were transcribed by the researcher. To assist with the organization of the data the researcher used identification codes that will enable the researcher to determine where a piece of data came from originally.

Since the purpose of collecting qualitative data was to enhance quantitative findings data was thematically analysed according to the following pre-determined themes that relate to the aim and objectives of the study:

- Programme vision, mission, objectives and purpose,

- The rehabilitation process,
- Advantages of the programme,
- The role of the programme in the community,
- Lacks, barriers and challenges experienced in the programme,
- Client satisfaction with the programme.

3.11 Verification and trustworthiness of data

Since data on the same subject was collected from various sources, data was verified through a process of triangulation where information from clients on the rehabilitation programme was compared with information gathered from folders, as well as with information gathered from interviews with therapists. Qualitative data was verified through telephonic checking of transcript data with three participants. The researcher used member checking after data had been analysed to ensure that the information was analyzed correctly and to clarify any uncertainties in the meaning of data (Domholt, 2005).

Since quantitative tools were either self-designed or developed via a combination of existing tools they were not tested for reliability and validity.

3.12 Ethical concerns

The study was registered with the Committee for Human Research at the University of Stellenbosch. (Reference NO: NO09/05/147). Permission was obtained from the Western Cape Department of Health to perform the study and to peruse client records.

Written informed consent was obtained from all the participants. This included consent for the use of a tape recorder and in the one instance where a participant refused the use of a tape recorder, none was used. While an assent form and consent form for legal guardians was available for children, none of the participants were younger than 18 years and these forms were not used.

All the participants were informed that participation in the research was totally voluntary and if they refused to participate it would not have any future negative consequences for them. In addition, all aspects regarding confidentiality were explained to the participants, i.e. that no

names would be written on the questionnaires and that their names would not be mentioned on the tapes or in the reports. The researcher did explain that the only people that would have access to the information would be the researcher, the research supervisor and the professor that would be responsible for statistical analysis of the data. After the interviews with the participants the tapes and notes were stored in the researcher's office in a locked cupboard that no one except the researcher had access to. The data will be kept at the researcher's office until the researcher graduates and has published an article on the research. Following this, the data will be kept for eight years before it will be destroyed. It was also agreed that should someone need intervention, the contact details and names of the therapists working at Elangeni were to be provided to that person.

3.13 Summary

The study aims to describe and evaluate the amputation rehabilitation services offered at Elangeni for clients with lower limb amputations. A mixed methodology was used. After exclusion criteria were implemented 30 participants were left. No further sampling was done. Data collection instruments consisted of quantitative questionnaires, a level of function scale and folder audit form as well as qualitative interview schedules. Before data was obtained for the study, a pilot study was conducted at Bishop Lavis rehabilitation centre. Quantitative and qualitative data were collected and analysed simultaneously.

Chapter 4

Results

4.1 Introduction

In chapter four the results of the study are presented. Since qualitative data was collected to enhance quantitative data, results are presented in an integrated fashion i.e. quantitative figures as well as any additional explanation which might have been identified in qualitative data are presented simultaneously. Where relevant, narrative examples were included.

Findings are presented according to the objectives of the study, thus chapter four commences with a description of the demographic details and amputation history of study participants. This is followed by a presentation of the findings on the amputee rehabilitation process at Elangeni. Finally participant outcomes and the impact of environmental factors are presented.

4.2 Demographic details of study participants

4.2.1 Age, Gender and Race

Figure 4.1 shows that of the thirty participants ten were females and twenty males. The majority (14) of the study participants were between the ages of 51 and 60 years. The youngest participant was 18 years old and the oldest participants were between 61 and 80 years old. The population consisted of twenty nine Coloured clients and one Xhosa client.

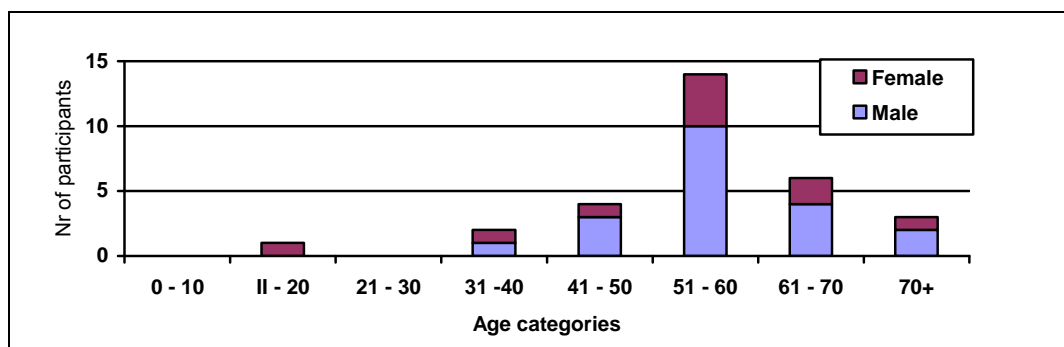


Figure 4.1: Age and gender distribution of participants (N = 30)

4.2.2 Level of Education

The majority of participants (14) received some primary school education. Only three participants had no formal schooling. The highest level of education was some secondary school education which ten participants achieved, but no participants completed grade 12, the final year of secondary school. The other three participants completed grade 7.

4.2.3 Employment status and income

One participant was employed, three participants retired, the rest of the participants were all unemployed. The 26 participants who were unemployed cited their amputation and the resultant disability as the main reason for their unemployment. In keeping with participants opinion, that the disability caused them to be unemployed, 22 received a disability grant. Of the remaining eight one earned a salary and three received old age pensions. Therefore, as table 4.1 shows 26 families had a monthly income of between R1001 – R2000. (The DG and OAP was R1080 - 00 per month at the time of the study). One of the participants earned between R5001 – R10 000 per month. Of the other two participants one had an income of between R1 – R1000 per month and the teenager had no income at all.

Table 4.1: Employment status and income of participants (N = 30)

		Nr of participants
Employment status	Employed	1
	Unemployed	25
	Retired	3
	Scholar, not attending school	1
Monthly income	R0 – R1000.00	3
	R1001.00 – R2000.00	26
	>R 5000.00	1

4.2.4 Housing circumstances

The majority of participants (21) lived in houses, while four participants lived in flats. Of the other five, four lived in old age homes and one in an informal dwelling. Most dwellings (houses and flats) 24 had two or more bedrooms. Only two participants did not have a toilet

inside the house and six did not have a bathroom in the house. All the participants had access to electricity and running water inside or on the premises.

4.2.5 Transport

Figure 4.2 shows that six participants made use of a taxi for transport while seventeen used private transport, either their own vehicle (seven) or a hired vehicle (ten). Six of the participants had no access to transport.

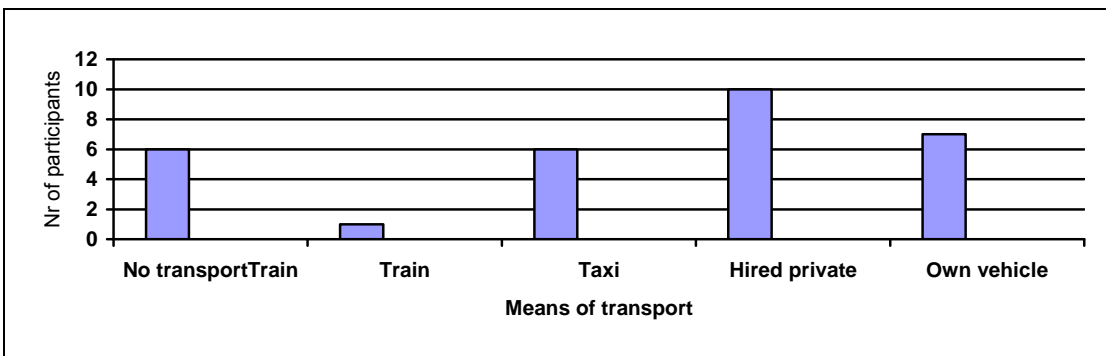


Figure 4.2: Means of transport used by participants (N = 30)

4.3 History of amputation

4.3.1 Level and side of amputation

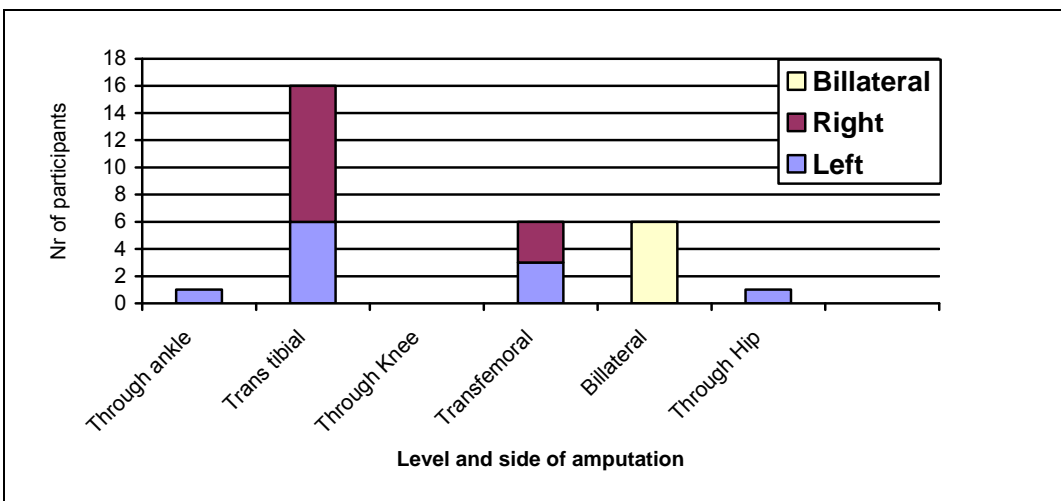


Figure 4.3: Level and side of amputation (N = 30)

As shown by figure 4.3 the most frequent level of amputation was trans tibial (16). Of the six bilateral amputations two were trans tibial on both legs, three trans femoral on both legs and one trans femoral and through knee.

4.3.2 Hospital where the amputation was done

The clients' last amputation was done either at Paarl hospital (21) or at Tygerberg hospital (9).

4.3.3 Time since amputation

Of the thirty seven amputations twelve were done between the years 2008 and 2010, twenty three between 2002 and 2007 and two between 1996 and 2001.

4.3.4 Cause of amputation

Diabetes mellitus caused amputation in nineteen participants. The other participants had their amputations done as a result of trauma (4), infection (6) and one due to unspecified reasons.

4.3.5 Need for assistance

From the study population, ten indicated that they do not need any assistance at all, four indicated that they do need occasional help with activities like shopping, two needed supervision, nine of the participants required minimal physical assistance, and four required moderate physical assistance, while one indicated that everything needs to be done for him/her.

4.4 Amputee Rehabilitation at Elangeni

4.4.1 Mission, vision and objectives

These were not documented and the therapists could not provide information on them during interviews. According to the therapists the advantages of the programme were:

- Client education
- Improvement to client life style

- Community re-integration of clients
- Improvement of client capability
- Education for the caregiver and broader community in the prevention of secondary complications post amputation

4.4.2 Programme inputs and efficiency

Due to a lack of records such as annual reports, financial statements and client registers it was not possible to develop an overview of programme inputs. Therefore it was also not possible to determine programme efficiency.

With regard to the process, no documented protocols for treatment of lower limb amputations at Elangeni could be found at the time of the study. Thus, the following description is based on information gathered during completion of the questionnaire and folder audit as well as the therapists' and clients' responses during the interviews.

4.4.3 Referral

According to interviews with therapists, on the first visit to Elangeni, clients usually have a referral form or letter from Tygerberg or Paarl Hospital. The referral form or letter includes the medical and personal background of clients and the main reasons for their referrals. Another method of referring clients to Elangeni is by means of telephonic appointments by the referring hospitals. However, clients can also access the service without a referral.

4.4.4 Accessing rehabilitation services at Elangeni

In terms of distance; three participants stayed less than five kilometres from the centre, seven participants stayed between five and ten kilometres, while ten participants stayed further than eleven kilometres from Elangeni. None of the participants stayed further than 20 kilometres from Elangeni. Figure 4.4 show that the majority of participants (22) used private transport to access Elangeni. Of these thirteen had to hire transport. It is therefore not surprising that half of the population (17) indicated that transport problems limited their ability to access the rehabilitation service. When one of the therapist was asked about the main

problems or challenges for the clients to attend rehabilitation sessions she replied: “transport problems and financial difficulties limited clients to attend treatment sessions”.

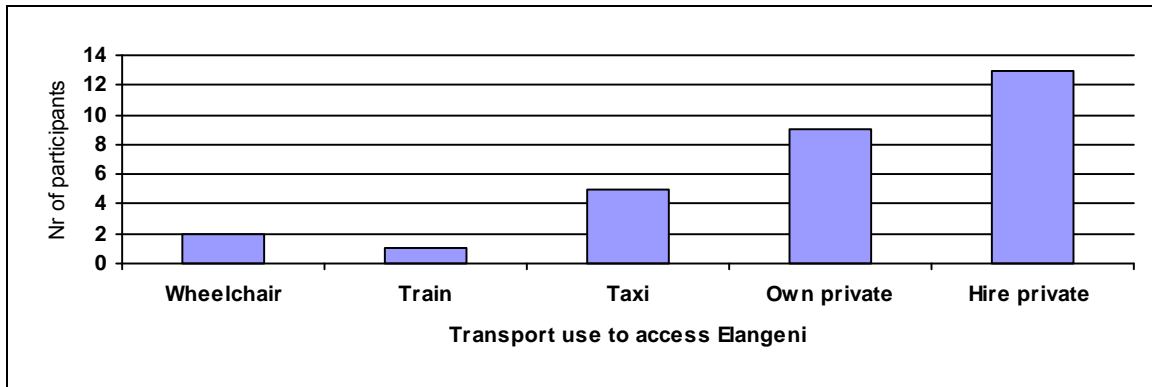


Figure 4.4: Transport used to access Elangeni (N = 30)

This problem was further exacerbated by transport costs as is shown in figure 4.5, which indicates that 16 participants paid more than R20.00 per session for transport to Elangeni.

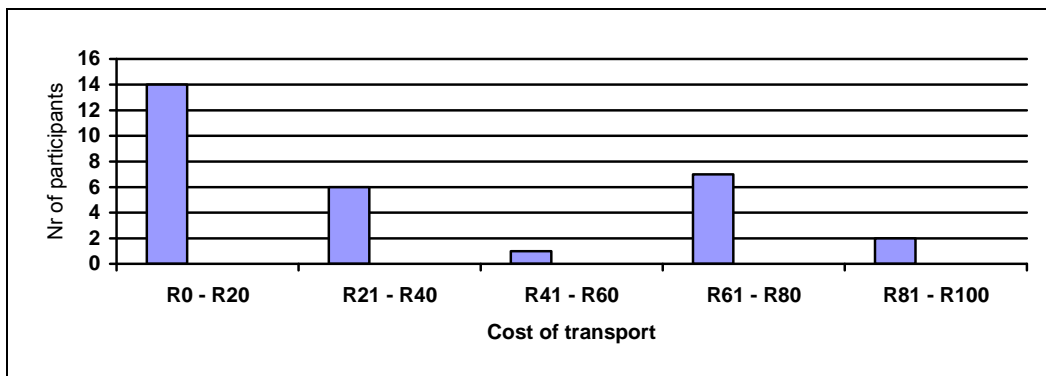


Figure 4.5: Cost of Transport to go to Elangeni (N = 30)

4.4.5 Waiting period before rehabilitation commenced

Although the researcher tried to collect the information he could obtain no precise data on the waiting period between the amputation and referral for rehabilitation. What could be gathered was data on how long participants waited to commence with rehabilitation after the amputation. As figure 4.6 shows the most common waiting time was 15 – 30 days, the shortest one was 14 days and the longest one was more than 90 days.

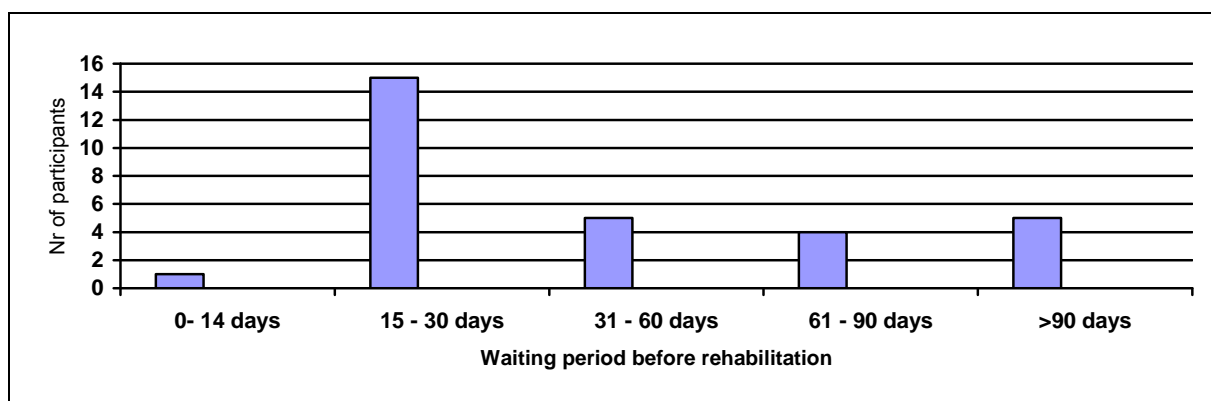


Figure 4.6: Length of waiting period between amputation and commencement of rehabilitation (N = 30)

4.4.6 Assessment

During the first visit, observations and an interview were performed with the aim of gaining information on the personal and medical background of clients as well as to elicit information about the clients' home and community environment. This session generally lasted between 30 and 45 minutes. After the interviews a physical examination was started which was completed during the second visit. This examination included a biological and psychological assessment. This evaluation seems to be very informal, in the words of a therapist: "*Informal observations are done where we look at their gait and assess what assistive device will be the best for them to use*" (Therapist). Balance tests and muscle strength testing were the only other investigations which were mentioned specifically. No standardised measurement tools were being used: "*...we have nothing in place to measure the outcomes of patients. Progress is measure by constant re-assessing of the patients and comparison is made from the first visit to the last visit or re-assessment dates*" (Therapist).

Re-evaluation was done, but information on when and why was vague: "*Re-evaluation is also done after some time*" (Therapist)

4.4.7 Goal setting

According to therapists they set goals and draw up a treatment plan based on the assessment findings: "*Goal setting for the patients takes place during the first visit*" (Therapist). Therapists indicated that they discuss the treatment plan with clients to

determine if it meets the expectations of the client. However, twelve clients felt they were not at all involved or only involved to a limited extent in treatment planning.

4.4.8 Treatment

Both prosthetic and non-prosthetic rehabilitation was rendered at Elangeni. Figure 4.7 shows that of the 30 participants thirteen received prosthetic rehabilitation and seventeen received non – prosthetic rehabilitation.

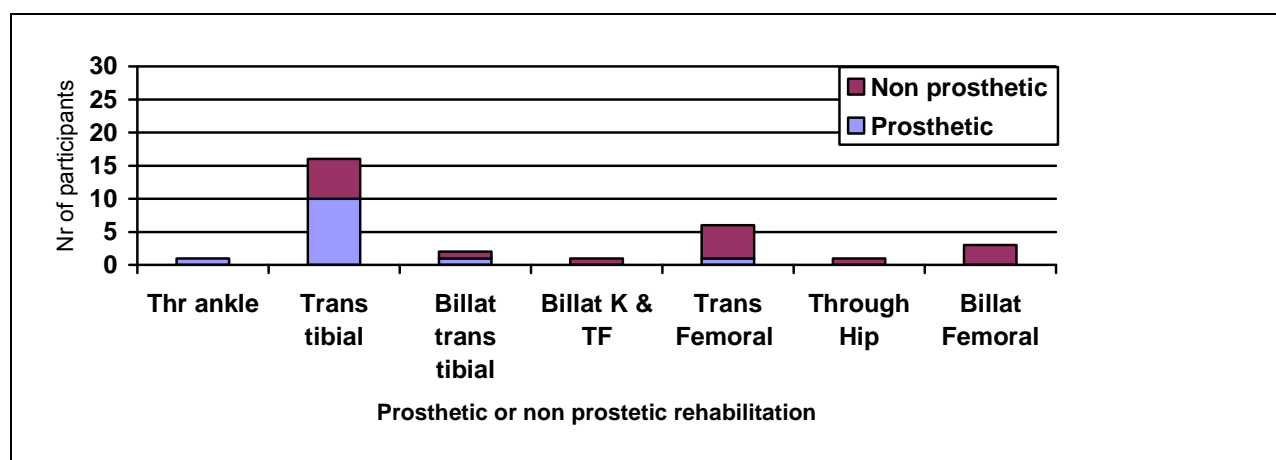


Figure 4.7: Type of rehabilitation received compared to level of amputation (N = 30)

According to therapists the content of prosthetic and non-prosthetic programmes was the same except for additional prosthetic training in the prosthetic rehabilitation programme. The contents of the programmes are described below from data gathered from therapists, the folder audit and clients. It included the following:

- Counselling

According to the occupational therapist counselling was provided on how to deal with the challenges that clients had to face and the adjustments that they had to make as a result of the amputation. However, 21 of the participants indicated that they did not receive psychological counselling

- Stump bandaging

- Muscle strengthening

Both upper and lower extremity exercises were done. Activities that required an element of resistance were mainly used. To increase muscle strength of the upper body, body

weight was used as resistance. Dumbbells which were made from water bottles with sand inside were used to increase muscle strength of the arms. No details were given on strengthening the lower limb and the amputation stump. No measuring instruments such as the Oxford scale were used to determine effectiveness of muscle strengthening programmes. These exercises were explained and demonstrated to clients who needed to do them at home as well. Part of this process was to educate and train caregivers and family members, so that they could assist clients at home.

- Balance education in sitting, standing and walking
- Stretching of the different muscle groups and active and passive range of movement of the upper and the lower limbs
- Endurance exercises of the vascular system
- The participants were trained to walk with crutches and walking frames
- Different transfers were done with the participants including car, toilet, bath, wheelchair and chair
- Participants were taught how to climb stairs / steps

A detailed summary of what treatment entailed according to clients is given in table 4.2. The table indicates that the areas covered most often by rehabilitation were muscle strengthening, stump range of movement, cardio vascular fitness and indoor mobility. Neglected areas were psychological counselling, stump maturation, stump desensitisation, transport, community mobility, environmental barriers, home visits and liaison with employers.

Table 4.2: Summary of Rehabilitation Services received according to clients (N = 30)

	None	Limited	A fair amount	Extensively	NA
Psychological counselling	21	4	3	2	
Education on stump care	6	12	10	2	
Education on prevention of further amputation	3	5	12	10	
Muscle		2	14	14	

strengthening					
Stump range of movement		2	15	13	
Stump maturation	12	13	4	1	
Stump desensitisation	14	11	4	1	
Cardio vascular fitness		2	18	10	
ADL retraining	8	7	10	5	
Indoor mobility	2	3	13	12	
Community mobility	15	3	5	7	
Assessing prosthetic fit and alignment*	4	3	1	3	17
Identified and addressed transport problems	15	11	3	1	
Identified and addressed environmental barriers	16	11	1	2	
Guidance towards self-directed health	2	10	16	2	
Home visit	29			1	
Work or school visit	1				29
Sport and recreation	3	1			26

* Missing Data = 2

4.4.9 Prosthetic rehabilitation

The therapists working at the centre made it clear that not all clients automatically qualified for a prosthesis. When asked about who qualifies for a prosthesis therapists said: *“We first look at the physical capabilities and motivation of the patient as well as their medical history...If we think that a patient will be suitable for prosthesis we will do formal assessments like range of motion, muscle strength, balance, general mobility and cardiovascular endurance”* (Therapist).

According to therapists: “the following criteria are being used to determine if someone is a prosthetic candidate”.

”Clients who are young and in the productive phase of their lives”.

”Clients with good physical endurance and who are able use elbow crutches without difficulty”.

”Clients with good upper and lower extremity muscle strength”

“Clients with ”Good cardio-respiratory fitness”

”No neurological co-morbidities”.

A prosthetist visited TC Newman Hospital once every four months and assisted with the assessments of clients to determine if they were prosthetic candidates.

On the topic of prosthetic training, therapists said: *“Before prosthetic training starts the patient must first wear the prosthesis to assess whether the fitting of the prosthesis is correct and if they experience any problems with the prosthesis”* (Therapist). In addition, the therapist discussed with the client whether they will use or not use crutches with the prosthesis. Treatment commenced in the parallel bars and the focus of the treatment was on static and dynamic balance retraining and weight transfer onto the prosthetic leg.

4.4.10 Assistive devices

The provision of assistive devices, especially wheelchairs was problematic as this quote indicates: “...difficult to supply our patients with resources like wheelchairs, due to limited budgets. We are better off to supply our patients with crutches and walking frames” (Therapist).

According to table 4.3 all the participants who had a need for crutches or walking frames received it. The picture for wheelchairs was slightly different with 18 participants having received one, while eight were still waiting for their wheelchairs. Twenty one of the participants needed wheelchair cushions. According to table 4.3 two participants were still waiting for their prostheses. Where participants needed devices which they did not have, they did not know whether the devices were ordered or not.

The information in table 4.3 was obtained from client participants and could not be verified from folders due to the unavailability of these and limited information in those that could be found. When the therapists were asked about waiting lists they said that they started a new one in 2010 since all previous data was on the computer that was stolen. No attempt was made to obtain lost data either from clients or other sources.

Table 4.3: Assistive devices that the participants need / has got (N = 30)

	Do not need	Have it	Need but do not have	Privately funded	State funded
Crutches	13	17		2	15
Walking frame	24	6		1	5
Walking stick	29	1			1
Wheelchair	4	18	8	4	14
Wheelchair cushion	6	3	21	1	2
Prosthesis	16	12	2		12

The researcher then followed other avenues with regards to wheelchair and prosthetic waiting lists. He contacted the chairperson of the Western Cape Mobility assistive devices committee

with regards to the wheelchair waiting periods in April 2011. However, he could not assist with this request and suggest that the researcher should rather ask the staff at Elangeni (Telephonic conversation with Samier Shaniem on 18 April 2011). With regard to prostheses, the researcher contacted the Orthotic and Prosthetic centre, but could also obtain no answer as to how long the study participants waited for their prostheses and how long the two still waiting had been waiting.

Wheelchair cushions were not ordered by therapists in previous years due to budget constraints. They started ordering them in 2010 again, but could not supply to those no longer in treatment since they had no waiting list or other records for these clients.

4.4.11 Education

Clients were provided with information to prevent further amputation. Healthy life-style habits were brought to the attention of the clients. According to clients, the following healthy life-style habits were brought to their attention during the education sessions:

Table 4.4 Education received on healthy life-style habits (N = 30)

Education On	Number that did received education
The need to stop smoking	11
The importance of the correct use of medication	26
The importance of maintaining healthy eating habits (Reduce intake of: oil or greasy food, sugar and red meat)	12
The importance of regular exercises	16
The importance of doing regular foot inspection to assess for blisters and redness	17
They were instructed to go a clinic or day hospital immediately if they spotted any blisters or redness on their foot	19
Clients were informed not to walk barefoot and that they should be careful when they are cutting their toe nails	4
Clients were encouraged not to sit with the foot close to open fires or heaters	1
Clients were instructed not to make used of home remedies	3

In addition, ten clients indicated that they received a fair or extensive amount of education on stump care.

4.4.12 Home programmes

All clients were given home programmes: “Give them home programmes and follow up whether they have done their exercises” (Therapist). Clients were told to report any problems which they might experience at home. Home programmes mainly focused on strengthening and maintaining range of movement.

4.4.13 Frequency of treatment

According to therapists, the distance that clients stay from Elangeni and their financial situation determined how regularly they would be treated. Figure 4.8 shows that 16 participants received rehabilitation once a week or more often. The one person who received rehabilitation on a daily basis did not receive prosthetic rehabilitation. On the other hand two persons who did receive prosthetic rehabilitation received rehabilitation less than once a month.

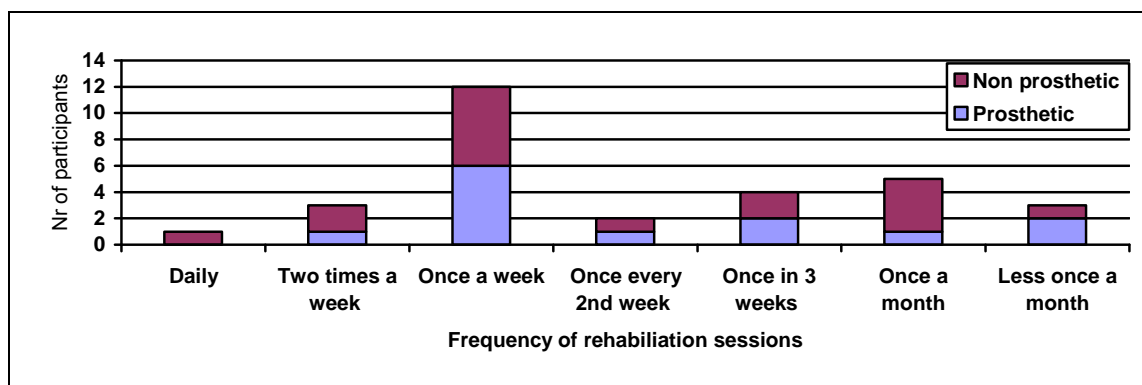


Figure 4.8: Frequency of rehabilitation sessions compared to type of rehabilitation (N = 30)

All the participants received individual treatment. According to therapists, treatment sessions were on average 30 minutes long. Clients felt that sessions were on average 30 minutes or longer, six clients indicated that treatment sessions were less than 30 minutes. Of the other 24, 16 said their treatment sessions were between 31 – 45 minutes and eight said they were between 46 – 60 minutes.

4.4.14 Termination of treatment

According to the therapists clients were discharged once all their goals were reached. Follow up of clients who received prostheses were done “*as needed*” (Therapist).

4.4.15 Community focus and involvement

When asked about the role of the programme in the community therapists said: “*...prevention program for the care givers and broader community because they are being educated about amputations and how to prevent secondary complications; clients have the opportunity to get rehabilitation near their homes; patients will be reintegrated to the community and it will help to prevent isolation*” (Therapist).

Therapists felt that the client’s family were very much involved in the programme, but that the broader community was not involved. They did no collaboration with other departments such as transport, labour and education or the private sector.

4.4.16 Barriers and challenges

Therapists identified client and service related challenges and limitations with regards to the programme. Client related challenges were:

- Transport problems
- Financial difficulty to attend sessions

Service related challenges were:

- Lack of resources
- Limited budget to buy equipment
- Lack of a wheelchair obstacle course
- Not being able to follow up clients as they were supposed to
- Long waiting times to see prosthetist
- Clients were sometimes discharged without assistive devices

These responses were not further explored.

4.5 Client satisfaction with the programme

Quantitative findings indicated high levels of client satisfaction with the programme. Fifteen participants indicated the services were very sufficient, while 13 indicated that the services were completely sufficient. All thirty clients found the staff to be very or extremely friendly and helpful. Clients felt that much or complete personal attention from staff was given to them. According to participants, they were seen punctually. Participants also experienced very little administrative problems. Two of the participants indicated that they found the process completely easy, 25 indicated that the process was very easy, and three has indicated that the process was mildly easy.

This trend was also seen in the meeting of expectations where three of the participants indicated that their expectations were not met while the rest indicated that their expectations were met. Similarly three of the participants had indicated that they were not happy with the rehabilitation they received.

However, qualitative data did expose some unhappiness on aspects like not receiving a prosthesis: “*would love to walk with prosthesis*” (client), prosthetic follow up: “*can replace my old prosthesis with a new one, because the current one is hurting me*” (client), too little prosthetic training, no counselling on stress management, a lack of support from therapists and: “*They rotate too much therapists*” (client), referring to the rotation of students at Elangeni. Lastly one of the clients indicated the therapist could have showed him how to do stump bandaging to cone the stump.

The staff at Elangeni was described as very friendly and well mannered. One client was very glad to be able to walk again and made the following statement: “*Can now walk*” (client). Lastly one client had indicated that she is now able to deal with her personal problems and was thankful for the positive feedback that was given by the therapist.

4.6 Programme outcomes

4.6.1 Compliance with preventative measures

According to 18 client participants they were taught measures to prevent further amputations. They rest said they did not receive this information. Table 4.5 provides a summary of the

data regarding participant compliance with measures that reduce the risk for further amputation. While the researcher acknowledges that preventative issues will be less applicable for persons who had amputations as a result of trauma they were not excluded from this question during data collection and answers reflect their practices as well. Where actions related to feet were concerned, the five bilateral amputees were scored not applicable.

Table 4.5: Participant compliance with preventative measures (N = 30)

Activity	Nr of participants		
	Yes	No	Not applicable
Smoke	11	19	0
Use medication as prescribed	27	2	1
Adhere to diabetic diet	11	10	9
Keep toenails short	21	1	8
Blood flow exercises	15	9	6
Daily washing and checking of the feet	20	2	8
Checking of water temperature	18	4	8
Fitting of shoes	18	4	8
Checking of shoes	19	2	9
Keep shoes in good repair	21	1	8
Wearing of clean socks	19	3	8
Go to the clinic for wounds and blisters	19	3	8
Make use of sunscreen	1	22	7
Soak feet in water	16	5	9
Cut corns	1	12	17
Walks barefoot	5	16	9
Making use of hot water bottles	3	22	5
Making use of chemical agents	2	20	8
Making use of heaters	3	18	9
Wearing of inappropriate shocks	3	18	9
Wear tongs	6	15	9
Making use of home remedies	5	16	9

A concern is the ten participants for whom it was relevant but did not adhere to a diabetic diet. Another concern is that nine of the participants did not do the blood flow exercises on a regular basis that can assist the prevention of future amputations especially since only two of the nine persons who did not do the exercises had the amputation done as a result of trauma.

Heartening findings were that only one client cut corns, three clients used a heater, three clients wore inappropriate socks and only five walked bare foot. Furthermore three made use of hot water bottles, two used chemical agents and five made use of home remedies.

4.6.2 Presence of secondary complications

As indicated in table 4.6 the most commonly experienced secondary complication was phantom limb pain (14). This was followed by joint and muscle tightness (13), stump pain (11) and depression (10).

Table 4.6: Presence of secondary complications in the past three months(N = 30)

Complication	Nr of participants suffering from it
Pain in the stump/s	11
Stump skin breakdown	4
Tightness in joints and muscles of the stump/s	13
Wounds on other leg/foot	3
Phantom pain that limits ability to function	14
Depression	10

4.6.3 Functional outcomes

Participants experienced few challenges with regard to function such as; self-care, mobility in and around the house, and domestic tasks.

Self-care activities presented the least problems to participants as 28 could wash and groom themselves while 27 could dress themselves. One indicated that it was very difficult to use the toilet; one indicated it was moderately difficult, while two indicated that they could not use

the toilet at all. The other twenty six participants experienced no difficulty with using the toilet. Similarly, two participants experienced severe to moderate difficulty with looking after their own health, two indicated that they could not do it at all; two indicated a little difficulty, while the other twenty four participants indicated no difficulty in this area. To live alone at home for a few days would not be possible for three participants while six indicated that it would be very difficult and another two indicated that it would be a little difficult.

As indicated by table 4.7 the main challenge around mobility was experienced with lifting and carrying objects.

Table 4.7: Participants residential mobility scores (N = 30)

Mobility	No Difficulty	A little difficult	Moderately difficult	Very difficult	Could not do	NA
Lifting and moving/carrying objects	6	3	3	5	12	1
Standing up from sitting	20		1		4	5
Walking inside the house	20			1	5	4
Getting around inside the house with a wheelchair/other device	24	3		1	2	
Doing transfers	25	1	1		3	
Get up from floor (e.g. from falls)	16	3		3	5	3
Leaving the house	21	4	1	1	3	
Going up and down stairs with a hand-rail	14	1	2	1	3	9
Moving around outside the house in the yard	20	2	4	1	3	

Preparing meals and doing chores in and around the house also did not pose great difficulties for most participants as table 4.8 indicates.

Table 4.8: Participants ability to participate in domestic life (N = 30)

Domestic life	No Difficulty	A little difficult	Moderately difficult	Very difficult	Could not do	NA
Preparing meals	19	3	2	2	1	3
Doing your normal chores in and around the house	15	6	4	2	2	1
Assisting others	14	7	4	2	2	1

The impact of prosthetic versus non prosthetic rehabilitation on residential integration scores were statistically analysed with the Mann-Whitney U test and results are presented in table 4.9. Significantly more participants who received prosthetic rehabilitation could walk in the house ($p = 0.039$), pick up objects from the floor ($p = 0.031$) get up from the floor ($p = 0.00069$), leave the house ($p = 0.023$), go up and down stairs with a handrail ($p = 0.037$) and move around in the yard ($p = 0.0069$) than those who did not receive prosthetic rehabilitation.

Table 4.9: The impact of prosthetic versus non prosthetic rehabilitation on residential mobility scores (N = 30)

Mann-Whitney U Test (Data in Analysis - 02Oct2011.stw)							
By variable Type of rehab							
Marked tests are significant at $p < .05000$							
Variable	Rank Sum Group 1	Rank Sum Group 2	U	Z	p-value	Valid N Group 1	Valid N Group 2
Lifting Objects	147.5000	287.5000	56.50000	-2.06109	0.039296	13	16
Standing from sitting	136.5000	188.5000	45.50000	-1.74057	0.081760	13	12
Walking in House	136.5000	214.5000	45.50000	-1.97436	0.048342	13	13
Getting around house	162.5000	302.5000	71.50000	-1.61129	0.107117	13	17
Pick objects off floor	149.5000	315.5000	58.50000	-2.15537	0.031134	13	17
Get up from floor	120.0000	345.0000	29.00000	-3.38999	0.000699	13	17

Leave house	143.0000	292.0000	52.00000	-2.25842	0.023920	13	16
Go up/down stairs with rails	126.0000	174.0000	35.00000	-2.08572	0.037005	13	11
Moving around yard	136.5000	328.5000	45.50000	-2.69944	0.006946	13	17

Spearman rank order correlations found that a lack of indoor mobility training had a statistically significant negative impact on the ability to lift and carry objects ($p = 0.011$), standing up from sitting ($p = 0.042$), getting around inside the house ($p = 0.00023$), picking up objects from the floor ($p = 0.00068$), getting up from the floor ($p = 0.0072$), leaving the house ($p = 0.0016$), going up and down stairs with a handrail ($p = 0.019$) and moving around in the yard ($p = 0.0013$) (table 4.10). Similarly a failure to identify and address environmental barriers during rehabilitation had an inverse relationship with doing chores in and around the house (-0.48).

Table 4.10: Impact of retraining indoor mobility on residential mobility scores (N = 30)

Spearman Rank Order Correlations (Data in Analysis - 02Oct2011.stw)				
MD pairwise deleted				
Marked correlations are significant at $p < .05000$				
Pair of Variables	Valid - N	Spearman - R	t(N-2)	p-value
Retr indoor mob & Lifting Objects	29	-0.464812	-2.72782	0.011070
Retr indoor mob & Standing from sitting	25	-0.408882	-2.14876	0.042413
Retr indoor mob & Walking in House	26	-0.408148	-2.19024	0.038459
Retr indoor mob & Get around house	30	-0.623463	-4.21954	0.000233
Retr indoor mob & Pick objects floor	30	-0.585055	-3.81732	0.000684
Retr indoor mob & Get up floor	30	-0.480422	-2.89857	0.007208
Retr indoor mob & Get out house	29	-0.558460	-3.49818	0.001641
Retr indoor mob & Up down stairs rails	24	-0.472964	-2.51781	0.019589
Retr indoor mob & moving around yard	30	-0.557947	-3.55761	0.001357

As indicated by table 4.11, failure to address community mobility during rehabilitation had a statistically negative impact on all aspects of residential mobility except lifting and carrying objects.

Table 4.11: The impact of retraining community mobility on residential mobility scores (N = 30)

Spearman Rank Order Correlations (Data in Analysis - 02Oct2011.stw)				
MD pairwise deleted				
Marked correlations are significant at $p < .05000$				
Pair of Variables	Valid - N	Spearman - R	t(N-2)	p-value
Retr com mob & Lifting Objects	29	-0.312707	-1.71066	0.098611
Retr com mob & Standing from sitting	25	-0.446132	-2.39067	0.025394
Retr com mob & Walking in House	26	-0.482463	-2.69840	0.012553
Retr com mob & Get around house	30	-0.464622	-2.77642	0.009689
Retr com mob & Pick objects floor	30	-0.559068	-3.56801	0.001320
Retr com mob & Get up floor	30	-0.621366	-4.19640	0.000248
Retr com mob & Get out house	29	-0.504755	-3.03822	0.005231
Retr com mob & Up down stairs rails	24	-0.698792	-4.58201	0.000146
Retr com mob & moving around yard	30	-0.560447	-3.58083	0.001277

4.6.4 Community integration

Table 4.12 indicates that clients experienced some problems with community mobility such as covering distances in excess of 1km, braving inclement weather and using various means of transportation.

Table 4.12: Participants community mobility scores (N = 30)

Community integration	No Difficulty	A little difficult	Moderately difficult	Very difficult	Could not do	NA
Going up and down stairs without a hand-rail	14	1	2	1	6	6
Going up and down a kerb	18			1	7	4
Walking/wheeling for a long distance – 1km or more	16		3	6	5	
Walking outside in bad weather (rain, strong wind)	11	1		10	8	
Using transport (Car, taxi, donkey cart)	18	4	6	1	1	
Driving (Car, bicycle, horse)	6			4	6	14

According to table 4.13 six participants indicated that they had moderate or severe difficulty with doing shopping and to access services like the post office or the bank, while one indicated inability to do it at all.

Table 4.13: Community integration scores (N = 30)

Community integration	No Difficulty	A little difficult	Moderately difficult	Very difficult	Could not do	NA
Doing shopping & accessing services like post office, bank etc.	10	5	5	6	1	3
Participating in religious activities	19	3	2	4	1	1
Participating in sport	4	1		1		24
Managing own finances	17	5	2		2	4
Participating in politics and citizenship			2		1	27

The Mann-Whitney U test indicated that prosthetic rehabilitation had a significantly positive effect on the ability to climb stairs ($p = 0.037$), go up and down a kerb ($p = 0.0082$) walk or wheel more than 1km (0.0089) and walk in inclement weather (0.017) (table 4.13).

Table 4.14: The impact of prosthetic versus non prosthetic rehabilitation on community integration scores (N = 30)

Mann-Whitney U Test (Data in Analysis - 02Oct2011.stw)							
By variable Type of rehab							
Marked tests are significant at $p < .05000$							
Variable	Rank Sum Group 1	Rank Sum Group 2	U	Z	p-value	Valid N Group 1	Valid N Group 2
Up down stairs without rails	126.0000	174.0000	35.00000	-2.08572	0.037005	13	11
Up Down kerb	123.5000	227.5000	32.50000	-2.64103	0.008266	13	13
Walking 1 km / more	138.5000	326.5000	47.50000	-2.61573	0.008904	13	17
Walk bad weather	144.0000	321.0000	53.00000	-2.38555	0.017054	13	17
Doing transfers	169.0000	296.0000	78.00000	-1.33926	0.180488	13	17
Using transport	161.5000	303.5000	70.50000	-1.65314	0.098303	13	17
Driving	19.0000	36.0000	9.00000	-0.53300	0.594033	4	6

According to the Spearman rank test, failure to address indoor mobility during rehabilitation had a statistically significant negative impact on going up and down stairs with-out a hand-rail ($p = 0.019$), going up and down a kerb ($p = 0.0022$), walking or wheeling 1km or more ($p = 0.0032$) and using transport ($p = 0.0034$) (table 4.15).

Table 4.15: The impact of retraining indoor mobility on community mobility scores (N = 30)

Spearman Rank Order Correlations (Data in Analysis - 02Oct2011.stw)				
MD pairwise deleted				
Marked correlations are significant at $p < .05000$				
Pair of Variables	Valid - N	Spearman - R	t(N-2)	p-value
Retr indoor mob & Up down stairs without rails	24	-0.472964	-2.51781	0.019589
Retr indoor mob & Up Down kerb	26	-0.571356	-3.41057	0.002297
Retr indoor mob & Walking 1 km/more	30	-0.519779	-3.21949	0.003241
Retr indoor mob & Walk bad weather	30	-0.342206	-1.92713	0.064166
Retr indoor mob & Doing transfers	30	-0.228596	-1.24252	0.224351
Retr indoor mob & Using transport	30	-0.386888	-2.22011	0.034681
Retr indoor mob & Driving	10	-0.102062	-0.29019	0.779050

Failure to address community mobility during rehabilitation had a statistically significant impact on all aspects of community mobility scores except doing transfers and driving as indicated by table 4.16.

Table 4.16: The impact of retraining community mobility on community mobility scores (N = 30)

Spearman Rank Order Correlations (Data in Analysis - 02Oct2011.stw)				
MD pairwise deleted				
Marked correlations are significant at $p < .05000$				
Pair of Variables	Valid – N	Spearman - R	t(N-2)	p-value
Retr com mob & Up down stairs without rails	24	-0.698792	-4.58201	0.000146
Retr com mob & Up Down kerb	26	-0.599644	-3.67083	0.001205
Retr com mob & Walking 1 km/more	30	-0.500108	-3.05593	0.004889
Retr com mob & Walk bad weather	30	-0.373630	-2.13143	0.041969
Retr com mob & Doing transfers	30	-0.310004	-1.72539	0.095480
Retr com mob & Using transport	30	-0.502289	-3.07374	0.004677
Retr com mob & Driving	10	-0.366618	-1.11456	0.297401

When asked about preparation for community integration, therapists indicated that the programme: “... *improve the general mobility of the patient on different surfaces*” (Therapist).

4.6.5 Productive activity

Table 4.17: Productive activity scores (N = 30)

Productive activity	No Difficulty	A little difficult	Moderately difficult	Very difficult	Could not do	NA
Working/going to school		1			1	28
Getting all your work done as you have to	4	2	3	1		20
Being economically self sufficient	1				15	14

According to table 4.17, 28 participants indicated that it was not applicable for them to work, and one indicated that it was not applicable to attend school, in addition 15 indicated that they were not economically self-sufficient.

4.7 Environmental factors

4.7.1 Products and technology

According to table 4.18 where environmental barriers were experienced, it was in the area of design and construction of private and public buildings. However, most aspects concerning products and technology were seen as facilitators by participants.

Table 4.18: Impact of products and technology on function (N = 30)

Factor	Barrier								Facilitator
	Complete	Severe	Moderate	Mild	No barrier or facilitator	Mild	Moderate	Severe	Complete
Personal Consumption									30
Personal use Electricity									30
Personal In and Outdoor mobility									30
Communication									30
Design, Construction public build.		2	3	2				1	22
Design, Construction private build.		2	3	2	1				22

4.7.2 The natural environment and human changes

As indicated by table 4.19 the aspects of the natural and human made environment were mostly experienced as neutral. The aspects which caused barriers in most instances were climate, temperature and terrain. These aspects were never complete barriers and only in eleven instances severe barriers.

Table 4.19: Impact of the natural environment and human made changes on function (N = 30)

Factor	Barrier			Facilitator			Facilitator		
	Complete	Severe	Moderate	Mild	No barrier or facilitator	Mild	Moderate	Severe	Complete
Climate / Temperature		3	4	1	19		1	1	1
Terrain		6	4	5	12		1	1	1
Lighting		1	2	1	20		1		5
Sound/Noise			1	1	25		1		2
Crowds		1	3	3	19		1	2	1

4.7.3 Support and relationships

According to table 4.20 immediate family and friends were seen by twenty five of the participants as complete facilitators, two saw them as severe facilitators while three saw them as severe to complete barriers.

Table 4.20: Impact of support and relationships on function (N = 30)

Factor	Barrier								Facilitator
	Complete	Severe	Moderate	Mild	No barrier or facilitator	Mild	Moderate	Severe	Complete
Immediate family	1	2						2	25
Friends	2	2							26
Acquaintances, colleagues, community members ECT	1			1			1	5	22
People in authority	1				10		4	3	12
Personal care providers						1	1	7	21
Health professionals			1			1		6	22

4.7.4 Attitudes, discrimination and prejudice

According to table 4.21 participants did not experience much discrimination, prejudice or negative attitude.

Table 4.21: Impact of attitudes, discrimination and prejudice on function (N = 30)

Factor	Barrier								Facilitator
	Complete	Severe	Moderate	Mild	No barrier or facilitator	Mild	Moderate	Severe	
Family members	2	2		1		1		1	23
Friends	1	1	1		1		1	1	24
Acquaintances, colleagues, community members ECT	1			2	2	1	3	3	18
People in authority	1				9	1	2	2	15
Personal care providers			1	1		1	2	6	19
Health professionals			1			1	3	5	20
Societal norms, practice and ideologies					9	2	2	6	11

4.7.5 Services, systems and policies

According to table 4.22 the biggest barrier in this respect according to participants was transport while the biggest facilitators were housing, communication and general social support.

Table 4.22: Impact of services, systems and policies on function (N = 30)

Factor	Barrier								Facilitator
	Complete	Severe	Moderate	Mild	No barrier or facilitator	Mild	Moderate	Severe	Complete
Housing								2	28
Communication								1	29
Information							4	3	23
Transport	2	2	1		2	1		1	21
Legal	1			1	12	1	2	3	10
Social security					3		1	5	21
Social support			1		1			2	26
Health care						1	2	4	23
Education/ Training					10	3	2	1	14
Labour					29				1

When therapists were asked about the environmental barriers most often encountered by the clients and how they addressed these they focused on the home environment: “We will look if there is enough space inside and outside the patient house to move around” and “We will assess the bathroom if any adjustments will be needed to make” (Therapist). In addition, they will do home visits to assess aspects like sand, grass, rocky terrain, stairs, curbs and hills.

4.8 Recommendations to improve the services at Elangeni

One of the therapists working at Elangeni said “*First I would say the expansion of the physical building*” and “*state of the art equipment*”. The need for a wheelchair mobility course was indicated. The therapists also emphasised the need for an increased budget and an increase in the number of therapists. Furthermore, they identified a need to run preventative programmes in the community and to link up with NGO’s or companies for work placement of clients.

Recommendations that were made by client participants were that Elangeni should arrange transport for them to attend rehabilitation sessions.

4.9 Summary

The majority of participants were males (20), between the ages of 41 and 60 (14) years old. One participant was employed and 22 received a disability grant from the government. The most prevalent problems experienced by clients according to the results were problems such as unemployment which was the main reason for client’s low income. Participants experienced transport and financial challenges with regard to accessing rehabilitation services. Another problem was the lack of proper counselling following client’s amputations. The lack to address issues such as community mobility, identifying and addressing transport problems, as well as environmental barriers and no home visits seems to be also problematic. No written or verbal mission statement, vision or programme objectives could be identified for the programme. There was not enough information available on programme inputs to determine programme efficiency. No outcome measures were used during assessments. Goals and treatment were impairment focused with no attention on community integration and economic self-sufficiency. Clients indicated high levels of satisfaction with the programme and experienced few preventable secondary complications. Prosthetic rehabilitation was found to have a significantly positive impact on the ability to get up from the floor, negotiate stairs and kerbs as well as walking or propelling more than 1km, and in inclement weather. A failure to address community integration during rehabilitation had a statistically significant negative impact on carrying objects, standing up from sitting, walking inside the house, doing transfers, getting up from the floor, climbing stairs, getting out of the house, moving around in the yard, going up and down kerbs, walking or wheeling more than 1km, walking in bad

weather and using transport. The design and construction of private and public buildings, climate, terrain and transport were identified by clients as their biggest environmental barriers.

Chapter 5

Discussion

5.1 Introduction

The findings of the study will be discussed in an integrated manner in chapter five in order to highlight the positive aspects as well as the needs and challenges with which amputee rehabilitation at Elangeni is faced.

5.2 Demographic and amputation profile of the study population

The demographic profile of the population reflected a group of people with poor socio-economic circumstances, who were dependent on government services for health care and assistive devices, as can be expected from a study done in a government health care facility. The population consisted of twenty males, one African and nineteen coloured, and ten coloured females. This increased ratio of males to females is in accordance with study findings by Bakkes (1999), Kidmas et al (2004), Asano et al (2008), and Gutacker et al (2010) which indicate that men have a higher amputation incidence rate than women in both industrialised and developing nations.

The majority of the participants (21) were younger than 60 years old, a finding similar to the results from other African studies (Kidmas et al, 2004; Bakkes 1999). In contrast with these findings, Hendry (1993) found in a Tygerberg study, a mean age of 60.3 years. It appears that the age of amputation is decreasing in the Western Cape. This might, in part, be due to high violence figures in the area. The Paarl area has a violent crime incidence rate of 12.36% - 18.67% (Unit for Religion and Development Research, 2006). However, only four (13%) of the amputations in the current study were due to trauma which means that vascular conditions and DM caused amputations at relatively younger ages in the current study population. According to literature, possible reasons for this might be multifaceted and related to race, the stage of development of South Africa and poverty. Chronic vascular conditions occur generally in younger individuals in developing countries than in developed countries (Yusuf, Reddy, Ôunpoo & Anand, 2001). In addition conditions such as hypertension occurs at a younger age in the coloured and black population groups, of which

the current study participants were members, in South Africa, compared to the white and Indian population groups (Smith, Kok, Rothberg, Groeneveld, 1995). Finally poverty caused increased vulnerability to chronic vascular diseases (Yusuf et al, 2001). The current study population can be described as poor since only one participant had an income of more than R2000.00 per month.

The findings also pointed to a lower rate of traumatic amputations than what was found by Bakkes (1999) and Kidmas et al (2004) and were more in line with findings from Hendry (1993) and findings from developed countries (Unwick et al, 2009). Another finding that was in conflict with literature from Africa and South Africa (Hendry, 1993; Kidmas et al, 2004) was that the majority of amputations (16, 60%) were performed at a trans tibial level.

The researcher has no explanation for these conflicting findings and realised that a study population of 30 participants may have been too few to draw any epidemiological inferences from. However, the findings, together with a shortage of literature on the subject indicated a need for epidemiological studies on amputations in the Western Cape, South Africa and Africa since it is virtually impossible to plan services and design rehabilitation programmes without adequate epidemiological data.

5.3 Programme inputs and outputs (efficiency)

No information on programme inputs such as allocation of funding and therapist time was available. This made it impossible to determine programme outputs or efficiency. While it was expected that specific allocation of funds and therapist time for specific programmes might not be available since therapists treat clients with various diagnoses it was not expected that no annual budgets and annual reports would be available. Nor was it expected that no statistics on client numbers and conditions and treatment periods or units would be kept. The author expected this information to be available and that he would be able to use this to make some determination of financial and therapist time input into the programme. This lack of statistics and poor record keeping necessitates some discussion on the topic although it was not one of the objectives of the study.

5.4 Statistics and records

A poor state of recording and retaining of information on services and statistics was found throughout the study. No output, such as for instance, recording head counts of the number of clients treated per day, was measured. In fact, all documentation seemed to be treated as of little or no importance since, in many instances, not even client clinical notes, which are legal documents (Health professional's council of South Africa (HPCSA), 2008; Netina, 2011), could be found. In addition, to being legal documents there are other reasons for storing client notes such as the performing of clinical audits, teaching and research and for administrative purposes (HPCSA, 2008). According to the HPCSA (2008) clinical records should be stored for no less than six years after the final consultation with the client. Of the 24 client folders that could not be located in the current study twenty two were still within the prescribed six year period. Where records are stored in electronic format a backup copy must be stored in a different physical location from the original (HPCSA, 2008). This procedure was not followed, even after repeated computer theft. Thus the therapists were left with no records. They also made no attempt to capture at least some of the lost information such as client contact details, in order to ensure follow up services.

In addition the inability to produce statistics had serious auditing implications. The therapists were unable to provide any verification of how they spent their days and if the money spent on the Centre was actually worthwhile. Therapists indicated a need for more resources and additional staff. Without the above data, it will be impossible to motivate for these resources. The seriousness of the situation is underscored by the fact that according to the grapevine the Western Cape Department of Health (WCDoH) is looking into closing down Elangeni and using the site for offices. This rumour could however not be substantiated. Despite this, lack of the proper adherence to the protocols described above could very well lead to the closure of a rehabilitation facility such as Elangeni.

5.5 The lower limb amputee rehabilitation programme at Elangeni

5.5.1 Vision, mission and objectives

The use of the term rehabilitation programme is a misnomer since no evidence of a programme could be found during the study. No written protocol or vision and mission statements existed with regard to amputation rehabilitation at Elangeni. Neither could the therapists verbalise mission or vision statements during the interview. They made no attempt to answer the question related to the vision and mission of amputee rehabilitation. No programme or treatment objectives were documented or could be articulated by the therapists during the interviews. In addition, the length of the treatment period and number of sessions per week seemed to be randomly decided, depending on client funds and transport rather than on client needs.

This lack of vision and objectives might be one of the reasons why the programme failed to address certain very important rehabilitation aspects such as community mobility and integration, economic self-sufficiency of clients, liaison with local government and other district and provincial departments and the community as well as equalisation of opportunities. Even though therapists indicated that community re-integration of clients was one of the advantages of the programme, the findings indicated that community integration was poorly addressed during rehabilitation. Furthermore, it showed a lack of insight into the importance of programme monitoring and measurement since one cannot monitor and evaluate a programme if it does not have measurable objectives (Kettner et al, 1999).

No treatment protocols or pathways existed on paper, but according to findings, treatments did follow a predictive pattern and were mostly impairment focused as a progression through the discussion will show.

5.5.2 Waiting periods

A heartening finding was that 42% of clients waited 30 days or less to start with their rehabilitation. On the other hand a waiting period of more than 30 days and even more than 90 days as experienced by 14% of clients in each instance is worrying. The clients who received rehabilitation more than 90 days is a huge concern. According to (McColl et al,

2001; Schoppen, Boonstra, Groothoff, Van Sonderen, Goeken and Eisma, 2001a; Bruins, Geertzen, Groothof, Schoppen, 2003; Pedretti, 2006; Burger and Marincek, 2007; Manderson & Warren 2010 and WCDoH, 2010) the clients will have missed out on important rehabilitation interventions that were necessary for them to reach their optimal level of functioning. These clients will have limitations of how to take care of their stumps. They will not be informed about how to prevent secondary complications and they will lack the knowledge and the skills for proper mobility. Another scenario might be that some of these clients will miss the opportunity to be referred to other health care professionals, such as referrals to the psychologist for counselling and most important referrals for a possible prosthesis. Lastly these clients will not be fully reintegrated into the community and the possibility exists that they will also have little knowledge in terms of their rights as a person with a disability, especially in the field of employment.

This is especially true in instances where a person will receive a prosthesis, as 57.8% of the study population did, since earlier prosthetic fit leads to improved prosthetic outcomes (Gauthier – Gagnon et al, 1998). There was unfortunately not enough data available to determine how long clients waited for their prostheses.

5.5.3 Assessment, goal setting and teamwork

Rehabilitation is a “goal-oriented” process (DoH, 2000). An effective goal is to adhere to certain criteria such as; being client centred, appropriate, specific, realistic, participation focused, measurable and time limited (http://en.wikipedia.org/wiki/Goal_Setting; Visagie, 2008). In order to be able to set goals according to the above criteria, it is essential that a comprehensive client assessment is done during which valid, reliable and relevant measuring instruments are used (Landrum et al, 1995). According to the description provided by the therapists in the current study, their assessment focused on impairments such as muscle strength, range of movement, balance and gait. No mention was made of assessing the home environment, community integration and participation needs or assessing contextual barriers and facilitators. The lack of these requirements are further exposed when findings are triangulated with client data which indicates that transport problems and environmental barriers were poorly assessed in 26 and 27 instances respectively. In addition, therapists referred to re-assessment and measurement of progress; however, no measuring instruments

were used. Thus it was very difficult to quantify progress or even determine if progress was achieved.

According to the therapists, treatment goals were set and clients were involved in setting these. However, twelve of clients did not agree with this observation and the use of “for” by the therapists in the statement on goal setting (“*Goal setting for the patients*”) creates further doubt about client involvement in this process. In addition, three of the clients indicated that not all of their rehabilitation needs were addressed. One would expect all a client’s needs to be addressed if he/she were included in the goal setting process. Furthermore, no clear indication or evidence that goal setting was done could be found during the folder audit.

Since no written examples of goals could be found in folders it was not possible to assess goals according to the characteristics of an effective goal. Thus the researcher used the findings on what treatment entailed, from folder audits and participants, to shed some light on the probable nature of goals. This information paints a picture of treatment that was impairment and activity focused with strengthening and endurance training, exercises in the parallel bars, walking and activities of daily living forming the majority of activities. Treatment and thus goals seemed to be generic and not participation focused.

Goal setting and the way in which goals are set is closely related to the teamwork approach followed by the professional team (http://en.wikipedia.org/wiki/Goal_Setting). Comprehensive rehabilitation is best provided through a client centred multi-disciplinary or interdisciplinary process (Suddick & De Souza, 2006). The interdisciplinary teamwork approach is the most suitable model for rehabilitation, but literature acknowledges the challenges and struggles associated with it (Suddick & De Souza, 2006). However, the intimacy of the unit at Elangeni lends itself to an interdisciplinary teamwork approach. But the therapists gave no indication that they were aware of, or used an interdisciplinary teamwork approach. In inter disciplinary teamwork the client is an essential part of the team and treatment goals are set by the professional team in conjunction with the client. One set of integrated goals are used instead of every profession setting their own goals (Suddick & De Souza, 2006). Including clients in the planning of their treatment gives them a sense of belonging and allows them to take ownership for their rehabilitation.

This perceived failure to set client centred, participation focused goals might have caused the impairment focused routine like nature of rehabilitation in a setting where one would have expected a much larger focus on the environment and participation.

5.5.4 Treatment

As indicated above treatment was impairment focused and seemed to follow a set routine even to the point where therapists indicated that prosthetic and non-prosthetic rehabilitation was the same except for prosthetic training. While some aspects are expected to be similar one would definitely want a shift of focus for instance, because a client who would receive a prosthesis would require much more input into stump preparation with regards to maturation, strength and range of motion than clients who would use a wheelchair or crutches for mobility. In their case however, there needed to be a focus on upper limb strength that surpassed this need in prosthetic users.

A difference in treatment should become especially obvious as treatment progresses towards residential and community integration and participation. The wheelchair user requires wheelchair dexterity and transfer skills, an environmental and home assessment and management strategies focused on wheelchair access (Routhier, Vincent, Desrosiers & Nadeau, 2003), while the prosthetic walker requires mobility training with the prostheses in these different environments (Manderson & Warren, 2010).

All data sources were in agreement that muscle strengthening formed an important part of amputee rehabilitation at Elangeni. However, further information points towards generic strengthening programmes, rather than exercise programmes tailor made for the requirements and abilities of each individual client. Another aspect of rehabilitation which was covered adequately according to therapists and clients were education on the prevention of secondary complications. This is further discussed under programme outcomes.

On the other hand counselling was neglected. Therapist's claimed to do it, but when triangulated with patient data a different picture emerged. According to the participants, 21 of them received no counselling and 10 indicated depression as a complication that they experienced in the three months before the study. Even in instances where participants indicated that counselling was done, the effectiveness of the counselling was in question.

One of the participants indicated that she received extensive counselling, but she still experienced symptoms of depression. This specific client would have benefited from a referral to a psychologist or psychiatrist. Services that was available at TC Newman Day hospital which is situated opposite Elangeni.

Findings on stump care training and maturation were mixed. Although 12 of the client participants indicated that a fair or extensive amount of education on stump care was done information from both the clients and folder audits indicated that little attention was given to stump desensitisation, scar tissue massage and stump maturation. This left at least one participant with a stump which was poorly prepared for prosthetic fit. A prosthesis is an expensive device and successful prosthetic outcomes are very much dependent on a well prepared stump. If this area is neglected prosthetic rehabilitation might be unsuccessful with a resultant waste of money and negative psychological implications for the client.

The one area of treatment which seemed especially unfocussed and rather redundant was prosthetic rehabilitation. Acute prosthetic rehabilitation was not done at Elangeni, but at the Western Cape Rehabilitation Centre (WCRC). Once the acute part has been completed and the client was proficient enough with the prosthesis to be discharged to his/her home environment, he/she was referred to Elangeni where the community integration and productive activity parts of the rehabilitation process should have been done (WCDoH, 2007). Thus the focus of prosthetic rehabilitation at the Elangeni should be on community integration.

However, according to the therapists at Elangeni, prosthetic training provided by them included the following aspects: assessing the fit of the prosthesis, discussing with the client whether they will use crutches with the prosthesis, static and dynamic balance re-training as well as weight transfer onto the prosthetic leg in the parallel bars. These aspects were covered at the WCRC at the beginning of prosthetic training. On the other hand little attention was given to outside mobility, the negotiation of uneven terrain, slopes, busy streets, escalators and how to get in and out of cars, busses or trains as applicable, all important components of prosthetic rehabilitation (Manderson & Warren 2010).

The importance of prosthetic rehabilitation is brought home by the fact that, in spite of challenges in the rehabilitation provided, clients with prostheses still performed significantly better in various areas of domestic and community integration such as the ability to get up

from the floor, negotiate stairs and kerbs, walking or propelling more than 1km and walking in inclement weather. This improvement in function can in part be attributed to the prostheses, since a prosthesis allows walking, which decreases the barriers caused by the constructed and natural environment. It must however, be pointed out that individuals who received prostheses from the PGWC are by nature of the selection process fitter and more functionally able than their non-prosthetic counterparts (WCDoH, 2010) which could influence the above findings and prevent one from attributing them solely to the prosthesis. However, the positive impact on function cannot be ignored and one would like every person who could possibly function with a prosthesis to receive one. This might not have been the case for the current participants, since the guidelines provided by the PGWC (WCDoH, 2010) to determine if a client was a prosthetic candidate or not were not used. Only one of the criteria used, i.e. the ability to mobilise with ease with elbow crutches was actually in accordance with the guidelines. The other criteria used lacked specificity and sensitivity and might lead to incorrect decisions in this regard. The guidelines were researched (Bakkes, 1999) and should be used by all government institutions in the Western Cape Province. Why the therapists in the current study chose not to use them was not explored.

While crutches and walking frames were supplied to all clients who needed them, prostheses and wheelchairs were not. Many people who underwent lower limb amputations never learned to walk again or can manage to walk only short distances, leaving them dependent on a wheelchair for mobility (Rommeers et al, 2001; Manderson & Warren 2010). In the current study eight clients were waiting for wheelchairs.

One does not know whether their names were on Elangeni's waiting list since this was lost with the computer. What is difficult to understand is that the names of these eight clients who were waiting for wheelchairs could not be found on the provincial waiting list. According to the South African national guidelines on the standardisation of the provision of mobility assistive devices (DOH, 2003) in instances where wheelchairs are unavailable, the clients' particulars should be entered on the PGWC database form and the form submitted to PGWC head office. The therapists at the different institutions such as Elangeni are responsible for sending this information to the head office of the Department of Health and they must keep a copy. One can only surmise that client's names were never submitted to this list. However, the therapists indicated that there were no funds for wheelchairs and wheelchair cushions.

This information leaves one with the expectation that they would have submitted the names to the provincial waiting list. When funding becomes available, the clients whose names are on the waiting lists will be provided with a wheelchair (DOH, 2003). However, if not on the list clients cannot benefit from this service (DOH, 2003). Furthermore this waiting list is used to motivate for funds. If client names are not put on the list one cannot accurately quantify the need and thus motivate for funds to address the need.

Finally if a waiting list for devices was on the computer and it was lost, some measures must be taken to try and recapture the information such as; notices at the local clinic, the community centre, Paarl Hospital and in the local press. In addition, four clients bought their own wheelchairs. This would have put severe strain on their already meagre financial resources.

The training of wheelchair mobility is essential to ensure functioning and safety (PGWC, 2009). In instances where clients are unable to perform wheelchair dexterity activities on their own a caregiver must be taught how to assist them with the activities (PGWC, 2009). Some of the clients did indicate that they were trained to do different transfers including car, toilet, bath, wheelchair and chair.

No information could be found on the two clients waiting for prostheses. Since neither the Orthotic and Prosthetic centre nor the therapists at Elangeni had any information on them one can assume that they had been lost in the system. The responsibility belongs both to the prosthetist and the treating therapist. Clients should be followed up until they receive their prostheses.

Elbow crutches are preferred for amputees since their use promotes a more natural posture (Visagie 2004, WCDoH, 2010). Of the study participants six used walking frames. This seems a rather high number in the light of the relatively low ages of participants. Walking frames are cumbersome and limits the user's ability to climb stairs walk in narrow spaces, use public transport and walk amongst crowds.

5.5.5 Follow up

Part of comprehensive rehabilitation is to follow up clients that were discharged until there is no further need. In instances where clients received assistive devices such as prostheses and wheelchairs, that need does not stop while they are alive since these devices wear out and must be serviced and replaced (WHO, 2008; Manderson & Warren, 2010). While therapists indicated that this was done at least one client indicated it to be untrue and did not receive the required follow up and assistance with his prosthesis.

Furthermore, one seriously needs to question how follow up is done without client records. If there was no information to supply to the researcher to identify study participants then there was almost certainly also no information that could be used to identify clients that must be followed up. Elangeni has an open door policy, but in the researcher's experience, very few clients make use of this type of policy. Assessing one's own health needs and utilising an open door policy is part of an empowerment process that begins with guidance towards self-directed health monitoring which was only partially addressed during rehabilitation as findings indicated. To improve client follow-up in the community, one might consider the possibility where Elangeni could work with community based organisations as a way to follow-up their clients. Community based organisations with which Elangeni can work are the Hospice and the home based carer's services that are available in the Paarl area.

5.6 Outcome measurement

Therapists indicated that client's progress were constantly re-assessed or compared from one session to the next. However, the process was entirely subjective and based on the therapist's opinion. No outcome measures such as; level of function scales or standardised measures were used. Thus therapists have no way of gauging the impact of their interventions. According to findings from the folder audit and clients, therapy included muscle strengthening and range of movement exercises. However, range of movement and muscle strength were not measured and recorded. This raises the question on how the need for these activities was determined, how individual strengthening programmes were developed and progressed according to client need, and how therapists decided when these activities could be terminated.

With regards to overall client progress, vague statements such as clients are discharged when they reached their highest functional level were made. However, by whom and how this decision was made is unclear. Finally, no participation measurement was used, which might be one of the reasons why no attention was given to community integration and participation during the rehabilitation process. In addition, this lack of measuring of client status might have impacted negatively on the therapist's ability to set appropriate treatment goals.

There is no way to prove that clients indeed progressed and that the services provided were efficient, i.e. that both government and client received value for their money.

Measuring functional progress has the added advantage of motivating clients since they can see their progress.

Furthermore the rehabilitation programme was not monitored and evaluated. If monitoring and evaluation processes were in place the challenges identified in the current study could have been identified and rectified as they arose.

5.7 Client satisfaction with the programme

Most of the clients were satisfied with the services they received at Elangeni. According to the clients, the staff at Elangeni were always very friendly, supportive and well mannered. Clients could only speak well about the way they were treated. Another aspect that clients were very satisfied with and which they appreciated was that they could make appointments and were seen promptly at that time. This arrangement worked very well and is a positive finding in a government health care system where clients often spent entire days waiting to be assisted (Day & Gray, 2008).

However, the issues raised through qualitative data such as; poor stump maturation, too little prosthetic training, too little counselling and lack of follow up points towards the same challenges which were identified through the quantitative data.

5.8 Education, and prevention of secondary complications

A positive finding was that the clients received education on the prevention of secondary complications. They had a sound knowledge of aspects that might lead to common complications and according to the results most of this was adhered to except for smoking and following a diabetic diet in some instances. In this regard, a further heartening finding was that no-one was excluded from the study because they suffered further amputations, the ultimate secondary complication in a population of vascular amputees.

The second most commonly experienced secondary complication was joint and muscle stiffness. This problem could have been caused by two reasons or a combination of the two reasons. It is possible that stretching and positioning was not taught well enough during rehabilitation, or that clients did not comply with what was taught regarding these aspects at home. A set of positioning rules should go a long way towards alleviating this problem, but no evidence was found in the data that stump positioning was discussed with clients.

Two other findings in this regard raise concerns. Firstly, the ten clients that suffered from depression. The lack of effective counselling and effective use of the available referral services were addressed earlier. However, the depression might be aggravated by functional limitations and financial struggles. Thus the failure to address community mobility and integration and participation, during rehabilitation might also play a role here. Secondly, the three clients with wounds on the stump; these are generally caused by poor fitting prostheses. This brings us back to the lack of follow up. This is an aspect of the service that must be improved without delay.

5.9 Residential integration

While ICF scores indicated that clients experienced few problems with most aspects of functioning in and around the house, a lack of specific rehabilitation, in this instance indoor mobility training, already shows a negative impact on aspects such as getting around outside the house, doing chores and assisting others.

Therapists referred to actions that should be taken during home visits when asked about community mobility. While correct, one has to conclude that the aspects listed by them came

from cognitive knowledge and not practical implementation since no home visits were performed during which these assessments could have been done.

Therapists should do home visits. They have transport available for this purpose and none of the participants lived further than 20kms from Elangeni.

5.10 Community mobility and integration

A lack of focus on community integration such as identification and addressing of environmental barriers and retraining of community mobility were arguably one of the programmes biggest shortfalls. Statistical analysis showed that lack of training community mobility had a statistically significant impact on all aspects of domestic and community mobility except for driving a vehicle. Eighteen clients indicated limited or no training in this regard. The challenges with regards to community mobility were further exposed by ICF scores where twenty four clients could not drive, eighteen could not walk/propel outside in inclement weather, eleven could not travel more than 1 km on foot or in the wheelchair and eight could not negotiate kerbs. These findings lead one to conclude that not enough focus was placed on community integration.

Most of the mobility training was done at the centre and opportunities were not created to address the mobility of clients in the community. Therapists said that one of the things that would improve their service is a wheelchair obstacle course. While helpful such a course is still artificial and the therapists at Elangeni have the advantage of working in the community. They can exit the gates of the centre to find the very streets and obstacles that clients have to negotiate daily. Community mobility cannot be treated at the centre with simulation activities only. One needs to go with clients and assist clients with using the wheelchair, crutches and prosthesis in real life situations in the community.

Part of community mobility is accessing public transport. It is important that the therapists at Elangeni ensure that clients are able to make use of the taxis and trains. While therapists said the programme facilitated community integration and indicated that they were aware of transport problems, no liaison with the department of transport or with the local municipality was done.

In addition, many participants indicated that participation in sport (24) and citizenship (27) were non applicable to them. One could argue that at the age of 40 and older many persons give up sport, but what about citizenship? Were they really not interested or did the lack of mobility retraining leave them with an inability to pursue this? Or did they not receive the necessary mobility devices to pursue this?

5.11 Productive activity

One of the cornerstones of rehabilitation is reintegration of the individual into the community as an independent and productive member of society (Office of the Deputy president 1997; DoH 2000; McColl et al, 2001). The rehabilitation programme has failed its clients in this regard as 26 participants (86%) cited the amputation as the reason for their unemployment. Even if they had already lost their jobs at the time they accessed Elangeni for rehabilitation, service providers did have some responsibility in this regard such as; making contact with the previous employer and determining if re-instatement of the person was not a possibility. Study findings indicate that no liaison with employers occurred.

Re-employment figures compare badly with international figures that indicate a 60% to 87% return to work rate (Schoppen, Boonstra, Groothoff, de Vries, Göeken & Eisma, 2001b; Burger & Marinček, 2007; MacKenzie, Bosse, Kellam, Pollak, Webb, Swiontkowski, Smith D, Sanders, Jones, Starr, McAndrew, Pattersonh, Burgess, Trivison & Castillo, 2006).

However, there is a need to place employment figures into context. General unemployment rates in South Africa are high at 25.5% (Statssa, 2006) and the clients had a low level of education, both aspects that make it difficult to find employment (MacKenzie et al, 2006). On the other hand legislation in South Africa guarantees no discrimination and employment equity for designated groups that includes persons with disabilities (Employment Equity Act, 55 of 1998). In addition, the Code of Good Conduct (The Technical Assistance Guidelines on the Employment of People with Disabilities, 2002) and the Technical Assistance Guidelines (TAG) provide guidance with regards to implementation of employment equity legislation for persons with disabilities (TAG, 2002). The staff at Elangeni has the responsibility to empower the amputees so that they can familiarize themselves with the content of these documents to apply them in their lives. Employers have the responsibility to ensure that reasonable accommodations are in place for people with disabilities at the workplace. Therapists have

the responsibility to assist both the employer and the client with identifying what accommodations are needed and how they can best be provided.

It would have been ideal if clients were equipped with skills or referred to vocational rehabilitation. However, no participant was referred for vocational assessment or rehabilitation. The researcher acknowledges that it would be a challenge for these participants to access vocational rehabilitation since this particular service is not provided in the Paarl area. Vocational rehabilitation is only provided at the tertiary hospitals in the Western Cape Province (Gcaza & Visagie, 2008) which makes it difficult to access for clients living in rural areas.

Another very important part of rehabilitation at primary level is community liaison and liaison with various local and provincial departments such as; the municipality, the departments of labour, transport and education. In addition, rehabilitation therapists at primary level should be involved in mobilising community resources and play an advocacy role (DoH, 2000; Pollard & Sakellariou, 2008). The therapists should have initiated processes with the Department of Labour, the local municipality and private businesses in the area in order to identify employment and training opportunities for clients. There are companies such as Pick n Pay and Woolworths that do employ persons with disabilities. Therapists could have approached local branches of these companies and come to agreements with regard to placement of clients who have completed their rehabilitation. A process that was implemented with some success by the Association for the Physically Disabled in a neighbouring town (Breede Valley APD, 2011). This could be to the advantage of all the clients of Elangeni, not only those with amputations.

One of the participants was a scholar and for this participant re-integration into the schooling system was crucial. However, she dropped out of school after the amputation and consequently did not finish her school career. Again it appeared as if very little effort was made to assist this student to go back to school. No mention of counselling or discussion regarding going back to school with her or her parents, school visits or referral to education authorities could be found in her folder. During the interview with her she also indicated that she was not supported by the rehabilitation team in this regard.

The above findings that point towards severe challenges in the rehabilitation programme with regards to community integration and productive activity are in accordance with findings by Henn (2009). These two studies differ hugely with regards to design, setting, participants and instruments. However, both indicated challenges with regards to community integration and productive activity. This leads one to ask questions about the general rehabilitation philosophy in South Africa. CBR has been propagated in policy documents for the last 15 years. However, results from the above mentioned studies, albeit small and isolated generate the thought that CBR has not been accepted in the hearts and minds of managers, service providers and even clients. Changes in rehabilitation service provision from individualised medical model institution based rehabilitation to social model community based rehabilitation are not seen in practice. Possible reasons might be that:

- Managers, providers and clients have not bought into CBR
- CBR is seen as a strategy to be delivered in rural out posts by community workers not as part of rehabilitation as provided by professionals
- Weak management with no real commitment to improve the performance of health systems (Frenk, Chen, Bhutta, Cohen, Crisp, Evans, Fineberg, Garcia, Ke, Kelley, Kistnasamy, Meleis, Naylor, Pablos-Mendez, Reddy, Scrimshaw, Sepulveda, Serwadda, Zurayk , 2010)
- Professional education in medical fields is provided according to outdated curricula. As a result graduates have a narrow technical focus and tend to provide episodic care of a predominantly hospital based nature. They show limited understanding of the broader context of health and are not equipped to deal with patient and population needs on a continuous basis (Olaogun, Nyante, Ajediran, 2009; Pollard & Sakellariou, 2008 Frenk et al, 2010).
- Policy is not supported by practical implementation, resources and research (Pollard & Sakellariou, 2008).

CBR is complex and cannot be contained in a set of routine activities that service providers can be taught (Pollard & Sakellariou, 2008, Olaogun et al, 2009) Service providers need to adapt strategies on the ground as required for individual persons, communities and situations. Varying conditions, environments and needs present different opportunities and challenges

which must be assessed continuously and incorporated into strategy in order to ensure successful outcomes (Pollard & Sakellariou, 2008).

5.12 Environmental factors

As can be expected for a group of participants that suffers from a condition that impacts severely on mobility, design and construction of public and private buildings, climate and terrain were the environmental aspects that created the biggest barriers for participants. What is surprising is that all participants indicated in and outdoor mobility as a complete facilitator, especially since aspects related to this were identified as troublesome under 4.6.3 and 4.6.4. A positive finding was that clients experienced very little attitudinal barriers. Amongst services, systems and policies, transport services provided the biggest barrier.

Individual rehabilitation such as in and outdoor mobility training will assist some in addressing these barriers, however, the only way to really address and eradicate most of the above mentioned barriers is through universal design that insures access for everybody whether walking with a frame or using a wheelchair. While expensive to change existing structures incorporating universal access principle into new designs do not add much to overall construction expenses. All that is required is awareness raising and a communal will to apply the principles of universal design.

5.13 Programme challenges and barriers

Aspects that had a negative impact on client's ability to access rehabilitation were finances, transport and bad weather. Most of the participants lived poor socio-economic circumstances. Twenty six of them survived on a monthly income of between R1001 – R2000. This might be the reason why they sometimes did not have money for transport to attend rehabilitation sessions. Fourteen of the participants indicated that they had to pay more than R20.00 per session for transport to Elangeni. Thus it will cost them R60.00 to attend 3 sessions a week or R280.00 per month, i.e. more than a quarter of the disability grant. Therefore every session must be focused on the participants specific needs and provide the best possible value for money.

In addition, it drives home the importance of providing the client with the ability to use public transport and to advocate for suitable public transport services in the community. Secondly, therapists do have transport and some treatment sessions at home or in the community will be much more participation focused and can save the client money.

Service related challenges centred on resources. However, as already indicated in earlier discussion, it is virtually impossible to substantiate this need and address it without the necessary statistics.

5.14 Summary

Amputee rehabilitation at Elangeni was not underscored by a vision, mission or measurable objectives. The research findings pointed towards success with regards to client education and client implementation of preventative practices and shows high levels of client satisfaction. However, the rehabilitation provided was impairment focused and showed a lack of focus on community integration and productive activity. In addition, serious omissions with regard to keeping of client records as well as client and programme statistics were identified.

Chapter 6

Conclusion and recommendations

6.1 Conclusion to the study

With the establishment of Elangeni, the purpose for the centre was that Elangeni should provide a comprehensive rehabilitation service to all its clients. Services at Elangeni were to move away from the impairment focused, medical model, individual approach previously utilised at Paarl hospital. The focus should have shifted to social integration, equalisation of opportunities and collaboration as required by the social model of rehabilitation and underscored by the NRP and CBR principles (DoH, 2000; WHO, 2004; Bury, 2005). However study results indicated that for the current study population, Elangeni failed to implement a shift to the social model of disability and rehabilitation, and services were still provided according to the impairment focused medical model.

On an individual client level, the programme was impairment focused and issues such as community integration and participation in life roles were neglected. On a societal level, no evidence could be found of promotion and protection of the rights of persons with disabilities and inclusion of persons with disabilities through intersectoral collaboration, advocacy and the addressing of environmental barriers (International Labour Organisation, United Nations Educational, Scientific and Cultural Organisation, WHO, 2004).

Other shortcomings which were identified included no programme vision, mission or objectives, no monitoring and assessment and no use of measuring instruments, no interdisciplinary teamwork, a lack of basic administration procedures such as; recording statistics and maintaining comprehensive client treatment notes as well as more advanced activities such as the compilation of an annual report.

6.2 Study recommendations

The study focused on the management of one condition, i.e. amputations only. However, it is reasonable to assume that the challenges which were identified will be found in the management of other conditions too, since it is unlikely that therapist behaviour will change dramatically based on the condition treated. This assumption can be verified with a quick audit.

The challenges identified are severe and point towards a need for a fundamental shift in philosophy from institution based medical model rehabilitation to community based social model rehabilitation. This cannot be done through a few meetings and conversations. Management, service providers and client representatives must sit down and look at what policy requires from the service, decide what they want from the service and how they can achieve that. They must develop a vision for Elangeni and provide guidelines for service providers according to which they must work.

The following aspects must be addressed during this planning session:

- Develop measurable overall and programme specific objectives
- Develop monitoring and evaluation practices for the programmes
- Implement an interdisciplinary teamwork approach and client centred goal setting
- Individual treatment emphasis should be on client community integration and participation
- Suitable client outcome measures should be identified and implemented
- Fail safe systems for gathering and storing statistics and client notes should be developed and implementation of these should be monitored and enforced. These should culminate in a yearly report of services. In addition, the wheelchair waiting list must be re- established and the information should be sent to the PGWC Department of Health to be incorporated in the provincial waiting list
- Structured client follow up procedures should be established and adhered to
- Therapists should start to play an advocacy role in the community and through liaison start a process of collaboration with businesses and other government departments.

6.2.1 Recommendations specifically related to amputee rehabilitation at Elangeni

- The PGWC guidelines must be used to determine prosthetic candidates, as well as to provide guidance during non-prosthetic rehabilitation, prosthetic preparation and prosthetic rehabilitation (WCDoh, 2010).
- The occupational therapist must play a much more prominent role in counselling of clients. In instances where clients require more advanced counselling they must be appropriately referred to social workers, psychiatric nurses, psychologists or psychiatrists.

6.2.2 Recommendations to district and provincial management

This lack of implementation of sound rehabilitation principles did not arise overnight – in fact data was collected over a 10 year period and findings did not show deterioration in practices at a particular stage which means that the challenges have existed over time. The challenges identified in the study should have been identified and rectified through supervision and guidance from managers.

It is essential that the service providers receive supervision, guidance and mentorship in many areas including: clinical practice, community based rehabilitation practices, interdisciplinary teamwork, client and programme evaluation, and the importance of record keeping.

District managers are responsible for supervision, training and implementation of monitoring and evaluation practices. It seems as if that type of support and supervision were not forthcoming for service providers in the current study. It is recommended that the relevant practices are implemented without delay.

6.2.3 Recommendations for further study

- A clinical audit at Elangeni to determine if the challenges are indeed as wide spread as feared
- Follow up evaluation of the rehabilitation services at Elangeni after study recommendations have been implemented
- A national survey of rehabilitation and community based rehabilitation programmes with regards to monitoring and evaluation practices
- A provincial or even national epidemiological survey on amputations to determine baseline data such as incidence, prevalence, age distribution, causes and levels since services cannot be planned without this information.

6.3 Limitations of the study

- Thirty participants was a small group. This impacted negatively on statistical analysis and the interpretation of statistical findings
- It is unsure how many potential participants could not be identified through a lack of records. Thus, it is unsure if a representative sample of participants was indeed obtained
- In addition, some of the client's records were missing. This can contribute to the missing clinical data bias
- Determining the clients' employment status before the amputation would have provided additional insights into the employment challenges found in this study
- Base line data on ICF scores would have provided comparative information
- The district or provincial department could also has been sources for budgetary information

Based on the above document one has to conclude that for the study participants did not receive comprehensive rehabilitation as defined by the NRP and in accordance with the social model of disability. Managers, service providers, and clients should re-consider the purpose of Elangeni and develop a vision and objectives for the service. In addition, management should take an active role in service monitoring and evaluation and provide guidance and mentorship to therapists.

References

- Asano, M. Rushton, P. Miller, W.C. and Deathe, B.A. 2008. Predictors of quality of life among individuals who have a lower limb amputation. *Prosthet Orthot Int* 32: 231-
- Ayhan, K. Reyhan, U. Metin, E. Fusun, B. Yetkin, I. 2004. Change in amputation rate in a Turkish diabetic foot population. *Journal of Diabetes and Its Complications* 18: 169 – 172.
- Bakkes, E. S. 1999. Possible predictors of functional prosthetic ambulation in adults with unilateral above knee amputation in the Western Cape. Unpublished Master Thesis. Centre for Rehabilitation studies. Stellenbosch University.
- Basu, N.N. Nikolaos, F. and McIrvine, 2008. Mobility one year after unilateral lower limb amputation: a modern, UK institutional report. *Interact Cardio Vasc Thorac Surg*, 7:1024-1026.
- Boynton, P.M. 2004. Administering, analyzing, and reporting your questionnaire. *BMJ*, 328:1372-1375
- Boynton, P.M. and Greenhalgh, T. 2004. Selecting, designing, and developing your questionnaire. *BMJ*, 328:1312-1315
- Breede Valley APD. 2011. Jaarverslag
- Bruins, M. Geertzen, J.H. Groothof. J.W. Schoppen, T. 2003. Vocational reintegration after lower limb amputation: a qualitative study. *Prosthet Orthot Int*, 27:4-10
- Burger, H. and Marincek, C. 2007. Return to work after lower limb amputation. *Disability and Rehabilitation*, 29(17): 1323 – 1329
- Bury, T. 2005. Primary Health Care and community based rehabilitation: Implications for physical therapy. *Asia Pacific Disability Rehabilitation Journal*. 16(2)
- Community Agency for Social enquiry (CASE). 1999. We also count! The extend of moderate and severe reported disability and the nature of the disability experience in South Africa

- Couper, J. 2002. Prevalence of childhood disability in rural KwaZulu-Natal. *SAMJ*. 92(7):594 – 52
- Ciehanowski, P., and Katon, W. J. 2006. The interpersonal experience of health care through the eyes of patients with diabetes. *Social Science and Medicine*, 63(12): 3067 – 3079
- Chin, T., Sawamura, S., Fujita, H., et al. 2002. Physical fitness of lower limb amputees. *American Journal of Physical Medicine and Rehabilitation*, 81: 321-325
- Clark, P., Kelman, C., and Colagiuri, S. 2006. Factors influencing the cost of hospital care for people with diabetes in Australia. *Journal of Diabetes and Its Complications*, 20(6), 349-355
- Creswell, J.W. Plano Clark, V.L., Gutmann, M.L., & Hanson, W.E. 2003. Advanced mixed methods research designs. In A. Tashakkori and C. Teddlé (Eds.), *Handbook of mixed methods in social and behavioral research*. Thousand Oaks, CA: Sage Publications, Inc.
- Day, C. and Gray, A. 2008. Health and Related Indicators In: Barron P, Roma-Reardon J, editors. *South African Health Review 2008*. Durban: Health Systems Trust. URL: <http://www.hst.org.za/publications/841>
- Delehanty, R. and Trachsel, L. 1995. Effects of short term group treatment on rehabilitation outcome of adults with amputation. *Inter J Rehabil Health*, 1:61-74
- Department of Health (DOH) 2000. National rehabilitation policy, Rehabilitation for All.
- DoH 2003. Guidelines on the provision of mobility assistive devices
- De Vos, A.S.; Strydom, H.; Fouché; C.B and Delpont, C.S.L. 2002. *Research at grass roots. For the social science and human service professions*. Van Schaik Publishers, 2nd ed. Pretoria (SA)
- De Vos, A.S., Strydom, H., Fouché, C.B., Delpont, C.S.L. 2005. *Research at Grass roots. For the social science and human service professions* 3rd ed. Van Schaik, Pretoria.

De Wit, L., Putman, K., Dejaeger, E., Baert, I., Berman, P., Bogaerts, K., et al. 2005. Use of Time by Stroke Patients A Coparison of Four European Rehabilitation Centres. *Stroke*, 36: 1977-1983.

Domholdt, E. 2005. *Rehabilitation research: Principles and applications*. 3rd ed. Elsevier Saunders, Missouri USA

Donachy, J.E., Brannon, K.D., Hughes, L.S., Seahorn, T., Crutcher, T., and Christian, E.L. 2004. Strength and endurance training of an individual with left upper and lower limb amputations. *Disability and Rehabilitation*, 26(8): 495-499.

Emmett, T. 2006. Disability, poverty, gender and race. In: Watermeyer B, Swartz L, Lorenzo T, Schneider M and Priestley M (eds). *Disability and social change: A South African Agenda*, pp207-233 Human Sciences Research Council. Cape Town.

Engstrom, B. and Van de Ven, C. 1999. *Therapy for Amputees*. 3rd ed. Edinburgh. Churchill Livingstone.

Enabling Universal and Equitable Access to Healthcare for Vulnerable People in Resource Poor Settings in Africa (Equitable). 2011 Qualitative analysis of Work Package 3 (Phase 1) Country report: South Africa Unpublished

FIM user manual. 2003. Functional Independence Measure (FIM) User Manual version, 1.0, Department of Veterans Affairs, VistA Systems Designs and Development, created by John Owczarzak

Frenk, J., Chen, L. A., Bhutta, Z., Cohen, J., Crisp, N., Evans, T., Fineberg, H., Garcia, P., Ke, Y., Kelley, P., Kistnasamy, B., Meleis, A., Naylor, D., Pablos-Mendez, A., Reddy, S., Scrimshaw, S., Sepulveda, J., Serwadda, D., Zurayk, H. 2010. Health professionals for a new century: transforming education to strengthen health systems in an interdependent world. *Lancet*, 376: 1923–58

Galley, R. 2004. One Step Ahead: Preventing Secondary Complications in Long-Term Prosthesis Users. 14(4)

- Gauthier-Gagnon C, Grise MC, Lepage Y. 1998. The locomotor Capabilities Index: Content Validity. *J of Rehab Outcomes measurement*. Sept
- Gauthier-Gagnon C., Grise M.C., Potvin D. 1998. Predisposing factors relating to prosthetic use by people with a transtibial and transfemoral amputation *J of Prosth & Orthot* 10(4)
- Gayle E. and Reiber. 1995. Lower Extremity Foot Ulcers and Amputations in Diabetes,” in *Diabetes in America*, eds. Maureen I. Harris, PhD, et al., 2 nd ed., 409-28 Bethesda, MD: National Institutes of Health publication.
- Gcaza S. and Visagie S.J. 2008. An investigation into processes, mechanisms and resources required in order to (re) integrate recipients of disability grants into employment; Commissioned by the Department of Social Development, (Unpublished)
- Global Lower Extremity Amputation Study Group. 2000. Epidemiology of lower extremity amputation in centres in Europe, North America and East Asia. The Global Lower Extremity Amputation Study Group. *Br J Surg*; 87: 328-337.
- Godlwana L., Nadasan T. and Puckree T. 2008. Global trends in Incidence of Lower Limb Amputation: A review of the literature. *SA Journal of Physiotherapy* 64(1) 8 – 12
- Groenewald S. J. 1999. Trans tibila prosteties gebruik post rehabilitasie in die Wes Kaap. Unpublished Masters Thesis MSc (Rehabilitation). Centre for Rehabilitation studies. Stellenbosch University.
- Gutacker N., Neumann A., Santosa F., Moysidis T. and Kröger K. 2010. Amputations in PAD patients: Data from the German Federal Statistical Office, *Vasc Med* 15:9
- Ham R.O. and Kerfoot S. 1986. Considerations for staff involved in amputee rehabilitation. *Physiotherapy Practice*; 2:161-165
- Health Professions Council of South Africa (HPCSA). 2008. Guidelines for good practice in the Health Care Professions Guidelines on the keeping of patient records booklet 14 Pretoria

- Hendry J. A. 1993. A descriptive survey study of lower – limb amputees admitted to Tygerberg Hospital (1985 – 1987). Unpublished Master of Medical Science (Epidemiology) thesis, University of Stellenbosch
- Henn, M. 2009. Evaluation of the rehabilitation program for persons with complete paraplegia at Netcare rehabilitation hospital. Unpublished Masters Thesis MSc (Rehabilitation). Centre for Rehabilitation studies. Stellenbosch University.
- Horgan O. and MacLachlan M. 2004. Psychological adjustment to lower limb amputation: a review *Disability Rehabilitation*, 26: 837-50
- Huang G.F., Chou Y.L. and Su F.C. 2000. Gait analysis and energy consumption of below-knee amputees wearing three different prosthetic feet. *Gait and Posture*; 12:162-168
- Humm W. 1997. *Rehabilitation of the Lower Limb Amputation*. 3rd ed. London
- Isakov E., Burger H., Gregoric M. and Marincek C. 1996. Isokinetic and isometric strength of the thigh muscles in below knee amputation. *Clin Biomech*, 11: 232 – 35.
- Inglis G. Faure M. Frieg A. 2008 The awareness and use of Outcome measures by South African physiotherapists. *SAJPT* 64(2): 5 - 11
- Joint position paper: ILO, UNECSO, WHO. 2004. Community-Based Rehabilitation: A strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities.
- Joubert G. and Ehrlich R. 2007. *Epidemiology. A Research manual for South Africa*. 2nd ed Oxford University press, South Africa
- Kautzky K. & Tollman S. 2008. A perspective on Primary Health Care in South Africa. In: Barron P, Roma-Reardon J, editors. South African Health Review. Durban: Health Systems Trust. URL: <http://www.hst.org.za/publications/841>
- Kettner, P. Moroney, R. and Martin, L. 1990. *Designing and managing programs*. Newbury Park, CA: Sage

- Kettner, P. Moroney, R. and Martin, L. 2008. *Designing and managing programs: An effectiveness-based approach*, 3rd edition. Thousand Oaks, CA: Sage Publications
- Kettner, P., Moroney, R and Martin, L. 1999. *Designing & Managing Programs: An Effectiveness-Based Approach*, 2nd edition. Thousand Oaks, CA: Sage Publications
- Kuechler C., Velasquez J. and White M. 1988. An assessment of human services programme outcome measures: Are they credible, feasible, useful? *Administration in Social Work*, 12, 17-89.
- Kidmas A.T, Nwadiaro C.H and Igun G.O. 2004. Lower Limb Amputation in Jos, Nigeria. *East African Medical Journal* 81(8).
- Kroll, T., Neri M.T., Miller K. 2005. Using mixed methods in disability and rehabilitation research. *Rehabilitation Nursing*. 30(3).
- Landrum P.K., Schmidt N.D., Mclean A. 1995. *Outcome-oriented Rehabilitation*. 1st ed. Gaithersburg. Aspen
- Leedy, P.D. and Ormrod, J.E. 2005. *Practical research. Planning and designing*. 8th ed. New Jersey: Pearson Education International.
- Maart, S. Eide, A.H. Jelsma, J. Loeb M.E & Ka Toni, M, 2007: Environmental barriers experienced by urban and rural disabled people in South Africa, *Disability & Society*, 22:4, 357-369
- MacKenzie E.J., Bosse M.J., Kellam J.F., Pollak A.N., Webb L.X., Swiontkowski M.F., Smith D.G., Sanders R.W., Jones A.L., Starr A.J., McAndrew M.P., Patterson B.M., Burgess A.R., Trivison T. and Castillo R.C. 2006. Early predictors of long-term work disability after major limb trauma. *J Trauma*. 61(3):688-94.
- Mackelprang, R.W. 2010. Disability Controversies: Past, Present, and Future. *Journal of Social Work in Disability & Rehabilitation*, 9(2):87 - 98

- Manderson L. and Warren N. 2010. The Art of (Re)Learning to Walk: Trust on the Rehabilitation Ward. *Qual Health Res* 20(10) 1418 - 1432
- Martin L. 1988. Consumer satisfaction surveys: Are they valid measures of program performance? Paper presented at the Eleventh National Conference on Specialized Transportation, Sarasota, FL.
- Martin L. L. and Kettner P.M. 1996. *Measuring the performance of Human services Programmes*. 1st ed. California (USA). SAGE
- May L.A. and Warren S. 2002. Measuring quality of life of persons with spinal cord injury: external and structural validity. *Spinal Cord*; 40:341-350.
- McColl M.A., Davies D., Carlson P., Johnston J. and Minnes P. 2001. The community integration measure: development and preliminary validation. *Arch Phys Med Rehabil*; 81:292-300.
- Millar R. and Millar A. 1981. *Developing client outcome monitoring systems*. Washington, DC: Urban Institute.
- Moreinfeld I., Ayalon M., Ben-Sira D., Isakov E. 2000. Isokinetic strength training and endurance of the knee extensors and flexors in trans-tibial amputees. *Prosthet Orthot Int*, 24: 221-25
- Nissen S.J., Newman W.P. 1992. Factors influencing reintegration to normal living after amputation. *Archives of Physical and Medical Rehabilitation*; 73:548-551
- Nurius P. and Hudson W. 1993. *Human services: Practice, evaluation and computers*. Pacific Grove, CA: Brooks / Cole.
- Office of the Deputy President (T. M. Mbeki) 1997. White paper on an the integrated national disability strategies, Rustica press
- Olaogun, M.O.B., Nyante, G.G.G., Ajediran, A.I. 2009. Overcoming the Barriers for Participation by the Disabled: An appraisal and global view of community-based rehabilitation in community development *AJPARS* 1(1) 24-29

Pedretti L.W. 1996. Occupational performance: a model for practice in physical dysfunction. In: LW Pedretti, ed. *Occupational therapy practice skills for physical dysfunction*. 4th ed. St Louis, Mosby

Pendleton, H.M.H. & Schultz-Krohn, W. 2006. Pedretti's occupational therapy: practice skills for physical dysfunction".

Penington G., Warmington S., Hull S., Freijah N. 1992. Rehabilitation of lower limb amputees and some implications for surgical management. *Australia and New Zealand Journal of Surgery*. 62(10) 774 - 779

PGWC 2009 Wheelchair service delivery manual Basic (professional) course.

Pollard N & Sakellariou D. 2008. Operationalizing community participation in community based rehabilitation: Exploring the factors. *Disability & Rehabilitation* 30(1) 62 – 70

Pollock, M.L., Gaesser, G.A., Butcher, J.D., Despres, J-P, Dishman, R.K., Franklin, B.A., & Ewing Garber, C. 1998. "The recommended quantity and quality of exercise for developing and maintaining cardiorespiratory and muscular fitness, and flexibility in healthy adults". *Medicine & Science in Sports & Exercise*, 30(6): 975–991.

Ray J. A., Valentine W. J., Secnik K., Oglesby A. K., Cordony A., Gordois A. and Palmer A. J. 2005. Review of the cost of diabetes complications in Australia, Canada, France, Germany, Italy and Spain. *Current Medical Research and Opinion*, 21(10)

Rhoda A., Mpofu R. & De Weerd W. 2009. The Rehabilitation of Stroke Patients at Community Health Centres in the Western Cape. *SA Journal of Physiotherapy*, 65 (3):3-8

Roth, E.J., Park, K.L., Sullivan, W.J. 1998 Cardiovascular Disease in Patients With Dysvascular Amputation. *Arch Phys Med Rehabil* , 79

Rommers G.M. 2000. The elderly amputee: rehabilitation and functional outcome. Rijksuniversiteit Groningen.

Rommeers G.M., Vos L.D.W., Groothoff J.W. and Eisma W.H. 2001. Mobility of people with lower limb amputations: scales and questionnaires: a review. *Clinical Rehabilitation* 2001; 15: 92-102

Rossi P. and Freeman H. 1993. *Evaluation: A systematic approach*. Newbury Park, CA: Sage.

Routhier F., Vincent C., Desrosiers J., Nadeau S. 2003. Mobility of wheelchair users: A proposed performance assessment framework. *Disability and rehabilitation*, 25(1) 19 – 34

Republic of South Africa RSA. 1998. Employment Equity Act No.55. <http://www.dpsa.org.za/policies/employmentequityact.php> Retrieved 04.2010

Ryser D. K., Erikson R.P., Cahalan T., 1988. Isometric and isokinetic hip abductor strength in persons with above-knee amputations. *Arch Phys Med Rehabil*, 840-845

Saloojee, G., Phohole, M. Saloojee, H. and IJsselmuiden C. 2007. Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township; *Child Care, Health and Development* 33(3) 230–235

SANPAD proposal. 2008. The alignment of rehabilitation services in the Western Cape with relevant policies and its impact on clients accessing these services. Unpublished research proposal, Centre for Rehabilitation studies, University of Stellenbosch

Schoppen T., Boonstra A., Groothoff J.W., van Sonderen E., Goeken L.N.H. and Eisma W.H. 2001a. Factors relating to successful job reintegration of people with lower limb amputation. *Arc Phys Med Rehabil*; 1425 – 1431

Schoppen T., Boonstra A., Groothoff J.W., van Sonderen E., Goeken L.N.H. and Eisma W.H. 2001b. Employment status job characteristics, and work-related health experience of people with lower limb amputation in the Netherlands. *Arc Phys Med Rehabil*; 82:239-45

Smith R.E., Kok A, Rothberg A.D., Groeneveld H.T. 1995. Determinants of blood pressure in Sowetan infants. *SAMJ*, 85:1339-1342.

South African Human Rights Commission. 2009. Public Inquiry: Access to Health Care Services

Statistics South Africa. Census 2006). www.statssa.gov.za/census01 (accessed 25 September 2008).

Suddick, K.M.. and De Souza, L. 2006. Therapists experiences and perceptions of teamwork in neurological rehabilitation: reasoning behind the team approach, structure and composition of the team and team working processes. *Physiotherapy research international* 11(2) 72 – 83

Tatara T. 1980. A report of the national conference on client outcome monitoring procedures for social services. Washington, DC: American Public welfare Association

Tate, D. G., and Forchheimer, M. 2002. Quality of life, life satisfaction, and spirituality: comparing outcomes between rehabilitation and cancer patients. *American Journal of Physical Medicine and rehabilitation*, 81(6), 400-410

Unit for Religion and Development Research. 2006. University of Stellenbosch in partnership with Transformation Africa

United Nations (UN) 2006. Division for Social policy and development. World programme of action Concerning Disabled persons.

Unwin J., Kacpersek L. and Clark C. 2009. A prospective study of positive adjustments to lower limb amputation, *Clinical rehabilitation*. 23(11) 1044 - 1050

Velema J. P. and Cornielje H. 2003. Reflect before you act: Providing structure to the evaluation of rehabilitation programmes. *Disability and rehabilitation*; 25(22):1252-64.

Visagie S. 2004. Lecture notes: Lower limb amputations. Developed for physiotherapy students at US, UWC and UCT.

Wade D. 2004. Assessment, measurement and data collection tools. *Clin Rehabil* 18, 233-237.

Wasserman S., De Villiers L. and Bryer A. 2009. Community based care of stroke patients in a rural African setting *SAMJ* 99:579–583

Western Cape Health Care 2010. 2007

http://www.capegateway.gov.za/Text/2007/7/may15,2007-csp_2.pdf

Western Cape Department of Health (WCDoH). 2010. Provincial Circular 176 of 2010.

Whiteneck, G.C., Harrison-Felix C.L., Mellick D.C., Brooks, C.A., Charlifue S.B. and Gerhardt K.A. 2004. Quantifying environmental factors: A measure of physical, attitudinal, service, productivity and policy barriers. *Archives of Physical Medicine and Rehabilitation*. 85(8): 1324-1335

WHO. 2001. International classification of functioning, Disability and Health. Geneva. Switzerland. [http://www.who.int/classification.icfwhoasii/en/index.html...2009/03/25](http://www.who.int/classification/icfwhoasii/en/index.html...2009/03/25)

World Health Organization (WHO) 2008 – Guidelines on the provision of manual wheelchair in less resourced settings

WHO. 2011. World report on disability

WHO-DASII. 1981. World Health Organisation. Disability assessment schedule II

Yusuf S., Reddy S., Ôunpuu S. and Anand S. 2001. Global burden of cardiovascular Diseases: Part I: General Considerations, the Epidemiologic Transition, Risk Factors, and Impact of Urbanization, *Circulation*, vol. 104, pp. 2746-2753.

Websites

<http://www.google.co.za/search?hl=en&defl=en&q=define:program&ei=ArnASezqB>

[Cited: 2009/03/18](#))

http://en.wikipedia.org/wiki/Goal_setting - cited 12 Augustus 2011

<http://www.education.com/definition/interdisciplinary-approach/>

http://www.google.co.za/search?sourceid=navclient&ie=UTF-8&rlz=1T4ADBF_enZA385&q=stats+on+violence+in+Paarl+

stbweb02.stb.sun.ac.za/urdr/downloads/Paarl.pdf

Appendices

APPENDIX 1 INFORMATION AND INFORMED CONSENT DOCUMENT

TITLE OF THE RESEARCH PROJECT:

The rehabilitation programme for persons with lower limb amputations at Elangeni Physical rehabilitation centre.

REFERENCE NUMBER: NO09/05/147

PRINCIPAL INVESTIGATOR: Jerome Peter Fredericks

ADDRESS: 164 Kleindrakenstein weg, Paarl, 7646

CONTACT NUMBER: 083 953 2084

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Committee for Human Research at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

The research study is to describe the services that are rendered for patients with leg amputations at Elangeni. The study will be conducted with the ex-patients of Elangeni physical rehabilitation centre in Paarl. Elangeni will be the only site for the study. The total number of people participating in the study will be 80 - 100 depending on the availability of participants. The reason why the researcher is doing the study is that, Elangeni has been providing rehabilitation services for the past ten years, but no research was ever done to describe the service that is rendered for the amputation patients its impact on the lives of its clients. By describing the service for the amputation patients, one would be able to point out the effectiveness, efficiency and quality of the service. This information can be used to win the trust and the support of all the stakeholders involved at Elangeni. Furthermore it serves as an indication of whether money is well spent or not. On the other hand with the description of the amputation service the challenges of the service are also identified, so that the proper strategies or intervention can take place to improve the effectiveness, efficiency and quality of the rehabilitation that are rendered. Most of all the importance of the study is to contribute to

improve the service that will be rendered to future amputation patients. The study will be conducted through interviews. Initially the researcher will contact all participants by means of a phone call or home visit. With the contact the study will be explained to them and if they agree to participate an appointment will be made. On the appointment date the researcher will again explained the reason for the study as well as the consent form. The researcher will also see that the participant fully understand the purpose of the study and the consent form before the participant sign the consent form. After which a questionnaire will be used to gather information from the participant. The researcher will ask the questions and fill in the answers of the participants on the form. If the participant requires a translator it will be arranged before the appointment with the participant. The researcher will complete the questionnaire with the participant at his / her own house or any other place that the participant might prefer. After the completion of the first questionnaire a few participants may be selected with whom the researcher will do in depth interviews. As previously an appointment will be made with the participant. If the need for a translator exists the translator will assist the researcher with the interview. All interviews will take place at the place where the participants live. Before the interview the purpose and the consent form will be explained to the participant. The participant will be informed that the consent form needs to be signed and that the interview will be audio recorded. The researcher will do the interview with the participant. After the interview the researcher will thank the participant. The participant will be informed that if the researcher requires any more information or needs any clarity that he / she will be contacted.

Why have you been invited to participate?

You have been invited to participate because, you were one of the patients that received rehabilitation at Elangeni. With the study the researcher would like to give you an opportunity to describe the services that was rendered to you at Elangeni. Your participation by means of sharing your experience in the study will contribute to better planning of the future service for persons with leg amputations.

What will your responsibilities be?

Your responsibility will be to answer the questions to the best of your ability. It will require of you to give some of you personal time to complete the interview and/or the questionnaire. It will also require of you to share your views, emotions and feelings on what you have experience during the period of rehabilitation at Elangeni.

Will you benefit from taking part in this research?

There will be no financial or other direct benefits for you. Future patients will benefit from the recommendations that will be introduced to improve the quality, effectiveness and efficiency of the services. But it will give you the participants the opportunity to participate in the study so that the service at Elangeni can improve for future patients. Should you require any treatment you will be referred back to Elangeni.

Are there in risks involved in your taking part in this research?

There are no risk involve to participate in the study. The interviews will take place in your home or another venue of your choice.

If you do not agree to take part, what alternatives do you have?

Not applicable for the study.

Who will have access to your medical records

Only the researcher will have access to your medical records. No information will be shared with others without the written permission of the participant. The information will be used for the study purpose only and after the study has been completed the information will be destroyed. So all medical records will be treated with confidentiality and will be protected. You as participant will remain as anonymous and one will know that the information shared comes from you as the participant. Only the researcher and the maybe the supervisor will have access to the information.

What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?

Not applicable. Chances are very little that any injuries can take place by completing a questionnaire or taking part in an interview.

Will you be paid to take part in this study and are there any costs involved?

No participant will be paid to participate in the study. The participants will have no cost to participate in the study, because the study will be done in their houses.

Is there any thing else that you should know or do?

- You can contact the researcher Jerome Fredericks at tel 021 938 9294 or at 083 953 2084 if you have any further queries or encounter any problems.
- You can contact the Committee for Human Research at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled **“The rehabilitation programme, for persons with lower limb amputations at Elangeni Physical Rehabilitation Centre.”**

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.

- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2010.

.....

Signature of participant

Signature of witness

Declaration by investigator

I Jerome Peter Fredericks declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2010.

.....

Signature of investigator

Signature of witness

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*) using the language medium of Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) on (*date*) 2010.

.....

Signature of interpreter

Signature of witness

APPENDIX 2

Structured questionnaire on demographic details, the rehabilitation programme, and client satisfaction with the programme and secondary complications.

Participant reference number:

Demographic data

1. Gender:

Male	Female
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2. Age group:

0 - 10	11- 20	21 - 30	31 -40	41 - 50	51 -60	61 -70	71 - 80	Older than 80
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3. Home Language:

English	Afrikaans	Xhosa	Other
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4. Educational status

No formal education	
Some primary school education	
Complete primary school education	
Secondary school education, but not grade 12	
Grade 12	
1 – 3 years tertiary education	
> 3 years tertiary education	

5. Employment Status:

Employed	Unemployed	Scholar/student	Homemaker	Retired
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6. If employed are you employed in the formal or informal sector:

Formal	Informal
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7. Reason for unemployment:

Disability	Other
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8. Income of family unit

No income	
R1 – R1000	
R1001 – R2000	
R2001 – R5000	
R5001 – R10 000	
R10 001- R15 000	
R15 000+	

9. Do you receive DG or CDG?

Yes	No
-----	----

10. What type of dwelling do you stay in? Choose one

House	
Traditional dwelling	
Flat	
Informal dwelling/shack	
Institution	
Other	

11. If house how many bedrooms? Choose one.

1	2	3	4+
---	---	---	----

12. Do you have the following inside your dwelling?

	Yes	No
Electricity / other source of power		
Toilet		
Bathroom		
Running water		

13 What type of transport do you use most frequently? Choose one.

No transport	Train	Taxi	Bus	Own private vehicle	Hired private vehicle	Employer provide transport	Horse cart	Bicycle	Other

If other please specify

History of Amputation and Medical status

14. Amputations (level, side and date)

	Left	Date of amputation	Right	Date of amputation
Through ankle				
Trans tibial				
Through knee				
Trans femoral				
Through hip				
Hemi pelvectomy				

15. Main cause of amputation. (Choose one)

Peripheral vascular disease	
Diabetes Mellitus	
Trauma	
Infection	
Cancer	
Congenital	
Other	

If other please specify

16. Prevention of further amputation due to lifestyle issues.

Answer each of the following questions by ticking yes, no or N/A if not applicable

	Yes	No	N/A
Do you smoke?			
Do you take your medication regularly?			
Do you follow your diabetic diet?			
Do you keep your toenails short?			
Do you do the blood flow exercises for your foot twice daily?			
Do you wash foot daily and dry it well esp between the toes?			
Do you check water temperature with elbow before putting your foot into it?			
Do you inspect all surfaces of foot daily for redness, blisters, cuts, cracks or sores?			
Do you wear proper fitting shoes that do not pinch or chaff?			
Do you check shoes daily for pebbles or nails that might stick through inner sole?			
Do you keep shoes and insoles in good repair?			
Do you wear a clean pair of socks or stockings every day?			
Do you go to the clinic or day hospital immediately for management of wounds or blisters on the foot?			
Do you use sunscreen on lightly pigmented feet when outside?			

Do you soak your foot?			
Do you cut corns or calluses?			
Do you walk barefoot?			
Do you use hot water bottles?			
Do you use chemical agents or adhesives on feet?			
Do you sit with feet close to heaters, open fires or cookers on the floor?			
Do you wear socks that are too big, too small, have tight elastic around the leg, was mended or have holes?			
Do you wear sandals with tongs between toes?			
Do you use any home remedies on blisters or wounds on the foot?			

17. Type of rehabilitation received

Prosthetic	Non prosthetic
------------	----------------

18. Name of hospital where last amputation was done

19. Date of referral to Elangeni after last amputation

20. Date of first appointment at Elangeni after above referral

21. How often did you receive rehabilitation at Elangeni?

Daily	Every second day	3 x a week	2 x a week	Once a week	Once every second week	Once every third week	Once a month	Less than once a month
-------	------------------	------------	------------	-------------	------------------------	-----------------------	--------------	------------------------

22. On average how long did the each rehabilitation session at Elangeni Last?

0 – 15 min	16 – 30 min	31 – 45 min	46 – 60 min	> 60 min
------------	-------------	-------------	-------------	----------

23. Were you seen individually or as part of a group?

Individual	Group	Both individual and group in 1 visit	Some visits group some individual (50/50)	Some visits group some individual (80/20)	Some visits group some individual (20/80)
------------	-------	--------------------------------------	---	---	---

24. Did you receive a home visit from a professional at Elangeni?

Yes	No
-----	----

25. Did you receive a work visit from a professional at Elangeni?

Yes	No	N/A
-----	----	-----

26. In your opinion how sufficient was the rehabilitation that you received at Elangeni?

Not at all	A little	Mildly	Very much	Completely
------------	----------	--------	-----------	------------

27. Could you please explain your answer?

28. Did they explain what to do to prevent further amputations?

Yes	No

If yes, can you tell me what you were told?

29. What assistive devices do you need / have you got?

	Do / do not need that (Yes/no)	Have got it (Yes/no)	Privately funded	State funded	Been ordered - waiting	Date ordered
Crutches						
Walking frame						
Walking stick						
Wheelchair						
Wheelchair cushion						
Prosthesis						
Special shoe						
Other						

If other please specify

30. How much care/assistance do you need?

None	Occasional help with activities like shopping etc.	Supervision	Minimal physical assistance	Moderate physical assistance	Everything must be done for me
------	--	-------------	-----------------------------	------------------------------	--------------------------------

31. Did you suffer from any of the following in the past 3 months or are you suffering from any of these currently? Tick all relevant blocks

Pain in the stump/s	
Stump skin breakdown	
Tightness in joints and muscles of the stump/s	
Wounds on other leg / foot	
Phantom pain that limits your ability to function	
Neuroma	
Depression	

32. Approximately how far do you live from Elangeni?

< 5km	5 – 10km	11 – 20km	21 – 30km	>30km
-------	----------	-----------	-----------	-------

33. How did you physically get there?

Walk / push wheelchair	Train	Taxi	Bus	Own private vehicle	Hired private vehicle	Employer provide transport	Other
------------------------------	-------	------	-----	---------------------------	-----------------------------	----------------------------------	-------

34. Did a lack of transport sometimes prevent you from attending sessions?

Yes	No
-----	----

35. Approximately how much did transport cost you per return?

36. How friendly did you find the staff at Elangeni?

Not at all	A little	Mildly	Very	Extremely
------------	----------	--------	------	-----------

37. How helpful did you find the staff at Elangeni?

Not at all	A little	Mildly	Very	Extremely
------------	----------	--------	------	-----------

38. How much training did you receive per week?

Once	Twice	Three times	Four times	Five times
------	-------	-------------	------------	------------

39. How long did you wait to be treated?

No waiting	A little waiting	About an hour	Hours
------------	---------------------	------------------	-------

40. Did you receive a lot of personal attention from staff during treatment sessions?

Not at all	A little	Mildly	Very much	Completely
------------	----------	--------	-----------	------------

41. The administrative processes at Elangeni were easy?

Not at all	A little	Mildly	Very much	Completely
------------	----------	--------	-----------	------------

42. Where your expectations met during rehabilitation?

Not at all	A little	Mildly	Very much	Completely
------------	----------	--------	-----------	------------

43. Who decided on the treatment goals?

Me	Therapist	Therapist and me	There were no goals
----	-----------	------------------	---------------------

44. How happy were you with the rehabilitation you received?

Not at all	A little	Mildly	Very much	Completely
------------	----------	--------	-----------	------------

45. Is there anything that you would still have like to have done during rehabilitation?

46. Is there anything else on the subject that you want to share with me?

APPENDIX 3**ICF based questionnaire on activities, participation and environmental factors****Participants reference number:**

The purpose of this questionnaire is:

- 1) To determine if you struggle to perform your normal duties and roles because of your amputation and
- 2) To determine what environmental factors act as barriers or facilitators in performing these tasks.

How difficult was it to perform the following tasks over the last month?

Scoring:

0 = No difficulty
 1 = A little difficult
 2 = Moderately difficult
 3 = Very difficult
 4 = Could not do it at all
 N/A = Not applicable / I do not need to do that

Mobility	
Lifting and moving / carrying objects	
Standing up from sitting	
Walking inside the house	
Getting around inside the house with a wheelchair / other device	
Pick up object from floor when standing / sitting in wheelchair	
Get up from floor (e.g. if you fall)	
Getting out of the house	
Go up and down stairs with a hand-rail	
Go up and down stairs with-out a hand-rail	
Moving around outside the house in the yard	

Get up and down a kerb	
Walking / wheeling for a long distance – 1km or more	
Walk outside in bad weather (rain, strong wind)	
Doing transfers	
Using transport (Car, taxi, donkey cart)	
Driving (Car, bicycle, horse)	
Self care	
Washing	
Getting dressed	
Using the toilet	
Grooming (Hair, Nails, Beard)	
Looking after your own health	
Staying alone for a few days	
Domestic life	
Doing shopping & accessing services like post office, bank etc	
Preparing meals	
Doing your normal chores in and around the house	
Assisting others	
Community integration	
Participating in social activities	
Participating in religious activities	
Participating in sport	
Manage your own finances	
Participating in politics and citizenship	
Productive activity	
Working / going to school	
Getting all your work done as you have to	
Being economically self sufficient	

Which of the following environmental factors act as barriers of facilitators to your ability to fulfil your social roles in the past month?

Scoring:

0 – No barrier	0 – No facilitator
1 – Mild barrier	+1 – Mild facilitator
2 – Moderate barrier	+2 – Moderate facilitator
3 – Severe barrier	+3 – Severe facilitator
4 – Complete barrier	+4 – Complete facilitator

Environmental factors	Score
Products & technology, including assistive devices	
For personal consumption (Water, food, medicine)	
For personal use in daily living (Electricity)	
For personal indoor and outdoor mobility (Including transport)	
For communication	
Design, construction etc of public buildings	
Design, construction etc of private buildings	
Environment: Natural and human made changes	
Climate/ temperature	
Terrain	
Lighting	
Sound/Noise	
Crowds	
Support & relationships	
Immediate family	
Friends	
Acquaintances, colleagues, community members etc	
People in authority	

Personal care providers / personal assistants	
Health professionals	
Attitudes, discrimination, prejudice	
Of family members	
Of friends	
Acquaintances, colleagues, community members etc	
People in authority	
Of personal care providers	
Of health professionals	
Societal norms, practice and ideologies	
Services, systems & policies	
Housing	
Communication	
Information	
Transport	
Legal	
Social security	
General social support	
Health care	
Education / Training	
Labour	
Other (Specify below)	

APPENDIX 4**Data coding form on relevant programme statistics**

General data and statistics on Elangeni and the amputation rehabilitation programme

1. Number of the amputation patients treated per year?

2000	
2001	
2002	
2003	
2004	
2005	
2006	
2007	
2008	

Treatment periods:

2. Length of shortest treatment period
3. Length of longest treatment period
4. Average length of treatment periods of amputee patients?

Treatment sessions:

5. Length of shortest treatment session
6. Length of longest treatment session
7. Average length of treatment sessions of amputee patients?
8. Fewest number of sessions
9. Longest number of sessions
10. Average number of sessions per patient

2006										
2007										
2008										
Total										

16. What were the numbers of home and work visits done for the amputation patients per year?

	Home visits	Work visits
2000		
2001		
2002		
2003		
2004		
2005		
2006		
2007		
2008		

17. At how many houses and workplaces where the staff involved to make physical recommendations?

18. How many amputation patients were able to returned to their work per year?

2000	
2001	
2002	
2003	
2004	
2005	
2006	
2007	
2008	

19. How many amputation patients where referred to the Western Cape Rehabilitation Centre for prosthesis assessment per year?

2000	
2001	
2002	
2003	
2004	
2005	
2006	
2007	
2008	

20. What role did the programme play in the society e.g. awareness raising, removal of barriers, equalisation of opportunities

APPENDIX 5

Folder audit form

Participant research number:

General information	
Date of entry into programme:	
Date of exit of programme	Total number of contact sessions:
Length of programme	

Management	
Scoring: 1 = Not at all; 2 = Too a limited extent; 3 = A fair amount; 4 = Extensively; NA = Not applicable	Score
Psychological counselling	
Education on stump care	
Education on prevention of further amputations e.g. foot care, nutrition, no smoking, medication	
Information to / education of family / caregiver	
Muscle strengthening	
Maintain / improve stump range of movement	
Stump maturation	
Stump desensitization	
Improve cardio vascular fitness	
Retraining of ADL	
Retraining of indoors mobility	
Retraining of community mobility	
Assessing prosthetic fit and alignment	
Training on prosthetic care, refitting etc.	
Identified and addressed possible transport problems	
Identified and addressed environmental barriers	

Assist patient to overcome barriers with regards to accessing public areas and doing his/her own business eg shopping, banking, etc.	
Guide patient towards self directed health monitoring (Medication, diet, visits to clinic etc)	
Did home visit	
Did work/school visit	
Liaise with employer/ teacher re integration, accommodations etc.	
Educate employer / teachers re the amputation and patients condition	
Identified and addressed issues around sport and recreation	
Evidence of inter disciplinary team planning and goal setting	
Evidence of client involvement in rehabilitation planning and goal setting	
Other	
Specify	

Assistive devices		
Type	Date Ordered	Date Received

APPENDIX 6

Interview schedule for occupational therapist and physiotherapist who present the amputee rehabilitation programme.

1. Can you tell me about the vision, mission aims and objectives of the programme?
2. Tell me about the amputee rehabilitation programme/process at Elangeni (Set protocols, length of sessions, home visits, work visits, goal setting etc?)
3. What do you generally do when you treat amputee patients?
4. What kind of information and/or education do you give to them?
5. What is your role in determining whether someone should receive a prosthesis?
6. Describe the process of prosthetic referral, measuring, fitting, receiving and training?
7. How easy is it to issue patients with other assistive devices e.g. crutches or a wheelchair?
8. What are the environmental barriers most often encountered by your patients with amputations and how do you assist them with addressing these?
9. What are the most common secondary complications that you see in amputation patients and what would you ascribe that to?
10. What do you see as the advantages of this programme?
11. What do you see as the limitations of this / challenges to the programme?
12. What do think is the role of this programme in this community?
13. To what extent does the rehabilitation programme at Elangeni prepare the client with lower limb amputation to function in the community?
14. To what extent and in what way is the family of the client involved in this programme?
15. To what extent and in what way is the community of Paarl involved in this programme?
16. How and to what extent do you liaise with other sectors e.g., transport, labour and education?
17. How do you measure patient's outcomes and or progress?
18. What recommendation can you make so that the services at the centre can improve?

APPENDIX 7

Interview schedule for clients

Participant reference number:

1. Tell me about the impact of the amputation on your life?
2. Tell me about the things that you used to do that you cannot do anymore and why you cannot do them anymore?
3. How do people make you feel?
4. Tell me about the rehabilitation you received at Elangeni after your amputation?
5. To what extent did the rehabilitation addressed your needs / was it satisfying?
6. What did you like about it?
7. What did you not like about?
8. Did the rehabilitation help you to do the things that you enjoyed and did previously again?
9. What needs was not addressed by the rehabilitation programme?
10. What recommendation can you make so that the services at the centre can improve?

APPENDIX 8

Letter to ask permission for the study to be performed at Elangeni Physical rehabilitation Centre.

164 Kleindrakenstein Weg
Paarl
7646
021 862 3066 (h)
083 953 2084 (cell)
jpfreder@pgwc.gov.ca

April 2009

Management of Elangeni Rehabilitation Center

Hereby I request permission do to a study at Elangeni Rehabilitation Center.

My name is Jerome Fredericks and I am masters student enrolled at the University of Stellenbosch. With this letter I would like to ask permission to undertake a study at Elangeni. As a previous employee at the center I would like to give something back to the center through this study.

The aim of the study is to describe the amputee rehabilitation programme at Elangeni. The research have been approved by the committee for Human Research at the University of Stellenbosch (Ref nr NO09/05/147)

As you know Elangeni have been offering rehabilitation services, based on Community based Rehabilitation and National Rehabilitation Policy, principles, for the past ten years, but very little documentation that describes the programmes offered is available and the services are also not being monitored on an ongoing basis. Programme description and monitoring is central issues in both policy documents mentioned above. Furthermore it is also the only objective way to prove to stakeholders that the service is effective, of a high quality and efficient.

The study will provide you as management with a detailed description of the amputee rehabilitation programme. The findings that will highlight both the strengths and challenges of the programme and will serve as an indication of whether resources are being optimally utilised, how utilisation can be improved if there is a need and results will also provide information that might be used to motivate for further resources such as funds and manpower. Furthermore the findings can assist with future strategic planning and provide a basis from which recommendations can be made.

Finally the study will also serve to provide publicity for Elangeni that will raise awareness of the centre and it services and will thus promote the programmes that are offered.

The researcher would also like to give the assurance that the purpose of the study is not to put the center in a bad light or to affect the center in any negative way, but rather to emphasize the good work that is being done at the centre and to further the centre's services.

I would greatly appreciate it if you as management can give me the permission to do the study at the center.

Yours faithfully

Mr. J. Fredericks

Appendix 9

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR THERAPISTS

TITLE OF THE RESEARCH PROJECT:

The rehabilitation programme for persons with lower limb amputation at Elangeni Physical rehabilitation centre.

REFERENCE NUMBER: NO09/05/147

PRINCIPAL INVESTIGATOR: Jerome Peter Fredericks

ADDRESS: 164 Klein Drakensteinweg, Paarl, 7646

CONTACT NUMBER: 083 953 2084

This is an invitation for you to take part in a research project. It is important to read the following information, which will explain the details of the project. Please feel free to ask any questions regarding the project. It is very important that you clearly understand what this research entails and how you could be involved. Your participation is **entirely voluntary** and you are free to decline to participate. If you do not want to participate it will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, if you don't want to be part of the study anymore.

This study has been approved by the Committee for Human Research at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

Why you have been invited to participate?

You have been invited to participate, because you are one of the therapists who work at Elangeni. With the study the researcher would like to give you an opportunity to describe the amputee rehabilitation services which are rendered at Elangeni. Your participation by means of sharing your experience will contribute to a better understanding of lower leg amputee rehabilitation at Elangeni.

What will your responsibilities be?

Your responsibility will be to answer the questions to the best of your ability. It will require of you to give some of your time to complete the interview. It will also require of you to share your views, emotions and feelings on what you have experience during the period of providing rehabilitation services at Elangeni.

Will you as therapist benefit from taking part in this research?

There will be no direct benefits for you in the form of money. Future patients might benefit from the recommendations that might be introduced to improve the quality, effectiveness and efficiency of the service.

Are there in risks involved in your taking part in this research?

There are no risks involved.

What will happen in the unlikely event of you getting injured in any way, as a direct result of taking part in this research study?

Not applicable

Will you be paid to take part in this study and are there any costs involved?

You will not be paid to take part in the study. There will be no costs involved for you

Is there any thing else that you should know or do?

- You can contact the researcher Jerome Fredericks at telephone 021 938 9294 or at 083 953 2084 if you have any further queries or encounter any problems.
- You can contact the Committee for Human Research at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I (*name*) agree to to take part in a research study entitled (*insert title of study*)

I declare that:

- I have read or had read to me this information and consent form and that it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to withdraw from the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished if the study doctor or researcher feels it is in my own best interests, or if I do not follow the study plan as agreed to.

Signed at (*place*) on (*date*) 2010.

APPENDIX 10

Letter to ask permission for a pilot study to be performed at Bishop Lavis Rehabilitation Centre.

164 Kleindrakenstein Weg
Paarl
7646
021 862 3066 (h)
083 953 2084 (cell)
jpfreder@pgwc.gov.ca

April 2009

Management of Bishop Lavis Rehabilitation Center

Hereby I request permission do to a study at Bishop Lavis Rehabilitation Center.

My name is Jerome Fredericks and I am a masters student enrolled at the University of Stellenbosch. With this letter I would like to ask permission to undertake a pilot study at Bishop Lavis Rehabilitation Center. The population for the pilot study will consist of one occupational, one physiotherapist and three amputation clients with lower leg amputations.

The aim of the pilot study is to describe the amputee rehabilitation programme at Bishop Lavis Rehabilitation Center.

The research have been approved by the committee for Human Research at the University of Stellenbosch (Ref nr NO09/05/147)

The study will provide you as management with a detailed description of the amputee rehabilitation programme. The findings that will highlight both the strengths and challenges of the programme and will serve as an indication of whether resources are being optimally utilised, how utilisation can be improved if there is a need and results will also provide information that might be used to motivate for further resources such as funds and manpower. Furthermore the findings can assist with future strategic planning and provide a basis from which recommendations can be made.

Finally the study will also serve to provide publicity for Bishop Lavis rehabilitation centre that will raise awareness of the centre and its services and will thus promote the programmes that are offered.

The researcher would also like to give the assurance that the purpose of the study is not to put the center in a bad light or to affect the center in any negative way, but rather to emphasize the good work that is being done at the centre and to further the centre's services.

I would greatly appreciate it if you as management can give me the permission to do the study at the center.

Yours faithfully

Mr. J. Fredericks