

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

A COMPARISON OF THE QUALITY OF LIFE BETWEEN SURVIVORS OF LEPROSY LIVING IN A LEPROSARIUM AND THOSE RE-INTEGRATED IN THEIR COMMUNITIES IN THE SOUTHERN REGION OF MALAWI

By:

Dorothy Chinguo
(CHNDOR004)

A thesis submitted to the Division of Occupational Therapy, University of Cape Town in partial fulfillment of the requirements for the Master of Science Degree in Occupational Therapy

February 2011

Supervisor:

Associate Professor Madeleine Duncan
**Division of Occupational Therapy, School of Health and Rehabilitation Sciences,
University of Cape Town**

Co- Supervisor:

Professor Seyi Ladele Amosun
**Division of Physiotherapy, School of Health and Rehabilitation Sciences,
University of Cape Town**

Plagiarism Declaration

1. I know that plagiarism is wrong. Plagiarism is using another's work and to pretend that it is one's own.
2. I have used the UCT Harvard convention for citation and referencing. Each significant contribution to, and quotation in, this project from the work, or works of other people has been attributed and has been cited and referenced.
3. This project is my own work.
4. I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.
5. I acknowledge that copying someone else's project, or part of it, is wrong, and declares that this is my own work

Signed by candidate

SIGNATURE: dorothychinguo

DATE: 11/02/2011

Abstract

Background: Before reaching the goal of eliminating leprosy in 1995 and re-integrating survivors of leprosy into their communities, Malawi had six leprosaria (leprosy villages) where persons with leprosy were provided with essentials such as food, housing and health care. In response to the decline in the number of people affected by leprosy due to the effects of Multi Drug Therapy (MDT), all leprosaria except Utale in the southern region of Malawi were closed. Most survivors of leprosy were re-integrated into their communities of origin. Little is known about the quality of life of survivors of leprosy living in the leprosarium and those living in the communities following the de-institutionalization process in Malawi.

Aim of the study: The aim of this research was to compare the quality of life being experienced by survivors of leprosy living in the remaining leprosarium and those re-integrated into their communities in the southern region of Malawi.

Methodology: A cross sectional quantitative survey was conducted by Leprosy Control Assistants (LCAs) who were trained in the use of the World Health Organization Quality of Life BREF questionnaire (WHO, 1996) (WHOQOL-BREF). The questionnaire was translated into Chichewa for use in the Malawian context. The WHOQOL-BREF instrument comprises of 26 questions which measure physical health, psychological health, social relationships and the environment. A higher score in the domains reflects a higher perceived quality of life by an individual. A total of 200 survivors of leprosy were recruited using convenience sampling. The composition of these survivors of leprosy was 100 from Utale leprosarium and 100 from the communities. In terms of gender composition, 47 males and 53 females were recruited from Utale leprosarium. In the communities, 43 males and 57 females were recruited. Quantitative data which was gathered from the questionnaire based interviews with the participants was statistically analyzed using the Statistical Package for Social Scientists (SPSS version 18.0).

Results: Demographic characteristics of the survivors of leprosy show that an elderly population of survivors lives in the leprosarium compared to those re-integrated in their communities ($p < 0.001$). The sample of survivors of leprosy in both research locations was similar with regards to educational levels with 67% from the leprosarium and 61%

from the communities respectively attaining primary school as their highest level of education. Seventy five percent of survivors of leprosy from the leprosarium were farmers compared to 62% of survivors from the community. Survivors of leprosy living in the communities had a wider range of paid jobs than those in the leprosarium. Marital status was different with 65% survivors from the communities being married as opposed to 45% in the leprosarium. The percentages of divorced and single participants in the leprosarium were 10% and 19% respectively whereas in the communities, these proportions were 5% and 6% respectively. A similar proportion in both groups had lost a spouse to death (23% in the communities and 25% in the leprosarium). A larger proportion (58% of the survivors of leprosy) from the leprosarium reported that they had no contact whatsoever with relatives compared to 21% of survivors living in communities.

There was no statistical significant difference in the WHOQOL-BREF overall mean score between survivors of leprosy living in the leprosarium and those reintegrated in their communities. However, statistically significant differences existed in the psychological quality of life domain between male and female survivors living in the leprosarium and those reintegrated in the communities. Females in the community had a higher psychological quality of life domain score than females in the leprosarium ($p=0.03$). Male survivors living the leprosarium reported a higher psychological quality of life domain score than the female survivors living in the same context ($p=0.03$). Male survivors living in the leprosarium had a better psychological quality of life domain score than the males reintegrated in the communities ($p=0.03$). When age was analysed in relation to each of the four domains of well being addressed by the WHOQOL-BREF, it was discovered that elderly survivors of leprosy living in the leprosarium (from 70 to 90 years) had a better total WHOQOL BREF mean score than survivors of the same age band who had been re-integrated in their communities ($p=0.003$). This is evident in the scores of the physical, psychological and environmental quality of life domains. There were no statistically significant differences in the social relationship quality of life domain between the 2 groups.

Discussion and Conclusions: Although leprosy was declared eliminated in Malawi in 1995, survivors of the disease living in the leprosarium and those re-integrated in their communities are adversely affected by the disabling consequences of the disease in various ways. The research findings revealed that the quality of life being led by survivors of leprosy living in the leprosarium and those re-integrated in their communities does not differ. However, gender and age impact differently on physical, psychological and environmental quality of life domains depending on where the survivors are residing. Women survivors living in the communities have a better psychological quality of life than their counterparts in the leprosarium. Males living in the leprosarium have a better psychological quality of life than those in the communities. Males living in the leprosarium had a better psychological quality of life than female survivors living in the same context. Survivors of leprosy who are older than 70 years, resident in the leprosarium had a better physical, psychological and environmental quality of life than survivors of similar age living in the communities.

Recommendations: There is a need to improve the quality of life of survivors of leprosy living in both the leprosarium and those re-integrated in their communities. This could be achieved by having an inclusive society that provides persons with disabilities arising from health conditions such as leprosy with opportunities to participate in organizations that are available in their communities. In addition, there is need to extend care of the elderly which is available in the leprosarium to the survivors re-integrated in the communities. Most importantly, there is need to increase the number of Medical Rehabilitation workers specifically Occupational Therapists. These professionals are equipped with knowledge on the improvement of quality of life of the people with and without disabilities, including survivors of leprosy.

Key words: Survivors of leprosy, Malawi, Quality of Life, WHOQOL-BREF, Leprosy, Occupations.

Acknowledgements

My sincere appreciation goes to the survivors of leprosy who shared their life experiences in this study. I also wish to sincerely thank my supervisors, Associate Professor Madeleine Duncan and Professor Seyi Ladele Amosun for their tireless guidance and support throughout the research project.

I would also like to express my sincere gratitude to the Government of Malawi (GOM) in particular the Ministry of Health of Malawi and the Elizabeth Cason's Trust, for their financial assistance towards the research project. Professor Grossman, the principal of Dermatology School in Tanzania, Professor Terence Ryan and Fiona Cook of Leprosy Guild UK deserve special mention for their kindness and encouragement during the research journey. I would also like to thank Mr. Wilson Somba (the Senior Leprosy Control Assistant), for providing the history of leprosy in Malawi, and all the Leprosy Control Assistants who were research assistants in this project.

Sincere thanks to my husband for his support and for taking care of the children in my absence, to my mother for her continuous prayers which have made me to be where I am now, to almighty God for providing me with the opportunity to live and experience all this.

The idea of this research project was brought up by the 2008 MSc class of Occupational Therapists. I therefore owe the class a considerable debt of gratitude for their brilliant ideas on the choice of the project title.

I must also acknowledge the enormous support and encouragement from my friend, Matumo Ramafikeng. My heartfelt thanks to my daughter, Theresa for her motherly abilities which she displayed in looking after her siblings, Jomo and Innocentia in my absence.

Table of Contents

Plagiarism	
Declaration.....	2
Abstract.....	3
Key words.....	6
Acknowledgements.....	7
List of Tables.....	12
List of figures.....	13
List of Abbreviations.....	134
List of Appendices.....	15
Definition of terms.....	16
Chapter one.....	18
1.0 Introduction.....	18
1.1 Background.....	19
1.2 Background to Malawi.....	21
1.3 Health services in Malawi	22
1.4 Leprosy services in Malawi	23
1.5 Duties of the Leprosy Control Assistants	24
1.6 Leprosy and disability policy in Malawi	25
1.7 Problem	26
1.8 Aim of the study.....	26
1.9 Objectives of the study.....	26
Outline of the thesis.....	27
Chapter Two	28
Litetrature review	29
2.1 Introduction	29
2.2 Introduction to leprosy.....	29

2.2.1 Classification of leprosy	300
2.2.2 Treatment of leprosy	31
2.2.3 Duration of Multi Drug Therapy.....	31
2.3 Sinners and outsiders: Beliefs about leprosy	322
2.4 Leprosy and isolation policy	35
2.5 Leprosy villages in Malawi	37
2.6 Community attitudes towards people affected by leprosy	38
2.7 Elimination of leprosy.....	40
2.8 Life after leprosy: Leprosy and disability prevalence.....	400
2.8.1 Leprosy and World Health Organization impairment grading system	422
2.9 Leprosy from a gender perspective.....	43
2.10 Leprosy through an occupational lens	47
2.11 Survivors of leprosy and their quality of life.....	50
2.11.1 Determinants of quality of life.....	53
2.11.2 Measurement of quality of life	55
Chapter 3	56
Methodology	56
3.1 Introduction	57
3.2 Research context.....	57
3.3 Research design	58
3.4 Identification and recruitment of participants.....	58
3.4.1 Population.....	58
3.4.2 Sample size	59
3.4.3 Research Instrument	59
3.4.4 Scoring the WHOQOL-BREF.....	62
3.4.5 Gaining access to the leprosarium and communities.....	63
3.4.6 Recruitment of survivors of leprosy.....	63
3.4.7 Sampling: Selection criteria	64
3.4.8 Training of the Leprosy Control Assistants	65
3.5 Pilot study	65

3.6 Collection of data	66
3.6.1 Storage and capturing of data.....	66
3.7 Data Analysis.....	67
3.8 Ethics.....	67
3.8.1 Ethical approval	67
3.8.2 Ethical considerations.....	68
3.9 Conclusion	69
Chapter 4	70
Results.....	70
4.1 Introduction.....	71
4.2 Demographic profile.....	71
4.2 Range of total scores in WHOQOL-BREF domains for all survivors.....	75
4.3 A comparison of WHOQOL-BREF scores (WHO, 1998) using an independent student t-test.....	75
4.4 A comparison of WHOQOL-BREF using age and gender as confounding factors .	80
4.5 Conclusion.....	93
Chapter 5	94
Discussion	94
5.1 Introduction.....	95
5.2 Demographic profile and quality of life.....	95
5.2.1 Age	95
5.2.2 Education	97
5.2.3 Access to occupational opportunities.....	98
5.2.4 Marital status	98
5.2.5 Contact with relatives.....	99
5.3 Impact of gender on quality of life	100
5.3.1 Gender and total WHOQOL-BREF mean scores.....	101
5.3.2 Gender roles and psychological quality of life for women	102

5.3.3 Psychological quality of life for male and female survivors living in the leprosarium.....	104
5.3.4 Psychological quality of life of males reintegrated in the communities and males living in the leprosarium	104
5.4 Age, continuity of care and quality of care	105
5.4.1 Age and WHOQOL-BREF mean score.....	106
5.4.2 Age and impact on physical quality of life	106
5.4.3 Age and impact on psychological quality of life.....	105
5.4.4 Age and impact on environmental quality of life.....	106
5.5 Conclusion	107
5.6 Limitations of the study	1078
Chapter 6	1089
Conclusion and Recommendations	10810
6.1 Conclusion	10810
6.2 Recommendations	11011
6.2.1 Further Research.....	11112
Chapter 7	113
References	114
Chapter 8.....	127
Appendices.....	127
Appendix I: WHOQOL BREF questionnaire (1996).....	1278
Appendix II: WHOQOL BREF translated questionnaire (Chichewa).....	134
Appendix III: Research Consent form	15249
Appendix IV: Research consent form (Chichewa).....	153
Appendix V: Letter requesting permission.....	154
Appendix VI: Map of Malawi.....	156
Appendix VII: WHOQOL BREF domains.....	157

Appendix VIII: WHO leprosy grading system.....	158
Appendix IX Approval letter (University of Malawi).....	159
Appendix X Approval letter (University of Cape Town).....	160

List of Tables

Table 4.1 Demographic profiles of survivors of leprosy re-integrated in the communities and those living in the leprosarium.....	72
Table 4.2 Range of scores in WHOQOL-BREF domains for all survivors	75
Table 4.3 Mean scores in domains of WHOQOL-BREF for survivors re-integrated in the communities and those living in the leprosarium.....	76
Table 4.4 Mean scores in domains of WHOQOL-BREF for male survivors of leprosy re-integrated in the communities and those living in the leprosarium.....	77
Table 4.5 Mean scores in domains of WHOQOL-BREF for female survivors of leprosy re-integrated in the communities and those living in the leprosarium.....	78
Table 4.6 Mean scores of domains of WHOQOL-BREF for male and female survivors living in the leprosarium.....	79
Table 4.7 Mean score of domains of WHOQOL-BREF for male and female survivors re-integrated in the communities.....	80

List of Figures

Figure 4.1: WHOQOL BREF total mean scores of the survivors of leprosy re-integrated in the communities and those living in the leprosarium according to age category.....81

Figure 4.2 Mean score of physical domain of survivors re-integrated in the communities and those living in the leprosarium according to age.....83

Figure 4.3 Mean score of psychological domain of survivors re-integrated in the communities and those living in the leprosarium according to age.....84

Figure 4.4 Mean score of social relationship domain of survivors re-integrated in the communities and those living in the leprosarium according to age.....85

Figure 4.5 Mean score of environmental domain of survivors re-integrated in the communities and those living in the leprosarium according age.....86

Figure 4.6 Total WHOQOL-BREF mean score of survivors re-integrated in the communities and those living in the leprosarium by gender.....88

Figure 4.7 Mean score of physical domain of survivors re-integrated in the communities and those living in the leprosarium by gender.....89

Figure 4.8 Mean score of psychological domain of survivors re-integrated in the communities and those living in the leprosarium by gender.....90

Figure 4.9 Mean score of social relationship domain of survivors re-integrated in the communities and those living in the leprosarium by gender.....91

Figure 4.10 Mean score of environmental domain of survivors re-integrated in the communities and those living in the leprosarium92

List of Abbreviations

WHOQOL BREF	World Health Organization Quality of Life Brief
QOL	Quality of life
MDT	Multi Drug Therapy
WHO	World Health Organization
LEPRA	British Leprosy Association
LCAs	Leprosy Control Assistants
SPSS	Statistical Package for Social Scientists

List of Appendices

- Appendix I The WHOQOL- BREF questionnaire
- Appendix II The WHOQOL BREF translated questionnaire (Chichewa)
- Appendix III The informed consent form (English)
- Appendix IV Research consent form (Chichewa)
- Appendix V Letter requesting permission
- Appendix VI Map of Malawi
- Appendix VII World Health Organization Quality of Life Brief Measuring Tool domains
- Appendix VIII WHO grading system
- Appendix IX Approval letter University of Cape Town
- Appendix X Approval letter University of Malawi (College of Medicine)

Definition of terms

For the purposes of this study, using current the WHO grading system for leprosy as a point of departure (WHO, 2002), terms are defined as follows:

Active aging: It is whereby an older individual is involved in meaningful activities that contribute to the wellbeing of the individual concerned, his or her family, the local community and society at large, and should not be concerned only with paid employment or production (Walker, 2002:124).

Activity limitations: Difficulties an individual may have in the executing activities (Brandsma & Brakel, 2003: 368).

Disability: An umbrella term for impairments, activity limitations, and participation restriction. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors (Vrankrijker, 2003:561).

Dehabilitation: Loss of former place in society or social role, causing loss of dignity, job and /or position leading to physical displacement (Kaur & Brakel, 2002:347).

Elimination: Reduction in prevalence to less than one case per 10 000 population of leprosy patients (Lockwood & Suneetha, 2005:230).

Functioning: An umbrella term encompassing body functions, structures, activities and participation (Vrankrijker, 2003:561).

Impairment: Problems in body function or structure such as a significant deviation or loss (Brandsma & Brakel, 2003:368).

Inclusive society: A society that accepts every one and ensures that every one belongs regardless of their disability, the individual is treated, respected, valued equally and provided with equal opportunities (Thomas, 1997:103).

Leprosaria: Charitable institutions or colonies built for leprosy patients for treatment, isolation and housing purposes (Rawcliff, 2006:3).

Leprosy: A chronic disease caused by the bacteria called *Mycobacterium Leprae* which affects mainly the peripheral nerves and the skin (Seddon & Seely, 2006:4).

Multi Drug Therapy: Treatment for leprosy that consists of Rifampicin, Dapsone and Clofazimine (Malawi National Leprosy Skin Programme, 1994:12).

Occupations: Every day activities that people perform as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do (World Federation of Occupational Therapists, 2006: 2).

Participation restrictions: Problems an individual may experience in involvement in life situations (Brandsma & Brakel, 2003:368).

Quality of life: An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, and level of independence, social relationships, and their relationships to salient features of their environment (WHO, 1995:1405). Physical, Psychological, Social Relationships and Environment are

domains that relate to general health facets and the overall quality of life (WHO, 1996)
(Appendix VII)

Chapter One

Introduction

1.1 Background

In 1985, the World Health Organization formulated a policy to eliminate leprosy as a public health problem by the year 2000, through the effective implementation of Multi Drug Therapy (MDT) (Bechelli, 1997: 283). The aim of adopting the elimination policy by countries with a high incidence of leprosy was to reduce the prevalence to one case or less per 10,000 populations (Lockwood & Suneetha, 2005:232). In 2001, the World Health Organization (WHO) claimed that leprosy had been eliminated at the global level including Malawi. Ironically, 719,330 new patients were registered in 2000 globally (Richardus & Habbema, 2007:330). Having, attained elimination status, the Malawi Ministry of Health with assistance from the British Leprosy Association (LEPRA), initiated the reintegration process of survivors of leprosy into their communities of origin.

In the absence of published scientific literature on the elimination of leprosy in Malawi, information was obtained from personal communication with the Senior Control Leprosy Assistant who has worked with leprosy patients since 1975. He narrated that Malawi had eliminated leprosy as a public health problem by 1995. Elimination status was reached five years ahead of the World Health Organization target (Somba, personal communication 2009). This was a significant achievement for the country.

Having obtained elimination status, a policy decision was made to close all leprosaria except for one leprosarium that was kept in operation (Utale) in the southern region of Malawi. This leprosarium was kept open because some survivors of leprosy could not trace their homes, while others were rejected by their families. These therefore had to remain in a care facility where they would receive basic needs and assistance (Somba,

personal communication, 2009). The number of survivors of leprosy re-integrated in their communities of origin as a result of the closure of leprosaria is not known.

A study by Lockwood and Sutheena (2005:232) reporting on elimination of leprosy, has shown that the attainment of elimination status brought some challenges in the management of leprosy. These challenges include the failure by health planners and donors fund health care to understand the concept of elimination to a prevalence of less than 1 case per 10,000 populations. The study reported that elimination was confused with eradication. Government officials understood elimination to mean an absence of cases of leprosy (eradication). This was not entirely true since many new cases were being reported. Such cases voluntarily report to health facilities in the southern region of Malawi to seek treatment (Somba, personal communication 2009).

The misunderstanding of elimination inhibited leprosy research being conducted because of absence of funding and the lack of appreciation about the personal, social and functional consequences of the disease. The disease was no longer perceived as an important public health problem (Lockwood & Sutheena, 2005:232). In addition, little or no follow up was made on the living conditions and service needs of survivors of leprosy after the re-integration process in Malawi. This suggests that poor funding affects the continuation of activities like case detection and prevention of deformities that were available before the attainment of elimination by the Leprosy Control Programme.

According to Somba (personal communication, 2009) and based on the researcher's personal experience as an Occupational Therapist in the country, new cases of leprosy report at the health facility at an advanced stage, when they have already developed deformities. The researcher's interest in the quality of life of survivors of leprosy living in the leprosarium and those re-integrated in their communities started when an opportunity arose for her to work at a leprosarium in southern Malawi, rendering rehabilitation service.

The common denominator to all survivors whether still living in a leprosarium or re-integrated in their communities, is that they had all been affected by leprosy in the past. Limited or no information is available on the quality of life experienced by survivors of leprosy living in the leprosarium and those who have returned to their communities. Experience has shown that rehabilitation care facilities and community based rehabilitation is accessible to people with disabilities due to other ailments apart from leprosy. In the leprosarium however such interventions are available for survivors of leprosy.

The Ministry Responsible for the Elderly and Persons with Disabilities was established in Malawi in 1998. Its aim was to formulate and provide policy direction and coordinate sectoral programmes and services through the monitoring of service providers. This has enabled persons with disabilities due to other diseases to have access to essentials of life and participate fully in areas of socio- economic development (International Labor Organization, 2006:12).

This study therefore attempted to assess the quality of life of the survivors of leprosy who are still living in the Utale leprosarium and those re-integrated in their communities in the southern region of Malawi. The research findings are a first step towards providing health professionals including Occupational Therapists and policy makers in Malawi with information about factors that impact on the lives of this client group and on their health and social service needs. In addition, this thesis attempts to bridge the gap in knowledge about the differences in quality of life in people living with disabilities associated with leprosy.

1.2 Background to Malawi

Malawi is a land locked country, located to the south of the equator in sub- Saharan Africa. The total area is 118,484 Km (sq) of which 94,276 Km (sq) is land and the remaining area is composed of Lake Malawi and other smaller lakes (National Statistical Office (NSO) [Malawi], & ORC Macro, 2005:1). Malawi is bordered by the Republic of

Zambia to the West, the Republic of Tanzania to the North and People's Republic of Mozambique, which surrounds it to the East, South, and West.

The country is one of the most densely populated and least developed countries in the world. It is ranked the 6th poorest country in the world with 65.1% of the population living on an income of less than one US dollar a day (National Statistical Office (NSO) [Malawi], and ORC Macro, 2005:5). Recent demographic estimates place the population of Malawi at 13.066320 million people. The composition of this population by gender is 49% males and 51% females (National Statistical Office, 2008:2). Citizens are referred to collectively as Malawians. The country's official languages are Chichewa and English. Malawi is a predominantly rural society with 90% of the population living in the rural areas, in villages comprising huts that are grouped together into clusters and presided over by village headmen (National Statistical Office(NSO) [Malawi], & ORC Macro,2005:1).

The economy is largely agro-based with tobacco being the main cash crop. Other important cash crops include tea, sugar, cotton and to a smaller extent coffee (Arregh et al., 2006:34). Tourism and mining are also playing increasingly important roles in the economy. Popular tourist resources are located along the shores of Lake Malawi which occupies approximately 30% of the total land surface (Arregh et al., 2006:35). Uranium mining ventures have recently been introduced in Northern Malawi.

Maize is the main staple food and other secondary staple foods include rice, cassava, sweet potatoes and beans. Fish also contributes significantly as a source of protein although fish stocks are declining due to overfishing on Lake Malawi and other lakes (Arregh et al., 2006:34).

1.3 Health services in Malawi

The health system of Malawi is monitored by the Ministry of Health and Population and delivered through Zonal Health Support Offices (Republic of Malawi Ministry of Health, 2008:12). Currently, the country is divided into five zones. These are defined as the

northern zone, central eastern zone, central western zone, south eastern zone and south western zone. The Ministry of Health and Population is by far the largest provider of health services, followed by the Christian Health Association of Malawi (CHAM) which runs Christian church-owned health centres (Loeb & Eide, 2003:33). The health services provided by all government health facilities are generally rendered at no cost to patients or clients (Republic of Malawi Ministry of Health, 2008:20). The exception is those patients who are admitted to “paying wards” in selected government health facilities who pay user fees which are subsidized. In addition to the government and CHAM hospitals, private hospitals owned by individuals also fill the gap in providing health services. These hospitals charge user fees for their services. A medical insurance is available to those who can afford it through the Medical Aid Society of Malawi (MASM) and other private medical insurance service providers.

Malawi has five referral hospitals. Queen Elizabeth Central Hospital, the largest of referral hospitals is located in Blantyre, the commercial capital of the country. The researcher is currently working at this hospital having been deployed by the Ministry of Health and Population. Zomba Central Hospital and Zomba Mental Hospital are also located in the southern region of Malawi. In the central region of Malawi, the referral hospital is known as Kamuzu Central Hospital. This hospital is based in Lilongwe which is the capital city of Malawi. Mzuzu Central Hospital is located in the northern region of Malawi, in the city of Mzuzu.

1.4 Leprosy services in Malawi

In order to continue with the elimination of leprosy as a public health problem, Malawi introduced the Tuberculosis and Leprosy Control Program which later developed into the National Leprosy and Skin Program (Malawi National Leprosy Programme, 1994:10). This program which is still being implemented falls within the general health services of Malawi. The objectives of the program as stipulated in the Field Workers' manual (Malawi National Leprosy Programme, 1994:10) include the following: to diagnose and treat as many patients as possible with Multidrug Therapy at an early stage of the disease; to prevent disability in diagnosed patients and assist disabled

leprosy patients as necessary; to reduce sources of infection in the community and to diagnose and treat leprosy reactions. As a strategy towards achieving the aforementioned objectives, the program has supervisory staff assigned at central, zonal and district levels in the country.

At the central level, the Programme Manager is responsible for planning, securing resources, supervision of leprosy control activities, monitoring and evaluating the results throughout the country. The manager is also responsible for provision of supplies and the training of staff taking part in the program (Malawi National Leprosy Programme, 1994:11).

At the zonal level, Regional Leprosy Supervisors are responsible for guidance and the supervision of leprosy control activities conducted by the Leprosy Control Assistants (LCAs). They are also responsible for the provision of supplies and training of staff (Malawi National Leprosy Programme, 1994:11).

At the district level, Leprosy Control Assistants provide guidance and supervision to the Health Surveillance Assistants who are responsible for the implementation of leprosy control activities in their respective districts (Malawi National Leprosy Programme, 1994:12). No academic literature could be traced verifying the nature or impact of the National Leprosy and Skin Program in Malawi making it difficult to ascertain whether the stated objectives are in fact being achieved.

1.5 Duties of the Leprosy Control Assistants (LCAs)

After the attainment of the elimination status in Malawi, all British Leprosy Association (LEPRA) activities were handed over to the Ministry of Health including the trained LCAs who had been trained by LEPRA (Somba, personal communication 2009). The LCAs had received a two year full time training in Malawi by LEPRA projects. The first class graduated in 1975. The programme was discontinued when LEPRA was phased out and the integration of the health services was taking place. The LCAs had received training in the diagnosis, classification and treatment of leprosy, recognition and

treatment of leprosy reactions and simple complications. The training included the taking of slit skin smears and keeping of records, clinic cards, treatment registers and monthly clinic returns (Malawi National Leprosy Programme, 1994:10). Currently there are sixteen Leprosy Control Assistants practicing under the Ministry of Health. Seven of them are allocated to the hospitals in the southern region of Malawi where this study was conducted.

Presently, the LCAs main activity is providing treatment to the new cases that voluntarily come to health facilities. Their duties, which are critical to the success of the leprosy control program, involve going into communities for case identification and prevention for further deformities to old survivors of leprosy are more likely to be limited due to poor funding by the Ministry of Health to the Leprosy Control Program. This stems from the already mentioned perception by the government that leprosy was eradicated and therefore does not need require the same attention as other diseases such as malaria and HIV/AIDS.

To date, no research has been conducted to identify the outcomes of the reintegration process from the perspectives of the people directly affected by either staying in leprosarium or being re-integrated into their communities in Malawi. Therefore, the study aimed to provide relevant information on quality of life of survivors of leprosy to policy makers, program managers of skin and leprosy control programme and health workers providing services to survivors of leprosy. The findings of this study will enable them to integrate needs of survivors of leprosy in their service planning.

1.6 Leprosy and disability policy in Malawi

Survivors of leprosy develop deformities due to delayed presentation to the hospital for medical care. Delayed presentation could be attributed to the negative attitude attached to the disease which prevents people from seeking medical intervention timeously. Unchecked by medical care, the disease progresses leaving the person with impairments that causes significant activity limitations and participation restriction (Lockwood & Suneetha, 2005:231).

No data could be found about leprosy related disabilities in Malawi since 1994 because according to the Ministry Responsible for People with Disabilities, there was no policy to guide the implementation of activities in the disability sector (Loeb & Eide, 2003:35). Disability is an important measure in evaluating the leprosy burden and the impact of control programs. However, data on disabilities are scarce in Malawi. Only one study was conducted in the country on disability prevalence among leprosy survivors (Chisi et al., 2003:636). This study reported a disability incidence of 5 per 1000 person in Nkhotakota district in the Central part of Malawi. This study will therefore, provide useful information for promoting services for people disabled by leprosy in Malawi by filling an existing information gap in the system.

1.7 Problem

According to available information, there are no published studies that have investigated the quality of life that survivors of leprosy are leading after Malawi attained the elimination status. This therefore prompted the researcher to investigate and compare quality of life of survivors of leprosy living in the leprosarium and those re-integrated in the communities.

1.8 Aim of the study

To establish the differences in the quality of life led by survivors of leprosy living in the leprosarium and those re-integrated in their communities of origin in the southern region of Malawi.

1.9 Objectives of the study

The objectives of the study focused on the domains of the World Health Organization Quality of Life BREF questionnaire (WHO, 1996) (Appendix VII) as outlined below:-

- To determine demographic profiles of survivors of leprosy still living in the leprosarium and those re-integrated in their communities.

- To determine the total mean WHOQOL-BREF domain score for survivors of leprosy living in the leprosarium and those integrated in their communities.
- To determine the total mean scores for each domain for survivors of leprosy still living in the leprosarium and those integrated in their communities.
- To determine associations and correlations between the profile variables and quality of life domains.

Outline of thesis

This dissertation consists of 6 chapters. Chapter 1 provides introductory information of the research context, the health services that are available in Malawi and the objectives of the study. A review of the related literature is presented in Chapter 2. The review discusses the prevalence of leprosy at global and national levels. Other related topics presented are beliefs about leprosy, the impact of leprosy on the quality of life of the survivors of leprosy, leprosy and disability, leprosy and gender and leprosy through an occupational lens.

In Chapter 3 the methodology is discussed in detail. The introduction of this chapter is followed by an outline of the study. The study design is explained and the data collection instrument introduced. A description of the pilot study and the sampling is discussed respectively. Data collection together with management and analysis follows.

The research findings are presented in chapter 4 followed by a discussion of the findings in chapter 5. The last chapter (chapter 6) consists of the conclusion and recommendations of the study.

Chapter Two

Literature review

2.1 Introduction

The literature review was conducted with the purpose of acquiring knowledge of leprosy according to its prevalence, at both global and national levels. Other related topics presented in the review include some beliefs about leprosy, the adoption of isolation policy in Malawi and the existence of leprosy villages in the country. Furthermore, the deformities and disabilities associated with leprosy, the impact of the disease on gender and engagement in occupations and its impact on the quality of life of the survivors of leprosy are also studied in the review.

2.2 Introduction to leprosy

Leprosy, also known as Hansen's disease, is one of the oldest diseases of mankind (Duarte & Ayres, 2007:775). The disease is caused by *Mycobacterium Leprae*, which was discovered by a Norwegian citizen, Dr Gerhard Henrik Armauer Hansen in 1873 (Horwitz, 2006:275). The causative organism is shed from the nasal mucosa of an untreated individual. Therefore, transmission of leprosy is primarily from person to person through nasal secretions (Kerr-Pontes et al., 2006:994). Literature describes that the organism can survive outside the nasal mucosa of an infected individual for up to 45 days before infecting the next host (Lockwood & Sueetha, 2005:231). The study also shows that leprosy has a long incubation period, ranging from 2 to 20 years. As a result, there is fear that newly diagnosed patients with leprosy may transmit the disease to others in their family or community long before their disease is detected. The long incubation period therefore would most likely result into the disease becoming endemic in areas where people are overcrowded and are living in poorly ventilated environments.

Globally, statistics have indicated that there were about 12 million cases affected with leprosy in 1985 (Lockwood & Suneetha 2005:231). Rad, Ghaderl, Morad & Salimzadeh (2007:857) reported that leprosy was a health problem in 23 countries in 1998. The study also reports the prevalence rate to be at more than one case in a population of 10,000 people. However, published statistics to show the prevalence of leprosy in Malawi were not available.

Literature has shown that leprosy is classified according to lesions. This helps an infected person to receive treatment which is compatible to the type of leprosy. The section below gives a description on the classification of leprosy and type of treatment a health worker can prescribe for people infected with the disease.

2.2.1 Classification of leprosy

Leprosy is classified by the amount of the bacteria in the lesion and the type of lesion that is present (Chisi et al., 2003:635). Leprosy has been classified into 2 types according to the number of lesions (Rad et al., 2007:856). The first type is called multibacillary which has a presence of more than 5 skin lesions with a more symmetrical distribution together with skin anesthesia. The second type is paucibacillary which has a presence of 1 to 5 lesions with asymmetrical distribution and skin anesthesia.

The classification of leprosy is important for the proper choice of the Multidrug Therapy (MDT) for the affected patients. Such a classification enables patients to be treated as Pauci Bacillary or Multi Bacillary leprosy. Above all, proper treatment will help in the prevention of leprosy from becoming endemic.

There have been different figures reported about the prevalence of the different types of leprosy. However, a study by Rad et al., (2007:859), indicates that there has been a higher prevalence of multibacillary type of leprosy than the paucibacillary type.

2.2.2 Treatment of leprosy

The treatment of leprosy was introduced by the World Health Organization (WHO) in 1981. The drugs were a combination of antibiotics namely Rifampicin, Clofazimine and Dapsone (Multi Drug Therapy) (MDT) (Lockwood, 2002:1516). MDT was recommended by WHO because it is highly effective in curing the mycobacterium infection with a relapse rate of 1%. However, the study found out that the MDT is not effective at treating the nerve damage (Lockwood, 2002:1516). The effectiveness of the MDT could have led to the reduction in the prevalence of leprosy in Malawi.

The reduction in the prevalence of leprosy therefore provided the basis on which the concept of elimination was developed (Shumin et al., 2003:215). However a report by WHO (2008:294) indicates that new cases are still being detected in Malawi and other countries like Tanzania. A study by Chisi et al., (2003:635) also indicated that paucibacillary if not well treated, can become a pandemic.

Malawi just like other countries adopted the use of MDT according to WHO recommendations. According to the Field Workers' Manual of Malawi (Malawi National Leprosy Skin Programme, 1994:4), MDT regimes consist of a supervised and an unsupervised component. For example, Rifampicin is one of the drugs given for four weeks while the patient is being supervised by the health worker. Supervision helps the affected person to get continuous education from the health worker. Most importantly, signs of any reaction to the disease or nerve damage would be detected and managed at an early stage, resulting in the prevention of deformities.

2.2.3 Duration of Multi Drug Therapy

The duration of MDT depends on the type of leprosy an infected person has been diagnosed with. In Malawi, according to the Field Workers' Manual, (Malawi National Leprosy Skin Programme, 1994:7), patients who have been diagnosed with Pauci Bacillary leprosy, receive six "four weekly" doses of a combination of Rifampicin and

Dapsone. After completion of the six doses, the patient is released from treatment. All the six doses are taken within a maximum period of six months.

In some cases, patients are unable to complete their treatment because of various reasons. These include failure to collect the medication from the health service or from the health worker. In such cases, a second course of MDT is started. This is done after the health worker has explained the importance of regular attendance to patient and the guardian, and the side effects of not taking the drug regularly. Such side effects include the development of resistance to the drugs by the affected patient.

Patients who have been diagnosed with Multi Bacillary leprosy receive 24 “four weekly doses” of triple combination of Rifampicin, Dapsone and Clofazimine. These doses, according to the guidelines are supposed to be completed within a maximum period of 12 months. In some cases, patients fail to collect the 24 doses of MDT within 12 months. In such cases; patients are given a second chance to complete a full course of MDT.

Research has shown that patients with Multi Bacillary leprosy have a high bacterial load and relapse rates are also high even after treatment, with 24 months of MDT (Girdhar, Girdhar & Kumar, 2000:150). As a result, such patients could probably be responsible for maintaining infection in their community (Lockwood & Suneetha, 2005:233), they could therefore transmit the bacteria to the non affected persons in their community.

Societies react differently to leprosy and also to people affected by the disease. This is due to the different beliefs which different societies have towards leprosy as a disease. The following section will explore some of the beliefs about leprosy that are prevalent in Malawi and in other countries and their impact on the affected people.

2.3 Sinners and outsiders: Beliefs about leprosy

Several beliefs exist in several cultures in different countries about leprosy. Beliefs are socially constructed and therefore influence the quality of life which people may

experience in their social environments. As such, several studies have listed different cultural beliefs on the causes of leprosy. For example, a study by Varkevisser et al., (2009: 68) mentioned several traditional beliefs that were thought to be traditional causes of leprosy. Some of the traditional beliefs were that leprosy was caused by the wrath of God for sins committed in the past. Varkevisser's study shows that the existing traditional beliefs had a negative impact on the health seeking behavior of women. They feared being abandoned by their husbands if they are diagnosed with leprosy.

Brown (2006:90) also mentions that the curse of an angered father and the breaking of food and other taboos are also other causes of leprosy. Therefore, he suggested that people suffering from leprosy should be pronounced as unclean and as a result should live in isolation. Leprosy is also related to impurity and divine punishment which contributes to the increase of prejudice and psychosocial problems (Duarte & Ayres, 2007:775).

Ebenso et al., (2007:104) also mention several beliefs about leprosy. The study mentions that leprosy was considered to be a sexually transmitted disease, an inherited condition, the result of witchcraft or punishment for sin. Try (2006:58) states that in areas where people believed that leprosy was connected with witchcraft, leprosy sufferers were pitied as innocent victims. As a result, the sufferers were excluded from society on the basis of the belief that the disease could be transmitted to anyone else in the society.

Another belief that was mentioned in Try's study was that people who were not infected by leprosy believed that people with leprosy were the witches themselves. As a result, they could only pass the disease on to other witches. This was all the more reason they were not excluded as they were not seen as a threat to ordinary people (Try, 2006: 58). The author further mentions that it was also commonly believed that leprosy was a very infectious disease. Touch or contact was believed to be the main cause of transmission. In southern Sudan, people believed that transmission occurs through eating meat of a wild pig, ostrich, monkey, python and other types of fish. While others believed that the disease was heredity (Hassan, Khalil & Hassan, 2002:23).

Cross (2006:368) also mentions that other societies have the belief that a person affected by leprosy is a curse. The inference was that a person affected by leprosy had been singled out by supernatural determinants or mysterious forces, therefore exclusion was justified.

The presence of negative perceptions about leprosy in many cultures shows that leprosy is viewed as both a public health and social disease (Shieh, Wang & Lin, 2006: 99). Despite modern medical advances, people affected by leprosy are still facing stigma. Try (2006:58) argues that the prevailing inaccurate beliefs about the disease are the cause of social exclusion and the fear (phobia) of people living with leprosy by their families and community. Try's findings also suggest that the socio cultural beliefs about leprosy affect health seeking behavior on the part of people affected by leprosy. As a result of the delay in seeking medical treatment, people affected by leprosy develop deformities which limit their participation in activities such as farming, socialization and accessing their environment through mobility.

While not much has been written about the traditional beliefs about leprosy in Malawi, similar reasons could be attributed to the creation of leprosaria. An interview with a LCA working with leprosy patients in Malawi since 1975, (whose mother had been infected with leprosy) gave some insight on the reasons of isolation of leprosy patients. The interviewee narrated that some people believed that a person affected by leprosy was connected with witchcraft and therefore such a person was considered to be a curse. As a result, people affected by leprosy were left in the bush to die (Somba 2008, personal communication). This idea was corroborated by Susinos (2007:119) who also reported that a person affected by leprosy was singled out by supernatural determinants and therefore social exclusion was justified because the person was regarded as an outcast.

Different authors have reported different traditional beliefs on the causes of leprosy. However, all the beliefs that have been reported and described are negative and most likely imply that the sufferer has done something wrong. This shows that even though

the patient could be clinically cured, he /she would experience rejection and exclusion from society. This has adverse consequences on the affected person's quality of life. Details on how the isolation process was adopted by Malawi and other countries that had an endemic of leprosy are discussed in the section below.

2.4 Leprosy and isolation policy

Nash (2007:193) states that in the early days of leprosy care, with very little use of medical treatment, the Leprosy Congress, which was held in Berlin in 1897, recognized isolation as a way of treating leprosy. This was done by removing the leprosy sufferers from their homes and putting them into leprosaria. Therefore, the 1897 Leprosy Congress recommended a mandatory isolation to control leprosy (Lesshafft et al., 2010:70).

However, Duarte and Ayres (2007:775) argued that there was no proof available to show that isolation controlled the spread of leprosy. The authors observed that rather isolation contributed to an increase in the fear of the disease and negative attitudes towards the affected people. Malawi also adopted the isolation policy with the aim of controlling leprosy.

There were also several ways of isolating people affected by leprosy from their community life. These, according to Lesshafft et al., (2010:70) ranged from expropriation of land, expulsion from the village, exclusion from community festivities and from shared meals as well as discrimination at work.

Apart from the isolation policy that was recommended by the 1897 Leprosy Congress, a study by (Cross, 2006:369) found that social exclusion was also contributed and exacerbated by the cultural beliefs different societies had towards the cause and transmission of leprosy.

Cross's study (2006:369) gave an example of India, where people affected by leprosy were socially excluded not because they were suffering from leprosy, but because of the disfigurement and deformities they had after suffering from the disease. This according to Leekassa, Bizuneh and Alem (2002:368) is because society maintains

negative feelings towards disabled people in general and people with leprosy in particular.

There were also several other factors that contributed to the social isolation of people affected by leprosy. Nicholls et al., (2005:310), isolate religious teachings, attitudes of the health care professionals, the practice of begging by the affected individuals, the image portrayed by fund raising agencies and the discriminatory language used by the media as some of the factors.

In a study carried out in South Asia, Rafferty (2005:119) revealed that the social isolation experienced by people affected by leprosy affected them socially and psychologically. This could be attributed to strong cultural ties and a sense of belonging to the family and the community. Rafferty (2005:120) cites the concerns of a participant who remarks that he can endure losing a finger, toes or eyes but he cannot endure being rejected by those who are near him. In most societies losing one's family would have a similar effect to losing one's identity.

This would also apply in Malawi where a culture of interdependence is more pronounced at village level. There is a culture of extended families where people depend on each for basic necessities such as food, salt and soap just to mention a few examples. It follows therefore that if a member of a family is isolated, he would find it extremely difficult to live alone in isolation.

In most African societies there is a strong belief of "Ubuntu". According to Murithi (2006:28), Ubuntu is an African concept which implies that "a person is a person through other persons". By this definition, all human beings are involved in a web of inter relationships, comprising of family, friends, co-workers and all others who provide services to each other. This process renders help that eases their day to day functioning. The cultural approach plays a vital role in promoting social order within communities. Ubuntu societies place a high value on communal life and maintaining positive relations. This arises from the guiding principle of Ubuntu being based on the

notion that parties need to be reconciled in order to re-build and maintain social trust and social cohesion.

Rafferty (2005:119) further reported experiences of young people who suffered from leprosy. It was observed that they were in most cases restricted from their education either because the school authorities were unwilling to admit them or due to limitations which were placed on them on their perceived abilities. As a result of limited opportunity to become educated, young people affected by leprosy were not able to make informed choices of what they wanted in life. This was a serious limitation on employment opportunities and had adverse consequences on their ability to earn income. Not surprisingly, people affected by leprosy are more likely lead a poor quality of life.

Isolation of individuals affected by leprosy was compulsory after the adoption of 1897 Leprosy Congress in Berlin as has been discussed above. Malawi being one of the countries that was hit by the leprosy endemic also adopted this policy. The section to follow gives a history of the existence of the leprosaria after the adoption of the isolation policy.

2.5 Leprosy villages in Malawi

Malawi had six leprosaria (also called leprosy colonies or leprosy villages) namely Malamulo, Ngabu, Utale and Malosa in the southern region, Mua and Kochilira in the central region and Chilumba in the northern part of the country. The leprosy villages were established in undeveloped remote areas where the affected people could not work to earn any income. Literature to justify reasons for the existence of leprosaria in Malawi is not available. According to a personal communication (Somba, personal communication, 2009), patients were confined to different leprosaria in different regions of the country.

Literature to show engagement in occupations by leprosy patients in the leprosarium is also not available in Malawi. However, a study by Shieh, Wang & Lin (2006:100) in China, indicates that leprosaria were set up to house indigent leprosy patients. Other

leprosaria were also used to offer treatment, Christian worship and Occupational Therapy services. People suffering from leprosy were encouraged to grow vegetables and rice within the leprosarium.

A study by Horwitz (2006: 271) revealed that the aim of leprosaria was to isolate and segregate patients from the outside world, to stop the transmission of infection and /or to provide care for leprosy sufferers. The belief was that the strict control and segregation would lead to a halting of new infections resulting in the eradication of the disease (Chen, Chu & Wang, 2005:336).

2.6 Community attitudes towards people affected by leprosy

Brown's study (2006:90) reveals that although leprosy cases reduced globally, the disease still remains a problem. This is a result of the high prevalence of negative attitudes that communities have towards people affected by leprosy, and leprosy as a disease. The study further observes that the prevalence of negative attitudes is as high as 80% in some countries (Brown, 2006:90).

Negative attitudes exist because of the different views that people have towards leprosy and those who are affected by the disease. Such attitudes could most likely have adverse effects on affected persons and their lives. These have been outlined by Brown in his study (2006:90) as problems with personal mobility, interpersonal relationships, marriage, employment, leisure activities. Furthermore there is exclusion from attendance at social and religious functions (Brakel, 2003:193). Additionally, negative attitudes can lead to emotional stress, depression and suicidal ideas.

Such negative attitudes are not only prevalent among the community but even among health workers. Brown's study (2006:91) gives an example of prevalence of negative attitudes among Nigerian physiotherapy students. Results of the study showed that 87% of the students felt that leprosy patients should be isolated. Sixty two percent would not agree to work in a leprosy hospital and only 8% of the students would eat with a person

affected by leprosy. According to the study, only one student from the sample would marry somebody who had leprosy. Brown's study acknowledges that the presence of negative attitudes of health workers towards leprosy patients is a result of limited knowledge of the causes of leprosy among the health workers themselves. The resultant fear of hospital staff by leprosy sufferers is responsible for most of them seeking treatment too late, when the disease is already at an advanced stage.

Similar attitudes were also reported in Ethiopia, where 95% of the population was found to be unwilling to work with or employ people affected by leprosy (Kaur & Brakel, 2002:347). Another study in India, reported statistics of the status of income and employment opportunities of people affected by leprosy. This study reported a fall in the income levels of people affected by leprosy (Rafferty (2006:120). This occurred because most of them had lost their employment due to the negative attitudes of their employers. These findings concur with the study by Kaur and Brakel (2002:348), which reported that 95% of the population in Ethiopia was unwilling to employ or work with people affected by leprosy. Such reduced opportunities of employment resulted into a loss of respect by their communities. Typically, such people are not able to support their families and this result in loss of self esteem and impacts on quality of life.

Calcraft (2006:77) argues that a person's sense of well being and the level, to which they perceive themselves as useful, is inextricably linked to their income generation and ability to secure employment and be able to support their families. Brown (2006:91), states that negative attitudes have a negative effect on the management of leprosy especially among women. For example, women could take long time to seek medical treatment for fear of rejection which could lead to being deserted by their husbands.

2.7 Elimination of leprosy

In 1991, the World Health Assembly set a target of eliminating leprosy as a public health problem by the year 2000 (Lockwood & Suneetha, 2005:230). Elimination was defined as the reduction of prevalence to less than one case per 10,000 people (Lockwood & Suneetha, 2005:230). However, Lockwood (2002:1517) observed that many policy makers were of the view that reaching prevalence would imply a reduction in incidence of leprosy. The idea of elimination was based on the hypothesis that the transmission of leprosy in the community would be interrupted. On the contrary, new cases were being registered. For example, Lockwood's study revealed that there were 719,330 new cases registered at the global level after the WHO claimed that leprosy had been eliminated in 2001.

In the southern region of Malawi, new cases are also registered although elimination status was reached in 1995. Such new cases seek treatment voluntarily from health centers (Somba, personal communication 2009). To counter the effects of the new cases, Lockwood and Suneetha (2005:230) propose that there is need to have a long term plan for sustainability of care for the leprosy patients. The long term plans according to Molyneux (2004:381) are continuous case detection, providing treatment and also prevention of disabilities. Such long term plans include, conducting research to provide evidence based information, as this would provide the best methods of detecting and treating nerve damage (Lockwood & Suneetha, 2005:232).

2.8 Life after leprosy: Leprosy and disability prevalence

Meima, Veen and Richardus (2008:242) define the prevalence of WHO grade 2 impairments as the number of people living with deformities worldwide at a given point in time. Infiltration of *Mycobacterium leprae* into Schwann cells results in inflammation of the nerves, which can lead to a progressive loss of nerve fibers' function (defined as neuropathy) mostly in the eyes, hands, and feet (Slim et al., 2010:1). Nerve dysfunction can lead to more severe impairments, such as wounds, clawing and shortening of digits, and visual impairments that are often indicated as World Health Organization (WHO)

grade 2 disabilities (Slim et al., 2010:1). These grade 2 disabilities are reported in up to 26% of newly detected leprosy patients (Slim et al., 2010:1). As a consequence of impairments, people affected by leprosy may experience limitations and restrictions in activities of daily living. The basic activities in which leprosy patients experience participation restriction include brushing hair, bathing, washing and eating.

In addition, individuals affected by leprosy are also restricted to social participation (Nichols et al., 2005:310). Examples of such social activities could include participation in church activities, attendance at weddings, farming and working. The restriction of the social participation could be due to visible deformities that cause the society to have negative attitudes towards the affected people (Ganapati, Pai & Kingsley, 2003:369). The deformities according to Joseph and Rao, (1999:516), lead to progressive physical, psychological and social disabilities leading to a decline in the overall quality of life of such persons.

Leprosy is less likely to cause death of an affected individual. However, the main issue of leprosy is the development of deformities (Lockwood & Suneetha, 2005:230). Thus, because the leprosy morbidity rate is low, leprosy is no longer a public health problem. Nevertheless the presence of survivors of leprosy with progressive deformities is a matter of serious concern by the WHO (Shumin et al., 2001:331).

Meima, Veen and Richardus (2008:242) on the other hand argue that the presence of impairments makes leprosy primarily to be a public health problem. Their argument is that impairments have a major impact on the quality of life of the affected individuals.

Brakel and Officer (2008:51) have reported that leprosy is one of the leading causes of preventable deformities in many developing countries. Although MDT has been highly effective in curing the mycobacterium infection, treatment of nerve damage has been much more difficult. Most of new cases are more likely to have impairments and disabilities after assessing them with WHO grading system at the time of registration (Appendix VIII for WHO leprosy related disability grading). Because of this reason,

Lockwood and Suneetha (2005: 230) have argued that leprosy is not only an infectious disease but also a chronic stable disease if not treated in time.

The estimated cumulative number of people disabled by leprosy by the year 2020 would be 0.6 million worldwide (Meima, Veen & Richardus, 2008:244). However, Brakel and Officer, (2008:51) have argued that the report has underestimated the disability prevalence. Their argument is that countries like India, Indonesia and Myanmar showed a prevalence rate ranging from 17% to 50% of leprosy disabilities after MDT completion.

However, Meima, Veen and Richardus (2008:245) have backed the use of estimated figures, citing the absence of statistics in most countries. The prevalence of disability among leprosy patients has not been monitored and recorded systematically and adequately by national programmes (Meima, Veen & Richardus, 2008:241). This lack of statistics is apparent in the current study being conducted in Malawi.

2.8.1 Leprosy and World Health Organization impairment grading system

The WHO developed a classification for grading leprosy disability since 1960 (Meima, Veen & Richardus, 2008:242). The system has become the most frequent used method of grading impairment in leprosy patients (Nienhuis, Brakel, Butlin & Werf, 2004:221). This is because the prevention of impairments is becoming a significant concern to the WHO. This is being advocated through prevention and management of deformities by use of self care and provision of footwear requirements (Cross, 2006:323).

According to a study by Brandsma & Brakel (2003:366), the original purpose of the WHO grading system was to record a baseline disability status and to monitor changes during follow up. Subsequently with the passage of time the purpose of the grading changed to being a case finding indicator and to estimate delay in case finding. The indicator showed less impairment in new patients at the time of diagnosis indicating early reporting for treatment. This is in direct contrast to the study by Meima et al.,

(1999:150) had revealed that most of the new cases had already grade 2 impairments at the time of reporting to the hospital.

Additionally, the grading system was used to evaluate and monitor patients' disabilities during the time treatment (Meima et al., 1999:153). According to the International Classification of Functioning, Disability and Health (ICF), disability includes physical impairments, activity limitations and participation restrictions (Brandsma & Brakel, 2003:369). This measurement scale consists of three grades: 0 to 2 and is assigned to each individual parts of the body (eyes, hands and feet) (Appendix VIII).

2.9 Leprosy from a gender perspective

Gender relations in Malawi are structured by a patriarchal system ((National Statistical Office (NSO) [Malawi], & ORC Macro, 2005:1). The system gives men more power and ownership over things of value for example land ownership and decision making (Schatz, 2005:495). As a result of the existence of the system, there is likely to be a male dominance in society and household as opposed to a female dominance or a situation of gender equality. In a patriarchal system, women are expected to be submissive to and economically dependent on men. Their socio economic dependency on men deprives the women the opportunity for early diagnosis and treatment of leprosy (Rankin, Lindgren, Rankin & Ng'oma, 2005:4). The women will need to ask for permission from their husbands to seek medication.

In addition, they need to be escorted to the hospital by their husbands or other relatives. Furthermore, they will need money for transport to the hospital to be provided by their husbands. All these factors prevented the women from reporting early for treatment. This may have resulted in the development of impairments. The issue of leprosy in women therefore becomes complex because it is aggravated by their socioeconomic status (Shieh, Wang & Lin, 2006:101).

Little information exists on the social and cultural status of women sufferers of leprosy in Malawi. Literature from other countries however provides evidence that leprosy has a

greater negative impact on women's lives than men (Rafferty, 2005:120). In addition, Moore (1996:4) argues that leprosy is a feminist issue because women are negatively affected by the disease more than men. From the arguments cited above, it can be argued that women, who suffer from leprosy in Malawi, are more likely to be disadvantaged because of the patriarchal nature of the society.

Zodpey, Tiwari & Salodkar (2000:505) observed that although both males and females are negatively affected by leprosy, the extent of the impact is more pronounced in women than in men. When a woman's status is revealed that she has leprosy, she is more likely to face aggravated isolation, rejection and discrimination than a man affected by the disease. She would be isolated from the community and stay away from her relatives and children without support. Clearly the isolation experienced by females shows cultural boundaries that exist between men and women in society.

The study further states that, in some cultures, if a married man had contracted the disease, the wife would encounter with more problems than the man himself. Such problems could be by way of rejection by her relatives or society. (Zodpey, Tiwari & Salodkar, 2000:508). The evidence provided above, does not exempt a Malawian woman suffering from leprosy from experiencing the similar types of discrimination listed above.

The study by Zodpey, Tiwari & Salodkar, (2000:508) revealed that even if women were independent to go for treatment, this favourable factor was nullified by some strong beliefs in traditional causes of leprosy for example that leprosy was infectious and could be transmitted through jutho (a person's food leftovers), sharing the same eating utensils, sexual intercourse, and being in proximity to the person affected.

In some other countries, several other reasons have been advanced for women's inability to have early diagnosis and treatment of leprosy. These have been cited by Varkevisser et al., (2009:68) as low social status, low literacy or none at all, poor knowledge, and awareness of clinical signs of leprosy and its treatment. Furthermore,

dependence on the permission of the mother in law or husband to leave the homestead exacerbated the situation.

Shieh, Wang & Lin (2006:106) revealed that women did not get early treatment of leprosy because many of them and their parents had limited education, thus having little knowledge of the disease prior to coming to the leprosy centre. As a result, they first tried local remedies such as pasting ashes on their skin to remove a skin rash or avoiding certain foods before seeking medical treatment (Shieh, Wang & Lin, 2006:105). In a study by John, Rao and Das (2010: 37), a majority of the women revealed that they had no knowledge of leprosy prior coming to the leprosy centre. They expressed that they had developed the deformities because they had reported late for treatment.

Varkevisser et al., (2009:68) mentions in his study that women are a socially vulnerable, group which suffers aggravated isolation and rejection from the society. For example women may suffer rejection from their husbands, children and relatives. The rejection experienced by the women, deprives them of an opportunity to engage in domestic roles like cooking, breast feeding their children, sleeping in the same room along with the other family members and mixing with them. In addition, the women were not allowed to have sex with their husbands. To crown it all, they were not allowed to share utensils and were not involved in decision making in the family matters.

Zodney, Tiwari and Salodkar (2000:509) reveal that such isolation from domestic roles degrades and dehumanize the self, projecting an image of being a less valued member of the family. This has adverse psychological consequences in that it negates the role of the woman as a natural care giver in the home. The deprivation of her natural role will most likely have a serious impact on her life. In extreme cases women have opted for escapism. Some have attempted or considered suicide by hanging themselves or by putting poison in the soup to drink.

According to Zodney, Tiwari and Salodkar (2000:509), some women have expressed the view that even if they were physically free of the microorganism, they would never be free of the leprosy emotionally. This phobia came as a result of physical changes to their faces, hands, fingers and feet. The physical changes could not be removed from their community. This adversely affected their daily routines and socialization.

Some literatures also suggest that women find it difficult to follow the medical advice given to them. According to John, Rao and Das (2010: 37) examples of such advice include avoiding prolonged walking and standing, and working with hot utensils. As natural care givers for their families, women had to care of their families. The woman cannot afford to follow such advice because of a fear of losing social support, in case the husband abandons her.

In a Malawian context, most patients are accompanied by a family member when they go to a hospital or health centre. It is often a female adult family member who takes up this role. The role of accompanying patients is seen as a female role (Nyirenda et al., 2006:74). Experience has also shown that naturally, women provide care more spontaneously than men within the family and kinship networks whenever the need arises.

Nyirenda et al., (2006:75) in a study done in Malawi, provide evidence that women's work is centered around the household, whereas men's role as primary income earners increases their values to and within the family, reducing the impact of stigma on their status. Shieh, Wang & Lin (2006: 105) seem to concur with this view. They observe that even though women developed leprosy symptoms such as burn spots on their fingers, hands and forearms, ulcers in their feet, skin rash and their sluggishness in cooking and doing domestic chores, they still could not afford to be sick and neglect care responsibilities.

Rafferty (2005:122) acknowledges the fact that the woman who has been disabled by leprosy suffers more isolation, loss of touch and rejection from the society than her male

counterpart. As a result women tend to be more disabled than men because of the occupational and social injustices which they face. Such occupational and social injustices contribute to their poor quality of life. The status of women varies from one society to another. However, everywhere disability poses additional challenges for women (Nagata, 2003: 12).

2.10 Leprosy through an occupational lens

There is need to consider the meaning of occupation. Literature has shown that there are various definitions of occupations that exist to date. Within occupational therapy, there is confusion about the meaning of occupation and little agreement on how the concept should be defined (Creek & Hughes, 2008: 457). For example, the Canadian Association of Occupational Therapists provides 2 different definitions of occupations.

Firstly, occupations have been defined as “groups of activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a culture (CAOT, 1997). Secondly, occupations have been defined as “everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity)” (CAOT, 2002).

On the other hand, the American Occupational Therapists Association defines occupation as the purposeful and meaningful daily activities that fill a person’s time. These are typically categorized as self-care, work, play or leisure, and rest (AOTA, 1995: 1015). The definition by CAOT was adopted for the purposes of this study because it categorizes and encompasses all daily activities into occupations. Furthermore, it enriches the Occupational therapy belief that human beings as occupational beings have the urge to participate in purposeful and meaningful activities.

Leprosy creates barriers for the survivors to participate in occupations of their choice in their communities. This is a result of the negative attitudes and beliefs that people have on the causes of the disease (Cross & Choudhury, 2005:317). Above all, studies have

indicated that social factors such as social rejection by the family and community have also contributed to the reduction in the engagement in occupations of the choice of the survivors of leprosy (Cross & Choudhury, 2005:318, Hassan, Khalil & Hassan, 2002:22).

As a result of the rejection, survivors of leprosy are likely to be deprived of the occupations that are meaningful and purposeful in their lives. For example, Hassan, Khalil and El- Hassan (2002:22) report that patients from eastern Sudan may quit home permanently if they experience a lot of stigma from their families. Absconding from home results in survivor to live in streets thereby engaging in occupations like street begging. Additionally, Raferty (2005: 120) stated that people with leprosy in Nepal may lose their employment because of the stigma of employers. This could be because people affected by leprosy remain trapped in the vicious circle of the disease-impairment stigma even after being cured from the disease.

Whiteford (2000:200) has defined occupational deprivation as a state in which the opportunity to perform those occupations that have social, cultural and personal relevance is rendered difficult if not impossible. It is generally assumed that survivors of leprosy are still in the state of sickness. The survivors experience such occupational risks as occupational deprivation. Occupational therapy practitioners are in a prime position to recognize the occupational implications of health problems and offer interventions to alleviate them through task analysis and modification and through addressing the participation restrictions experience as a result of stigma.

Wilcock (1998:340) argues that there is need to have social values that create an occupationally just society that provides the opportunity for all people to develop their potential for participation in their life situation. This idea arose from the basis that people are occupational beings who develop through doing, and that engaging in occupation is a basis for health (Wilcock & Townsend, 2000:85)

Wilcock (1998:340) acknowledges that humans *have* 'occupational needs' which are related to health. Therefore Jakobsen (2004:132) suggests that it is important to create a context that makes it possible for people with a disability to take control over their lives and to choose meaningful daily occupations. This could be done by creating an inclusive society which occupational therapists could promote by working in collaboration with people with disabilities.

Occupational therapists therefore have a duty to work with policy planners in various departments. They have the duty to promulgate information about humans as occupational beings, and the health consequences of not engaging in occupations of their choice (Wilcock, 1998:343). The author suggests that occupational therapists have to establish themselves as advisers at all levels of the society to increase awareness and understanding. This could be achieved by being involved in the development and promotion of inclusive policies. This will enable survivors of leprosy to access a wide range of occupations that are available in their community, hence promoting a full and equal participation in their community resulting in the improvement of their quality of life.

Wilcock (2003:168) argues that occupation is a mechanism by which people fulfill basic needs which are closely linked with survival, health and their ability to flourish in environments which allow them to grow toward their potential. The World Federation of Occupational Therapists (2004:1) position paper on the rights of people with disabilities acknowledges the idea of Occupational therapists' involvement in disability issues. The rationale behind this is that the Occupational therapist has the knowledge and skills to support persons who experience limitations or barriers to participation in occupation.

However, Occupational Therapy is a new profession in Malawi. There are currently only seven Malawian occupational therapists in the country. Of these, five are working for non-governmental organizations within the country and two in the government sector. The researcher is among the two working in the public sector. As a result very little information exists about the role of occupational therapy in the comprehensive

management of leprosy. This kind of intervention has hitherto not been available in Malawi among leprosy survivors living in their communities.

Much has been written about the role of the occupational therapist in other types of disabilities, for example in stroke or cerebral palsy but not in survivors of leprosy. However, studies have shown that there is a growing interest for occupational therapists in addressing unjust inequities that limit opportunities for participation in society (Braveman, & Bass-Haugen, 2009:7). Occupational therapists also have a role to promote policies that offer affordable, accessible health care to everyone, including people with disabilities. Furthermore, they also lobby for public funds to support research and program development in areas related to improvement in quality of life for people at risk and those with disabilities (Scaffa, Slyke & Brownson, 2008:697).

2.11 Survivors of leprosy and their quality of life

According to Liddle and Mckenna (2000:79), there are several different definitions of QOL. These definitions differ, reflecting the different backgrounds of the researchers who proposed them.

A definition proposed by the WHOQOL Group (1995:1405) is used in this study. The World Health Organization defines quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, and level of independence, social relationships, and their relationships to salient features of their environment.

However, few studies have been conducted to investigate the quality of life among leprosy patients. Most studies have focussed on other diseases, for example cancer, asthma stroke, HIV/AIDS other skin conditions like Vitiligo. Therefore, a discussion quality of life of survivors of leprosy will use literatures that have investigated the

diseases mentioned above. Such diseases are likely to cause disabilities in affected persons resulting in reduced quality of life just as is the case with leprosy. For example stroke has been classified by (Mayo et al., 2002:1035) as the most disabling chronic disease that could affect an individual's quality of life.

Chappel and Wirz (2003:165) state that the widespread view of a good quality of life is usually based on the idea of good health and experiencing personal wellbeing and life satisfaction. They cite factors such as independence, fitness, status and respect. It could therefore be argued that people affected by leprosy are incapable of experiencing a good quality of life because of the impairment that limits them from participating in productive activities.

The burden of leprosy consists primarily of impairments and disabilities of the feet and hands which, in turn, have a major impact on the quality of life of the affected individuals (Tsutsumi et al., 2007:2550). Such impairments are likely to make survivors of leprosy lose their ability to work. As a result their quality of life could be socially, economically and psychologically affected. As already stated, data to reveal the quality of life led by leprosy survivors in Malawi is scarce.

A study by Shen, Liu and Zhou (2007: 284), on the current situation of leprosy colonies/leprosaria and their future in People's Republic of China, revealed that most people living in a leprosarium led a poor quality of life. The paper explains that people who lived in the leprosy villages were neglected, and the budget for their care was insufficient for their needs. In addition to inadequate resources, most of the leprosy patients had grade 2 disabilities and were advanced in age. As a result they were not able to work to earn any income.

Furthermore, there were a decreased number of health workers available to work at the leprosy village and a shortage of medical materials such as dressing materials. Owing to this, many people suffered from serious foot ulcers and eye problems because they could not get adequate treatment (Shen, Liu & Zhou, 2007:286).

Joseph and Rao's study (1999:517) reported that individuals in India who had been cured of leprosy had a poorer quality of life than the general population. This is attributed to the stigma inflicted upon the cured patients by the general population at large.

According to available information, there are no published studies that have documented the quality of life led by leprosy survivors after the closure of the leprosy villages in Malawi. This lack of information prompted this research to investigate and compare the quality of life of the leprosy survivors living in the leprosarium and those integrated in their communities. Problems experienced by leprosy survivors in Malawi are not unique to the country alone, but have a propensity to be universal. This is evident in the study done in Nigeria by Ogbeiwu and Nash (1999:296) on the needs analysis in the resettlement of leprosy survivors. The study showed that there was fear of stigma by families of the survivors, because of their deformities. The survivors felt that they would not be fully accepted once they returned to their original homes and they would lack basic care due to their disabilities.

An unpublished survey by the researcher conducted amongst leprosy survivors at Utale revealed that dependency played a significant role in preventing the survivors from returning to their homes of origin (Chinguo, 2005:12). This dependency syndrome may play a role in determining the quality of life that leprosy survivors lead both in the leprosaria and in the community. A study by Velema (2008:319), suggests that working to improve the quality of life of the leprosy patients, involves both medical and socio economic interventions. Taking cognizance of this fact the Leprosy Mission in 1950 introduced the concept of self care and introduction of modern Occupational Therapy, helping clients to carry out activities in such a way that damage to the hands and feet would be avoided.

Unfortunately, occupational therapy and other preventative and rehabilitative services are currently not available in Malawi among the survivors of leprosy who were re-

integrated in their communities. Because of unavailability of these services, leprosy patients develop visible impairments that increase the social discrimination of the disease thereby decreasing the scores of their quality of life.

Studies have shown that the quality of life of leprosy survivors and their families is affected in terms of social, economical and psychological terms (Tsutsumi et al., 2007:2444). Patients suffering from leprosy sometimes delay in seeking proper care until they develop physical deformities. The quality of life of such persons declines because the leprosy survivors are not able to support themselves due to deformities (Joseph & Rao 1999:517). Kaur and Brakel (2002: 350) argue that the negative attitudes have been found to be stronger with regards to marriage, sharing of accommodation and any other physical contact with the infected person. This results in survivors of leprosy, being looked down upon by their communities. Hence, they are less likely to receive support from the communities.

2.11.1 Determinants of quality of life

A number of factors determining the quality of life have been discussed in different literatures. An individual's quality of life seems to vary with age, gender, functional status, socioeconomic status and social support respectively. These factors have been identified as some of the possible determinants of a person's quality of life (Owolabi, 2008:1219).

Other literatures have reported that apart from improving the quality of life, some determinants such as marriage, higher educational attainment and employment will increase the potential for awareness of disease, social support and the use of positive coping methods. Survival skills can also contribute to higher QOL score (Awadalla et al., 2007:116). Studies have shown that social support is significantly associated with better QOL scores although most such studies were conducted in industrialized countries (Bajunirwe et al., 2009:275).

An example of a social support programme discussed in Bajunirwe et al.,(2009: 275) regarding a study conducted in Western Uganda, shows the positive effects of social support in developing countries. In this programme social support was provided through Home Based Care and community services. Nutritional supplements have a proven positive effect on HIV patients on quality of life. Patients who reportedly received more social support perceived their health to be better than those who received less social support. Equally, patients receiving social support experienced less distress about their health situation.

In addition, from an occupational therapy perspective, participation in daily occupations has been identified as an important determinant in quality of life of health and wellbeing (Sandqvist & Eklund, 2008:27). The paper argues that there is need for an individual to engage in different types of occupations for example, domestic chores and self care. This is because occupations have been regarded as vital for the individual's wellbeing ever since occupational therapy was founded.

A study by Naidoo and Mwaba (2010:1325), indicated that people who have a lifelong or infectious disease and those who have limited social, psychological, and economic resources, find it extremely difficult to maintain a reasonable quality of life. They conclude that social support serves as a buffer to the challenges associated with illness. In their study, it was also noted that participants experienced positively about the social support of close relatives. For the participants in this study, their immediate family members, close friends, and those in close physical proximity (neighbors) were found to be their closest social allies. Family members were identified as the most significant providers of social support, followed by friends and neighbors.

In addition, Ohaeri, Awadall and Farah's study (2009:1329) reported that a higher QOL was also associated with younger age, being married, higher educational attainments and higher levels of employment. In Malawi, data on determinants of quality of life in survivors of leprosy are scanty. Thus, there is a need to determine such factors in Malawi.

2.11.2 Measurement of quality of life

Quality of life is being used to assess the burden of illnesses on an affected individual (Muldoon, Barger, Flory & Manuck, 1998:542). This has been termed as “health related quality of life”. The study states that quality of life measurement has also become an integral variable outcome in clinical research. The authors state that information gained from the research will provide the functional status of the individual and the patients appraisal of his health. In addition, Izutsu et al., (2005:1783) have also stated that assessments of an individual’s subjective feelings on aspects of life and health as QOL, have attracted a lot of attention. Therefore, the WHOQOL-BREF has been widely used in many countries to assess QOL. The investigator in this research has used this tool because of its global acceptance.

CHAPTER 3

METHODOLOGY

3.1 Introduction

This chapter gives a brief description of the research context, the research design and how the participants were identified and recruited. The chapter further describes the instrument administered in the study, how the data was collected, and how the collected data was analyzed. Finally, there is a discussion on the ethical considerations of this study.

3.2 Research context

The study was conducted at Utale leprosarium situated in Balaka (the only remaining leprosy village in Malawi) and in the three districts in the southern region of Malawi where survivors of leprosy had been reintegrated (Appendix VI) This region was selected for logistical reasons as it is where the researcher is currently working as an occupational therapist at Queen Elizabeth Central Hospital in Blantyre, the largest city in the region and also the commercial city in the southern region.

Queen Elizabeth Central Hospital is the main referral hospital for the southern region and also for some complicated cases for the whole country. It is also a teaching hospital for different health cadres who are trained at various institutions in Malawi including the University of Malawi.

There is no training facility for occupational therapists in Malawi. The six occupational therapists who are currently working in Malawi trained elsewhere in Africa or in Europe. An occupational therapy perspective on the research context, introduced by this study, will therefore promote the development of the profession in the region and also in other regions in the country, filling an existing gap in knowledge about the service needs of people disabled by leprosy.

The study was conducted in the three districts of the Southern region of Malawi namely Balaka, Thyolo and Chikwawa. The choice of the districts was determined by the following factors:

- The fact that Thyolo and Chikwawa districts previously hosted leprosaria, which have since been closed down, while the one at Balaka is still functioning.
- The researcher's familiarity with the health service infrastructures in southern Malawi.
- The researcher's familiarity with the only remaining leprosarium at Utale in Balaka.

3.3 Research design

A cross sectional comparative descriptive study design was used in the study. According to Burns and Grove (2007:249), a comparative design is used to describe variables and to examine differences in two or more groups that occur in a setting. In this study, such a design was used to describe and examine differences in the quality of life of the survivors of leprosy living in the leprosarium and those re-integrated into their communities in the southern region of Malawi.

3.4 Identification and recruitment of participants

3.4.1 Population

The intended participants in the study were all known leprosy survivors in the selected study sites. The exact size of the population of those re-integrated in their communities was not known. However, a record of cases visited by LCAs in each of the three districts indicated that approximately 200 survivors of leprosy aged from 50 to 90 years and above were reintegrated in the communities within the identified districts. There were about 100 survivors of leprosy living in Utale, the selected leprosarium at Balaka and all of them fell into the age band of 50 to 90 years. This age band was therefore used as inclusion criteria for sampling in the districts. It was also identified for the following reasons:

- Age is more likely to affect quality of life irrespective of whether the person has disability linked to leprosy or not, because of being dependent on help from others to maintain daily activities (Werntoft, Hallberg & Edberg, 2006:118).
- People are now living longer with advances in modern science, and people aged 65 years and over, now form a much larger share of the population than they did before (Werntoft, Hallberg & Edberg, 2006:118).
- When older adults encounter illness, or move from a long-time home, their life course, social roles and occupation may change or terminate (Odawara, 2010:15).

3.4.2 Sample size

In this study, a sample size of 232 participants was required to participate in the study to give a power of 80% at 5% significance level for both the leprosarium and the community. However convenient sampling was used since there are only 100 participants available at the leprosarium. The second reason for choosing this sampling method was the unavailability of official demographic data for the survivors of leprosy integrated in the community after the elimination status.

A total of 200 participants were recruited, giving the study results a power of 77%. Estimating the power of the sample size is important as it enhances comparisons between studies that have used the same instrument which in this instance is the WHOQOL-BREF (WHO, 1996). This instrument is described below.

3.4.3 Research Instrument

The study used the World Health Organization Quality Of Life Brief (WHOQOL-BREF) assessment tool to solicit information from the survivors of leprosy in the leprosarium and in the communities (World Health Organization, 1996). WHOQOL-BREF is a shorter version of WHOQOL-100 which was developed by the WHOQOL Group with the

aid of 15 collaborating centres around the world to measure quality of life (Izutsu, 2005: 1784).

The tool was designed to be used in a variety of cultural settings and in medical practices, research, audits and in policy making. The instrument was drafted on the basis of statements made by patients with a range of diseases, by people not afflicted by any disease, and by health professionals in a variety of cultures.

The tool is available in approximately 20 languages, including those of both developed and developing countries. It is also available in different religious settings such as Christianity, Islam and Hinduism thus demonstrating its cross-cultural validity (Izutsu et al., 2005:1784). The instrument has been found to be an adequate measure for assessing the quality of life in different cultures (Yao *et al.*, 2002:345). The validity and reliability of the instrument was confirmed in a previous study (Tsutsumi et al., 2006:495).

The WHOQOL-BREF contains 24 items divided into the following four domains: (1) physical health domain, (2) psychological domain, (3) social relationship domain, and (4) environmental domain. A higher score indicates a better quality of life and (Izutsu et al., 2005:1783). WHOQOLBREF was designed to use a 5 point scale for all questions. The anchor point 1 represents 'not at all', 2 'a little', 3 'moderately', 4 'mostly', 5 'completely'.

WHOQOL-BREF is a suitable instrument among the many QOL instruments for use in leprosy-endemic countries because it was developed to facilitate cross-cultural comparisons. (Tsutsumi et al, 2007:2450). It was used to measure QOL among people in Bangladesh by Tsutsumi et al, (2007) and by Joseph and Rao (1999) who confirmed the ability of the instrument to show differences in QOL between people affected by leprosy and a control group in South India (Brakel & Officer, 2008: 59).

According to O'Carroll *et al.*, (2000:122) data was taken from twenty field stations situated in eighteen countries, when the instrument was being constructed. Therefore the WHOQOL-BREF has been proposed as being an alternative brief instrument to measure quality of life because its response and return rates were high because of its brevity.

The WHO group (1998:551) listed reasons for developing this measuring tool. Some the reasons for the development of the tool were that it could be used in clinical practice. The valuable information obtained therein could indicate areas in which a person is most affected. The information would therefore help the practitioner in making the best choices in patient care.

The instrument could also be used to increase the physician's understanding of how diseases affect quality of life of the affected person. This will improve the interaction between patient and doctor. This will result in the patient being provided with comprehensive health care.

The WHOQOL-BREF was originally not available in Chichewa, the national language of Malawi. In order to communicate effectively with the participants who could not speak English but only Chichewa, it was necessary to translate the English language questionnaire into Chichewa. The components of the original English language questionnaire were translated into Chichewa by two independent bilingual translators. Such an approach had been made in Bangladesh where the WHOQOL-BREF questionnaire was translated into the Bangla version, in a study to determine the quality of life, general mental health and perceived stigma (Tsutsumi *et al.*, 2007:2443).

The current study used a Chichewa version of the WHOQOL-BREF (WHO, 1996) (Appendix II). Face validity of the Chichewa version of the WHOQOL-BREF measurement tool was confirmed in a pilot study by the researcher. No changes were made to the Chichewa translated version.

3.4.4 Scoring the WHOQOL-BREF

Each item uses a five point response Lickert scale. A scale of 1 represents 'not at all', 2 'a little', 3 'moderately', 4 'mostly', and 5 'completely'. The instrument is scored by adding up the score on each domain to yield a total score for the instrument. The four domain scores denote an individual's perception of quality of life in each particular domain. Domain scores are scaled in a positive direction (i.e. higher scores denote higher quality of life. A lower score indicates the opposite). The mean score of each domain is used to calculate the domain score. The total scores for each domain are as follows: physical: 35, psychological: 30, social relationship: 15, and environment: 40. The following changes were made to the tool:

- A) A section to capture the demographic data of the participants was added to the questionnaire.
- B) The last part of Question Number 26 was removed because of the low level of education of the research assistants. The part that was removed reads as follows: 'Do you have any comments about the assessment'?

It was believed that the shortfall in the educational qualifications of the research assistants would make it difficult for them to obtain and record the required qualitative information from the participants accurately. However, such a group of research assistants was ideal for the assignment because of their ability to identify survivors of leprosy in their locations.

In addition to the WHOQOL-BREF, additional demographic data was developed by the researcher and added to the questionnaire. This has been stated in (A) above. The socio demographic data were used to describe and compare the quality of life led by survivors of leprosy in the leprosarium and those reintegrated in their communities. Comparisons were made between gender, ages, and occupations, level of education, marital status and contacts with relatives.

Furthermore, age and gender were chosen as confounding factors on residence in both the leprosarium and the community in each of the four WHOQOL-BREF domains. This is because these were the only variables that were giving statistically significant results. The data provided information on the impact of these variables on quality of life between the two cohorts. The study instrument was administered by the researcher and (LCAs). The duration per individual interview was between 30 to 45 minutes.

3.4.5 Gaining access to the leprosarium and community

Permission to access Utale leprosarium and community was obtained after a letter introducing the researcher (Appendix V), a copy of the proposal and approval letters from the Universities of Cape Town and Malawi respectively (Appendix IX & X) were submitted to the District Health Officers of Thyolo, Chikwawa and Balaka District Hospitals. The Catholic Parish Priest of Utale was provided with an approval letter from Balaka District Hospital. Permission to use the Leprosy Control Assistants was also obtained from their respective District Health Officers.

3.4.6 Recruitment of survivors of leprosy

After permission for the study was received from the local parish priest in charge of Utale, it was agreed that the best way to ensure that participation was voluntary was to reassure the participants' that their refusal to participate in the study would not negatively affect the support they receive from the church, and the self care activities from the LCA based at the leprosarium (soaking and dressing of wounds). Recruitment in the leprosarium was done in the participants' households by the researcher and the research assistants.

Participants in the community were recruited by the researcher and Leprosy Control Assistants. This was done using registers in which the LCAs record their clients. However, survivors of leprosy who were not in the registry were identified through their respective village headmen. The aim of the study was explained and the approval

letters from University of Cape Town and College of Medicine which were signed by the respective District Health Officers were submitted to the village headmen. Participants were also advised that participation was voluntary and they were given the option to withdraw from the study at any point or refuse to answer any questions if they felt uncomfortable. Furthermore, declining the invitation to be part of the study would have no effect on the relationship between the survivors of leprosy and the LCAs. However, no participant from either of the research locations refused to participate in the study.

3.4.7 Sampling: Selection criteria

The following criteria were used for selection of participants

Inclusion criteria

- Females and males with non-active leprosy aged from 50 to 90 years. The selection of the age band has been explained in 3.4.1.
- Resident in a leprosarium after the attainment of elimination status OR
- Reintegrated into the community after the attainment of elimination status.
- Participant should have lived in any leprosarium that existed before the elimination status.

Exclusion criteria

- Persons aged 50 to 90 years who had active leprosy during the time of data of collection.
- Survivors of leprosy who were unable to give consent due to sickness for example malaria.

The expected number of participants was 100 survivors of leprosy from the leprosarium and 100 survivors from the communities. The data for 200 participants was entered into the SPSS. However, during the analysis, the software indicated that data for 2 participants from the communities was missing, and hence there were 98 participants from the communities.

3.4.8 Training of the Leprosy Control Assistants

In order to ensure uniformity in the administration of the instrument, attention was paid to the training of the LCAs. The training was done by:

- The researcher at a workshop in which the study was explained to the LCAs
- LCAs were equipped with basic implementation skills through a series of simulated research exercises.
- Contrasting the roles of a research assistant and a participant was practiced. This was done by play acting scenarios in the use of the instrument.
- The researcher conducting repeated interviews with simulated participants while the LCAs observed and scored the instrument.
- Discussing possible ethical issues that may arise in the study (see 3.8.1 below), with emphasis on:
 - Autonomy and confidentiality of the participants.
 - Participants living in the community could choose a place where they wanted the interview to be conducted for fear of stigma.
- Reinforcing the importance of monitoring the interview process. If the participants developed stress, the interview had to be discontinued and the participant had to be referred appropriately. During the interview process of this study, no participants showed any signs of stress. Therefore no referrals were made.
- Clarification of issues raised by the LCAs during training. Issues such as giving money or any form of gifts or inducements to participants as a motivation to participate in the study were discouraged.

3.5 Pilot study

A total of 15 survivors of leprosy, constituting of 5 from each district were interviewed as a pilot study for the adaptation of the WHOQOL BREF measuring tool. This was done to establish whether the language used during translation was appropriate and understandable. The participants (survivors of leprosy) of the pilot study were excluded from the main study. Findings from a previous study have shown that their continued participation in the pilot and thereafter the main study may reduce their willingness to be

interviewed in the proper study or may affect the responses given in the proper study (Burns & Grove, 2007:50).

Ethical considerations were also applied for the pilot study. The time taken to complete the questionnaire was noted, as this would be used to determine the time required for administering the questions during data collection.

3.6 Collection of data

Survivors of leprosy who gave their permission (Appendix III & IV) were interviewed by the researcher and 6 LCAs who were trained as research assistants. Four research assistants were deployed in the communities and the remaining 2 in the leprosarium. Collection of data took 21 days (3 weeks) in the communities. This was due to the long distances between villages where the survivors were living and also the fact that the roads were not in good condition for the motorcycles which were used for mobility. On average, only 5 instruments were done per day. However in the leprosarium, collection of data took only 7 days because survivors live in a cluster. Therefore, on average 14 instruments were done per day. The researcher was available for 2 days in each community to make sure that research assistants were maintaining the ethical considerations and were collecting data from the survivors of leprosy correctly.

The LCAs took their 24 days annual leave from their employment during the data collection period and they were paid for the activity. The duration of the leave and the payment was negotiated with the relevant employer to ensure the wages paid were in line with their normal salaries. It was necessary for them to go on leave during the research period to avoid a situation where they would be deemed to have been absent from their normal work.

3.6.1 Storage and capturing of data

Once the LCAs completed questionnaires, they placed them in a sealed envelope for safe keeping. They submitted their allocated questionnaires to their respective District Health Officers (DHOs) to keep them in a locked cupboard. The researcher was

informed by research assistants to collect the completed questionnaires from their respective DHOs. The researcher entered the data into SPSS V 18.0 data editor (a quantitative computer based programme used for statistical analysis. SPSS was used to record and check the data and to compute the scores of the four afore mentioned domains (physical, psychological, social relationships and environment) (University of Cape Town, Information Communication and Technology Service, Predictive Analytic SoftWare (UCT, ICTS, PASW (SPSS) 18, 2010).

3.7 Data Analysis

Data was analyzed using the following steps:

- A comparison of social demographic profile was made between survivors of leprosy living in the leprosarium and those reintegrated in the communities.
- Individual overall domain scores were obtained. The four domain scores denoted an individual's perception of quality of life in each particular domain.
- The overall domain scores were obtained from both groups.
- The total means score \pm standard deviation of all the domains was obtained from both groups.
- A comparison of the mean scores \pm standard deviation of all the domains was done in between locations, in males and females and between age groups. The level of significant difference was $p < 0.05$. Independent student t-test was used to examine if there were significant differences in the quality of life between the elderly, males and females survivors of leprosy living in the leprosarium and those reintegrated in the communities.

3.8 Ethics

3.8.1 Ethical approval

Ethical approval for the study was granted by the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee (FHS HREC REF: 495/2009) (Appendix IX) and University of Malawi, College of Medicine, REF: P.11/09/839) (Appendix X).

3.8.2 Ethical considerations

Informed written or oral consent depending on the level of literacy was obtained after explaining the details of the study to the participants. The ethical considerations of this study were guided by the Declaration of Helsinki (Puri, Suresh, Gogtay & Thathe, 2008: 131:134)

Informed consent implies that participants have adequate information regarding the research and are capable of comprehending the information (Polit & Beck, 2008:176). It was emphasized that participating in the study was voluntary and the participants had the right to withdraw at any point. Furthermore, declining an invitation to participate in the study would have no effect on the relationship between the participants and the LCAs as already stated above.

The participants' choice was respected. They were informed that their participation was voluntary and that they could withdraw from the study at any time, or refuse to answer any questions without any negative consequences. Respondents were assured of confidentiality and anonymity of the information that was obtained. Numbers were allocated on the question paper. Any publications from the study will not have any identifying information.

Interviews in the communities were conducted in a room or area of the participant's choice while in the leprosarium the interviews were done in the participant's home, but separate from the other members of the family. The importance of this was reinforced with LCA's during the training workshop and during the pilot study.

Respondents were treated with respect, integrity, right to self determination and dignity in spite of their social and economic status, in cognizance of accepted human rights practices. By actively supervising them, the researcher ensured that the LCAs adhered to these ethical guidelines. If participants developed signs of stress at any point during the interview, the LCAs were instructed to terminate the interview and refer

appropriately for care and attention. In this study, no referrals were made as participants did not develop any of stress. The LCAs were trained to discern stress by being kind and empathetic towards the survivors. Participants who entered into the study were informed about the outcome of the study to share any benefits that resulted from it. This dissemination of the findings was done using the same sources that interviewed them.

3.9 Conclusion

The chapter has provided information of the research sites and the process of acquiring the research participants. An overview of how data was collected, stored and analyzed has also been provided including the ethical considerations that were followed during data collection.

Chapter 4

Results

4.1 Introduction

This chapter covers details of the demographic profile of the 200 participants who were sampled for the study from Utale leprosarium and communities in the southern region of Malawi. It also presents an analysis of the data obtained from the WHOQOL-BREF.

All the questionnaires were completed representing a 100% response rate. Firstly, an analysis of the differences and similarities of the demographic data is presented. Secondly, the analysis of the total mean scores of WHOQOL-BREF (physical, psychological, social relationship and environmental domains) of the participants will also be presented. Thirdly, an analysis of WHOQOL-BREF and the 4 domains is presented based on the two statistically significant variables namely age and gender that were used as confounding factors for residence (leprosarium and communities). Conclusions of the results are provided and discussed in the next chapter.

4.2 Demographic profile

The demographic characteristics of the survivors of leprosy still living in the leprosarium and those re integrated in their communities are presented in Table 1.1 below. The total number of survivors of leprosy interviewed was 200 which comprised of 100 survivors from the communities and 100 from the leprosarium. However, data for 2 participants from the communities were missed after the data was entered in the SPSS during the analysis process (as explained in 3.4.7). Therefore, the number of participants analyzed from the communities was N=98. There were more females interviewed in the study than males in the communities and the leprosarium, representing 58.1 % of the participants from the communities and 53% of the participants from the leprosarium.

Table: 4.1 Demographic profile of survivors of leprosy re-integrated in their communities and those living in the leprosarium

Variable	No of participants in the community (N=98)	No of participants in the leprosarium (N=100)
Age (years):		
50-59	41	13
60-69	27	36
70-79	16	31
80-90	14	20
Gender		
Male	41	47
Female	57	53
Level of education:		
No formal education	38	33
Primary	59	67
Secondary	1	0
Occupational status:		
Builder	1	0
Cook	1	0
Business	1	4
Farming	62	75
Guard	10	2
Farm worker	15	0
Hospital attendant	0	1
Not working	9	18

Marital status:		
Married	64	46
Single	6	19
Widow	15	20
Widower	8	5
Divorced	5	10
Contact with relatives:		
Yes	76	42
No	22	58

A younger population between the age bands of 50 to 59 years was found in the communities (41.8%) than in the leprosarium which had more of the older population (20%) between the age bands of 80 to 90 years. Independent student t-test was used to test statistical differences between the two communities in terms of average age. The mean age of the survivors of leprosy reintegrated in the communities was 65.31 years (SD=11.193), which was lower than the mean age of the survivors of leprosy in the leprosarium (70.34 years; SD= 9.753). There is a significant difference of ($p < 0.001$). The findings indicate that survivors of leprosy living in the leprosarium reached an older age than those reintegrated in the communities.

The percentage on the level of education attained did not differ much between the survivors of leprosy living in the leprosarium and those reintegrated in the communities. Sixty percent of the survivors of leprosy from the communities and 67% of the survivors of leprosy from the leprosarium attained primary school education as their highest level of education. This suggests that survivors of leprosy in both residences attained primary school education as their highest level of education.

The work-related occupations (as opposed to self care, leisure and social occupations) of participants yielded interesting but statistically insignificant results. Survivors of

leprosy in both research locations engaged in farming activities or worked as farm laborers as their primary productive occupation.

Farming among survivors of leprosy was defined as any agricultural related activity on a small piece of land with the purpose of maize production for food. Being a farm worker was defined as being engaged in part time agricultural related activity on other people's big farms with the purpose of earning an income (personal definitions). Sixty two percent of the survivors from the communities and 75 percent from the leprosarium were engaged in farming. However, there was no statistical difference in the percentage of survivors of leprosy engaged in farming. There appeared to be a different range of work related occupations pursued by survivors of leprosy living in the two locations, with some respondents in the community being employed as guards and a few engaged in personal businesses. There were also isolated cases of a hospital attendant and a cook within the leprosarium.

Marital statuses of the survivors of leprosy living in the leprosarium and communities showed some differences although these were statistically insignificant. The percentage of the married participants in the communities was 65% and 46% in the leprosarium. The percentage of divorced and single participants also showed some differences. In the leprosarium, it was 10% and 19% respectively, whereas in the communities these proportions were 5% and 6% respectively. This suggests that survivors of leprosy who were reintegrated in the communities were able to find spouses. The percentage of survivors who had lost a spouse to death was 23% for those re integrated in their communities and 25% for those still living in the leprosarium, showing a similar proportion in both groups.

Fifty eight percent of the survivors of leprosy living in the leprosarium responded that they did not have any contact with relatives, compared to 21% of the survivors of leprosy in the communities who reported they had no contact with their relatives. The statistically insignificant findings suggest that a long duration of isolation of survivors in the leprosarium could reduce the chances of contact with relatives.

Table 4.2 Range of total scores in WHOQOL-BREF domains for all survivors

Domain	Total WHOQOL-BREF domain scores	Survivors (n=198) Range (x-y)
Physical	35	15-35
Psychological	30	8-27
Social relationship	15	3-13
Environmental	40	12-30
Total	120	43-98

The ranges of overall total WHOQOL-BREF domain scores are similar in all the survivors of leprosy. The responses range from the lowest to the highest indicating differences in the perceived quality of life among survivors in both research locations.

4.3 A comparison of WHOQOL-BREF scores (WHO, 1996) using independent student t-test

A comparison of WHOQOL-BREF mean score and domain mean scores below were analyzed using independent student t-test with $p < 0.05$ as level of significance for difference.

Table 4.3 Mean scores in domains of WHOQOL-BREF for survivors of leprosy living in the leprosarium and those re-integrated in the communities

Domain	Total domain score	Mean (SD) in community (n=98) (Range) (x-y)	Mean (SD) in leprosarium (n=100) (Range) (x-y)	Level of significance difference
Physical	35	25.2(5.1) (16-35)	25.8(5.0) (15-35)	0.29
Psychological	30	17.2(4.1) (10-22)	17.1(3.9) (8-27)	0.30
Social relationship	15	9.3 (1.8) (5-13)	9.9(1.9) (3-13)	0.16
Environmental	40	19.6 (3.8) (13-28)	21.1(3.5) (12-30)	0.45
Total	120	70.3(13.1) (47-97)	73.9(12.9) (43-98)	0.48

The results of the mean scores of WHOQOL-BREF domains do not show any significant difference between survivors of leprosy living in the leprosarium and those reintegrated in their communities. Domain total scores of the survivors in both contexts are above average indicating that their perceived quality of life is good. Significant differences were however evident when domain scores were analyzed using variables of age and gender as confounding factors on residence. The findings will be shown in figures (1.1 to 10.1).

Table 4.4 Mean scores in domains of WHOQOL-BREF for male survivors of leprosy re-integrated in their communities and those still living in the leprosarium

Domain	Total domain score	Mean (SD) in community (n=41) (Range) (x-y)	Mean (SD) in leprosarium (n=47) (Range) (x-y)	Level of significance difference
Physical	35	25.9(4.9) (16-35)	25.7(5.6) (15-34)	0.55
Psychological	30	17.5(3.2) (10-24)	16.4(3.9) (9-22)	0.76
Social relationship	15	11.2(1.9) (5-13)	10.8(2.2) (3-13)	0.23
Environment	40	21.4(3.8) (13-27)	21.5(4.7) (12-30)	0.14
Total	120	75.0(9.9) (55-97)	73.4(12.9) (43-94)	0.90

The results did not indicate any significant differences in the mean scores of WHOQOL-BREF domains among male survivors reintegrated in the communities and leprosarium. These findings indicate that the domain total scores of the male survivors living in both research locations were above average indicating a good perceived quality of life.

Table 4.5 Mean scores in domains of WHOQOL-BREF for female survivors of leprosy living in the leprosarium and those re-integrated in the communities

Domain	Total domain scores	Mean (SD) in community (n=57) (Range) (x-y)	Mean (SD) in leprosarium (n=53) (Range) (x-y)	Level of significance difference
Physical	35	26.5(5.1) (16-35)	21.4(5.13) (16-35)	0.55
Psychological	30	18.6(4.4) (10-21)	10.5(1.9) (8-27)	0.03*
Socio relationship	15	10.4(2.3) (5-13)	12.7(2.0) (4-13)	0.61
Environment	40	22.2(4.9) (13-28)	21.3(3.4) (12-30)	0.39
Total	120	72.4(13.2) (47-92)	72.5(10.6) (43-98)	0.25

The results show a significant difference in the mean score of psychological domain ($p=0.03$ among the female survivors of leprosy living in the leprosarium and those re-integrated in their communities).

Female survivors reintegrated in the communities had a mean score of 18.6(SD=4.37) in the psychological domain which is a higher score than the female survivors in the leprosarium who had a psychological mean score of 10.5(SD=2.99). The findings indicate that female survivors of leprosy re-integrated in their communities have a better psychological quality of life than the female survivors living in the leprosarium.

Table 4.6 Mean scores in domains of WHOQOL-BREF for male and female survivors of leprosy still living in the leprosarium

Domain	Total domain score	Mean (SD) in males (n=47) (Range) (x-y)	Mean (SD) in females (n=53) (Range) (x-y)	Level of significance difference
Physical	35	26.3(4.9) (15-34)	21.6(4.1) (16-35)	0.14
Psychological	30	17.2(3.2) (9-24)	10.7(2.9) (8-27)	0.03*
Socio relationship	15	11.5(1.9) (3-13)	13.4(2.0) (4-23)	0.57
Environment	40	21.2(3.8) (12-30)	21.8(3.4) (12-30)	0.22
Total	120	75.4(9.9) (43-98)	72.5(10.6) (43-94)	0.71

The results indicate a significant difference in the psychological quality of life domain score ($p=0.03$). Men survivors of leprosy in the leprosarium had a statistically significant higher mean score in the psychological domain of 17 (SD=3.23) compared to women who had a mean score of 10(SD=2.99). This difference suggests that males living in the leprosarium had a better psychological quality of life than females living in the leprosarium.

Table 4.7 Mean scores in domains of WHOQOL-BREF for male and female survivors in the community

Domain	Total domain score	Mean (SD) in males(n=47) (Range) (x-y)	Mean (SD) in women(n=41) (Range) (x-y)	Level of significance difference
Physical	35	26.8(4.9) (16-35)	26.5(5.4) (16-35)	0.55
Psychological	30	17.4(3.2) (10-22)	16.4(3.9) (10-21)	0.76
Socio relationship	15	11.6(1.9) (5-13)	10.3(2.2) (5-13)	0.23
Environment	40	21.2(3.8) (13-27)	21.5(4.7) (13-28)	0.14
Total	120	75.6(9.86) (55-97)	73.6(12.96) (47-97)	0.90

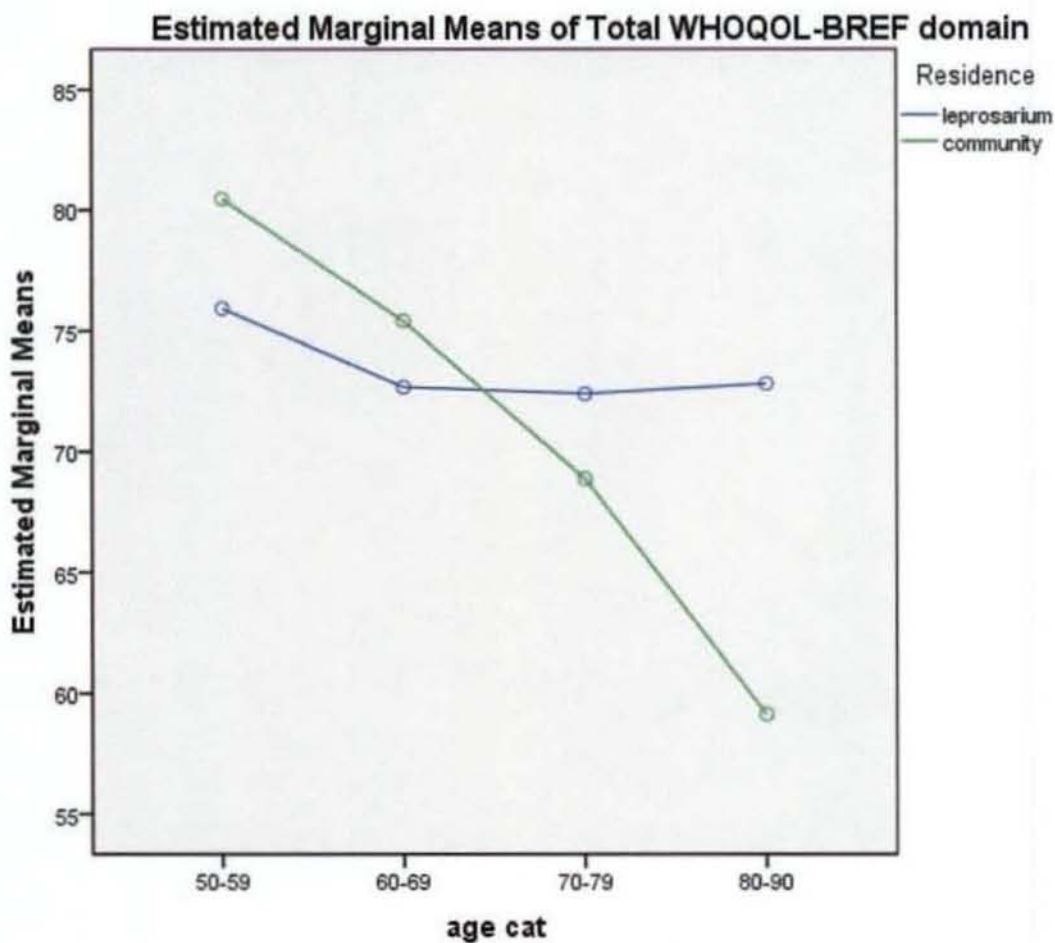
The results in the mean scores in domains of WHOQOL-BREF do not indicate any significant differences in quality of life between male survivors and female survivors who were re-integrated in their communities. This shows that the quality of life led by male and female survivors re-integrated in their communities was above average indicating a perceived good quality of life.

4.4 A comparison of WHOQOL-BREF scores using age and gender as confounding factors

A detailed analysis using age and gender as confounding factors was conducted. A two-way between-group analysis of variance was done on the impact of the confounding

factors on residence (leprosarium and communities). The findings are presented from figures 1.1 to 10.1.

Figure 4.1 WHOQOL-BREF total means scores of the survivors of leprosy re-integrated in the communities and those living in the leprosarium according to age category.

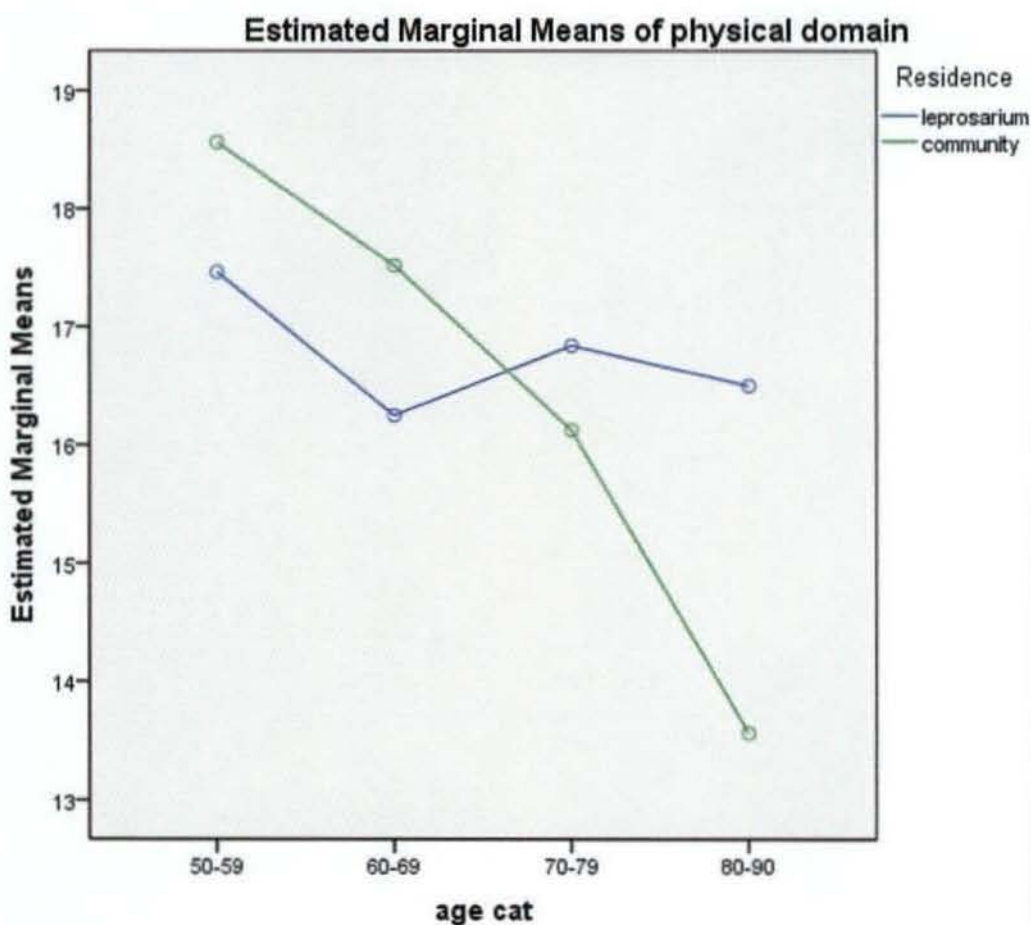


A two-way between-group analysis of variance was conducted to explore the impact of age on residence between survivors of leprosy re-integrated in the communities and the ones living in the leprosarium according to their age categories.

The findings in Figure 1.1 indicate that the mean scores across all age categories in the leprosarium did not show any statistical significant difference. This suggests that

survivors living in the leprosarium held a fairly consistent perception of quality of life across the age bands with those aged between 50 and 59 years having a slightly higher score than those in other age bands. However, there was a statistically significant decrease in the mean score of survivors of leprosy re-integrated in the communities in the age category of 70 to 79 years and 80 to 90 years ($p=0.003$) was revealed. The findings suggest that there is significant interaction effect of age and residence on the WHOQOL-BREF mean score in the communities. Results indicate that survivors aged 70 to 90 years living in the leprosarium had a better score of WHOQOL-BREF than survivors of the same age band re-integrated in the communities. This means that elderly survivors aged more than 70 years in the leprosarium had a better quality of life than elderly survivors aged more than 70 years who had been re-integrated in their communities.

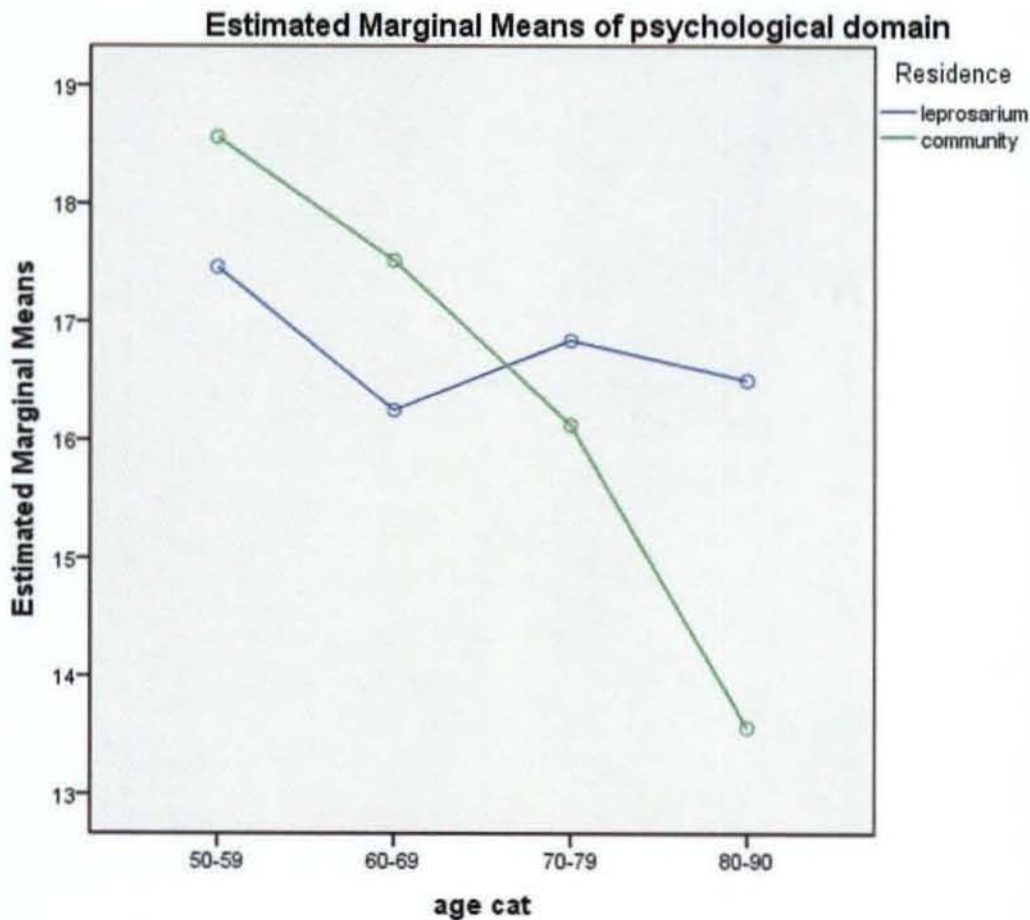
Figure 4.2 Mean score of physical domain of survivors of leprosy living in the leprosarium and those re-integrated in communities according to their age category



A

two-way between-group analysis of variance was conducted to explore the impact of age on residence. There was a decrease in the physical mean score of the survivors of leprosy re-integrated in the communities at the age category of 70 to 90 years. The results indicate that elderly survivors re-integrated in the communities had a reduced mean score than survivors of leprosy in the leprosarium with a significance difference of $p=0.006$. This suggests that quality of life for the elderly survivors living in the leprosarium was perceived to be better by those re-integrated in their communities.

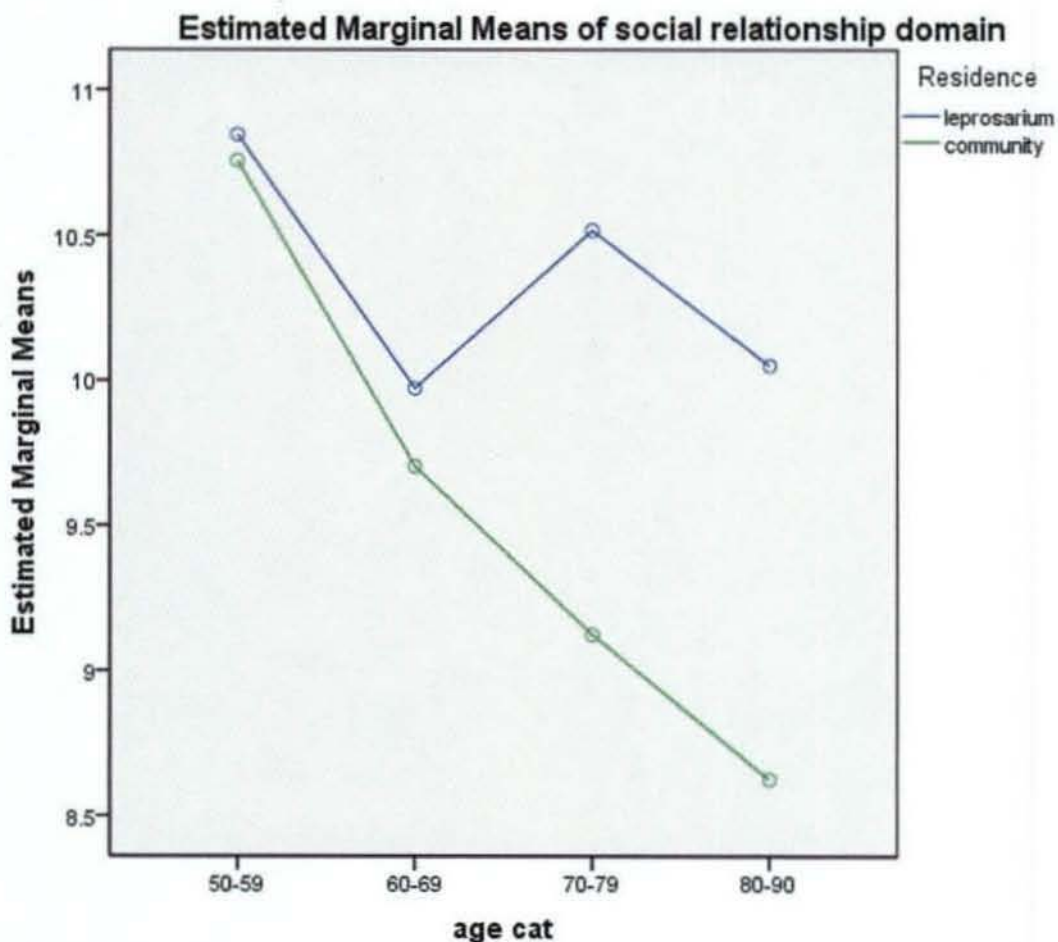
Figure 4.3 Mean score of psychological domain of the survivors of leprosy in the leprosarium and those reintegrated in the communities according to their age category



A two-way between-group analysis of variance was also conducted to explore the impact of age on residence. The score shows significant change across all age categories in survivors of leprosy re-integrated in the communities ($p=0.026$). Elderly survivors in the leprosarium had a better psychological domain mean score than the elderly survivors of leprosy re-integrated in the the communities. The findings suggest that while the psychological quality of life for survivors of leprosy aged 70 to 90 years

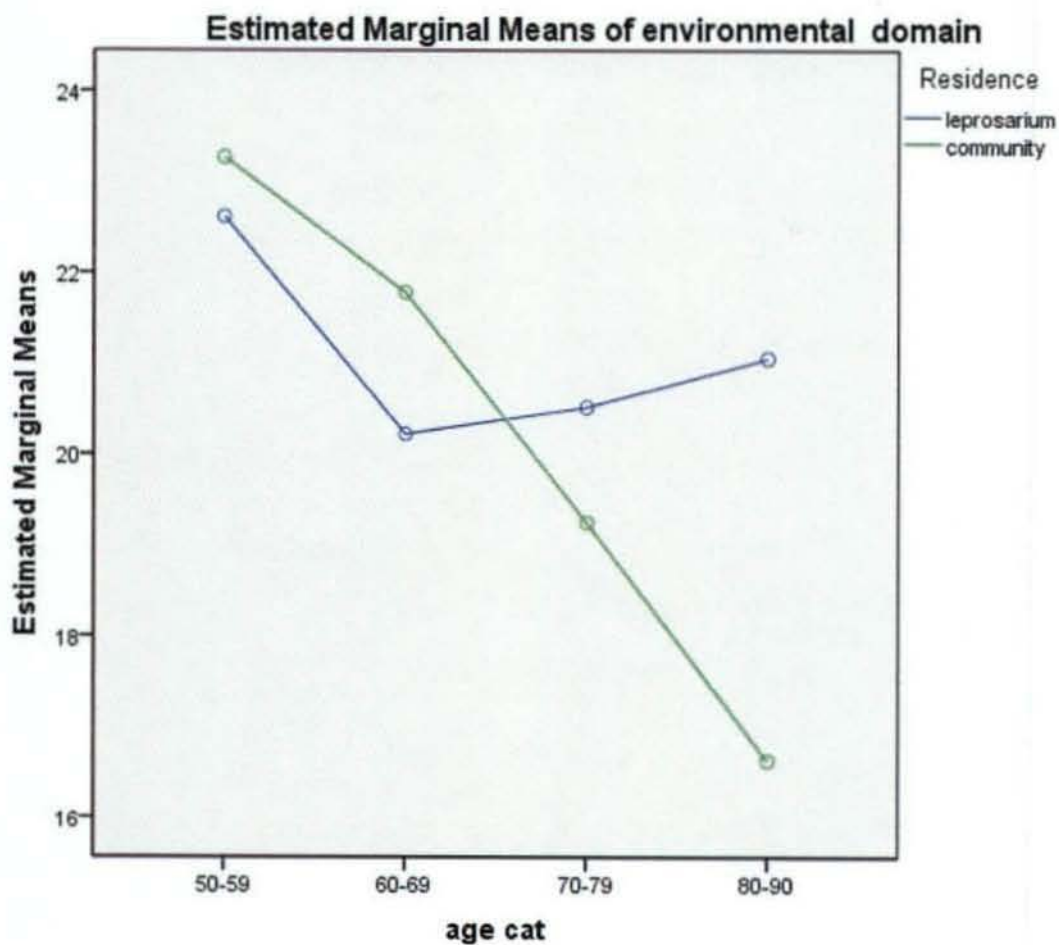
remains fairly constant when living in a leprosarium there is a significant decline in the same domain in the same age band for survivors reintegrated in their communities. This shows that elderly survivors aged 70 to 90 years who were living in the leprosarium led a better quality life than the ones re-integrated in their communities.

Figure 4.4 Mean score of social relationship domain of the survivors of leprosy living in the leprosarium and those re-integrated in communities according to their age category



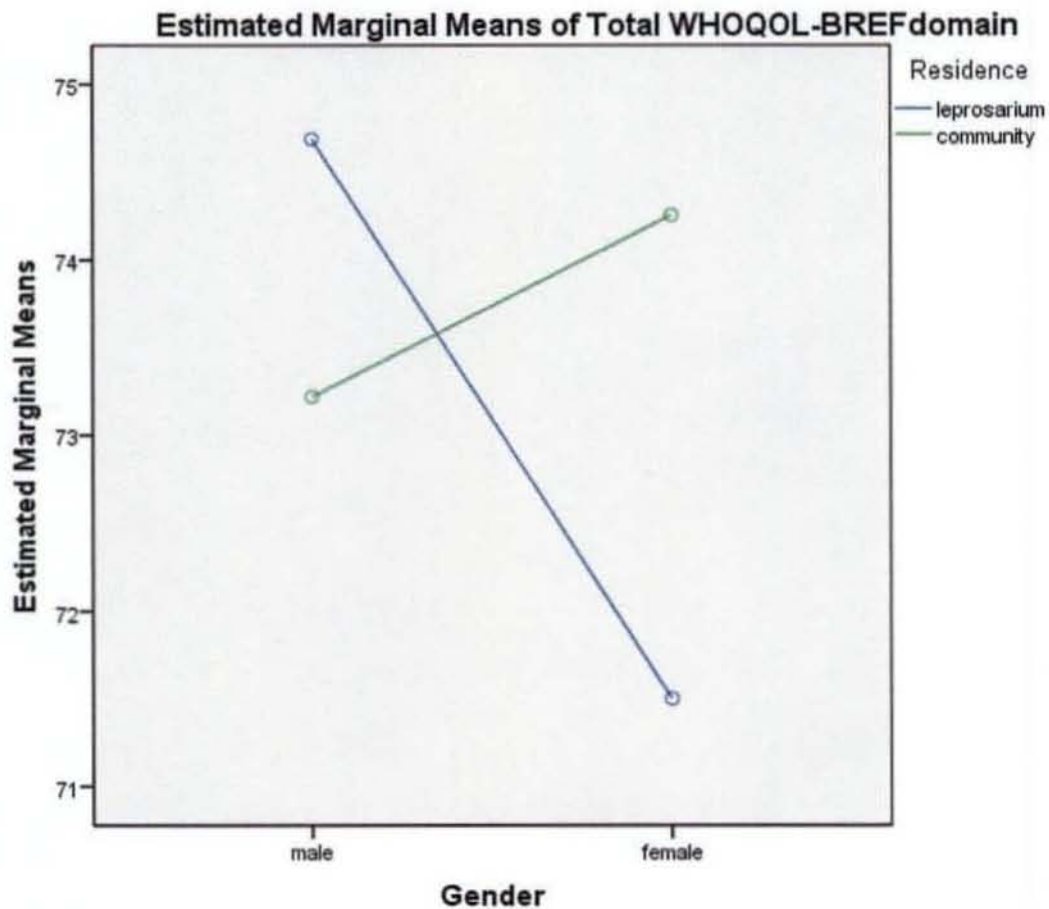
To explore the impact of age on residence, a two-way between-group analysis of variance was also conducted. Elderly survivors of leprosy in the communities and leprosarium had similar scores in the social relationship domain. The results do not show significant interaction effect of age on residence in social relationship mean domain score($p=0.274$) . This shows that the social relationship domain did not have any impact on quality of life of the survivors in both research locations.

Figure 4.5 Mean score of environmental domain of the survivors of leprosy in the leprosarium and those re-integrated in the communities according to their age category



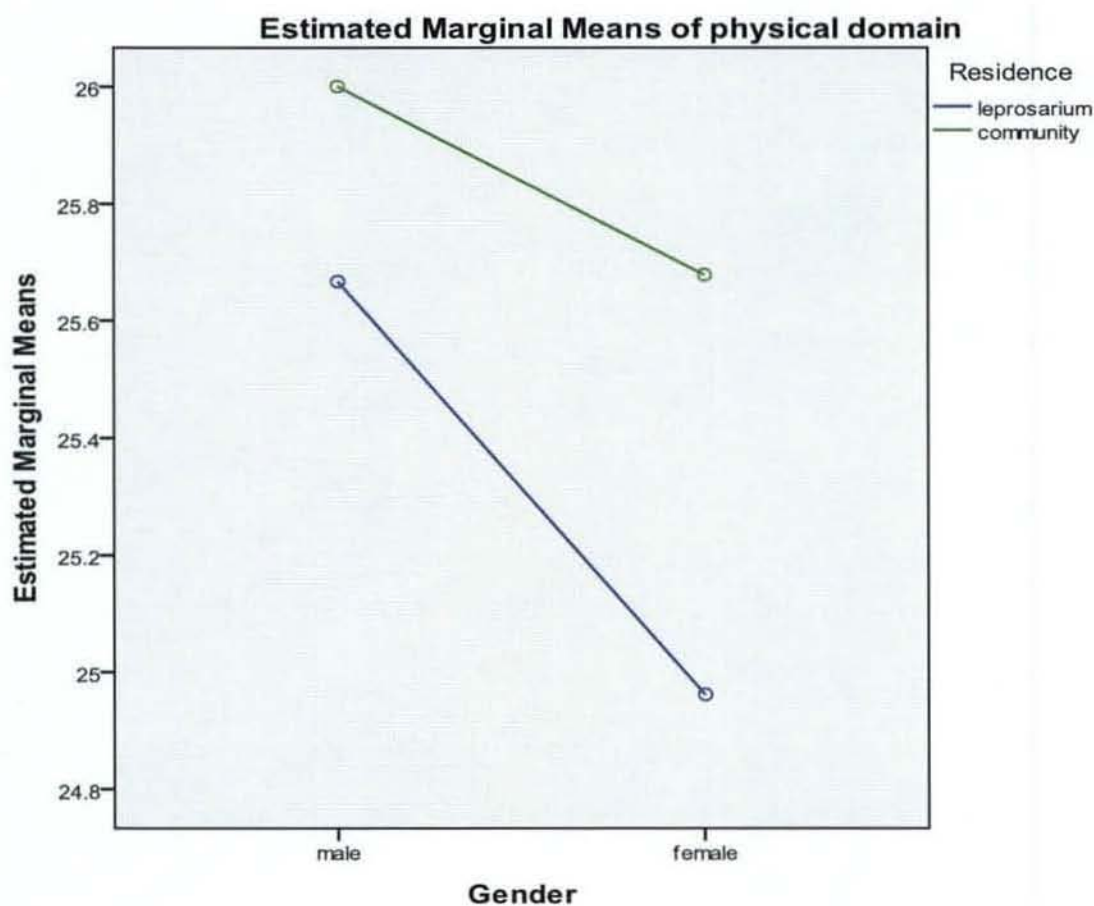
A two-way between-groups analysis of variance was also conducted to explore the impact of age on residence. There was a significant interaction effect of age on residence in the environmental domain score among survivors of leprosy re-integrated in their communities at the age category of 70 to 90 years. Survivors of leprosy living in the leprosarium appeared to remain constant on the environmental domain score across all age categories. The findings indicate that elderly survivors of leprosy reintegrated in the communities show a marked decrease in environmental domain scores than survivors of leprosy in the leprosarium ($p=0.003$). This means that environmental domain had a greater negative impact on the quality of life of the elderly survivors re-integrated in their communities than the elderly survivors living in the leprosarium.

Figure 4.6 WHO QOL-BREF total mean scores of the survivors of leprosy re-integrated in the communities and those living in the leprosarium by gender



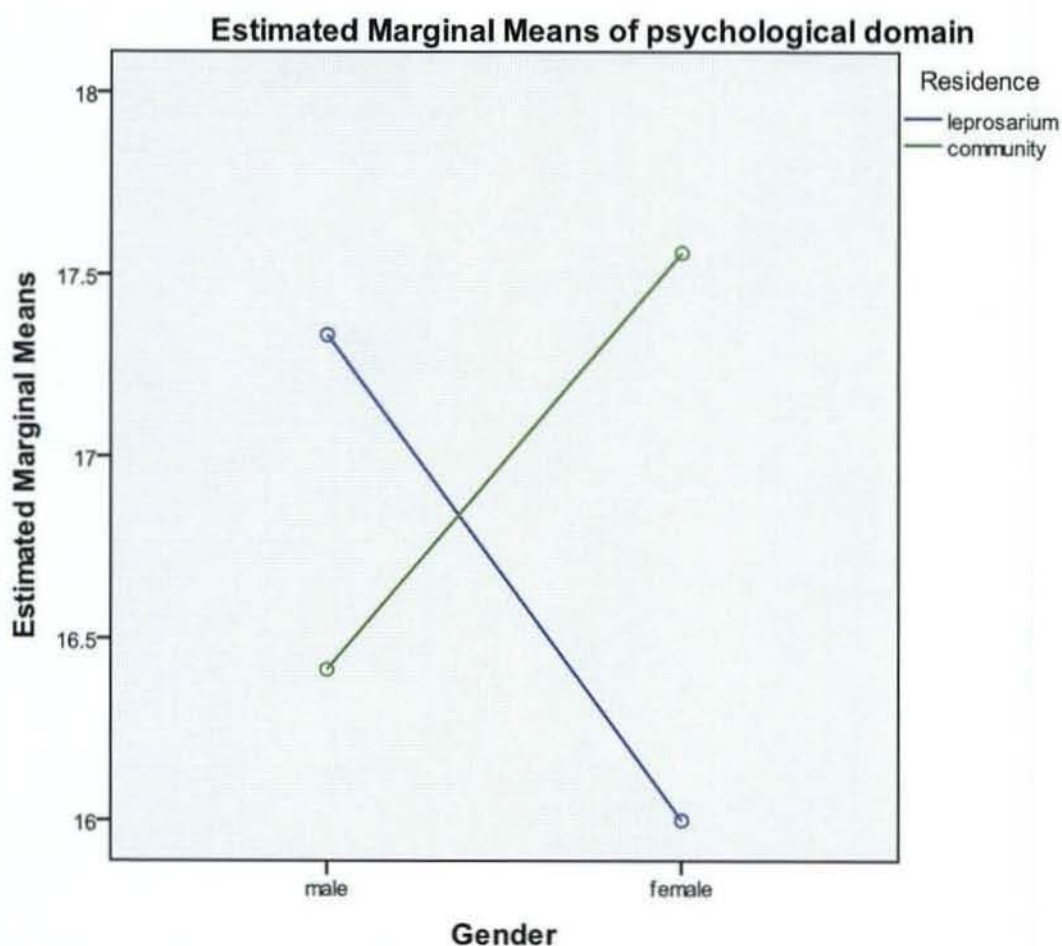
Female survivors of leprosy reintegrated in the communities and leprosarium had similar mean scores in the WHOQOL-BREF. The results do not indicate that there is significant interaction effect between residence and gender on the total WHOQOL-BREF score ($p=0.210$).

Figure 4.7 Mean score of physical domain of the survivors of leprosy living in the leprosarium and those re-integrated in the communities by gender



Using the tests of interaction of between subjects effects on residence and gender, results show that there is no significant statistical interaction effect between residence and gender on the physical domain mean score. There was no variation in the scores of males and female survivors living in the leprosarium and those re-integrated in the communities ($p= 0.793$). This implies that gender did not have any adverse effect on quality of life of male and female survivors living in the leprosarium and the ones re-integrated in their communities.

Figure 4.8 Mean score of psychological domain of the survivors of leprosy living in the leprosarium and those re-integrated in the communities by gender

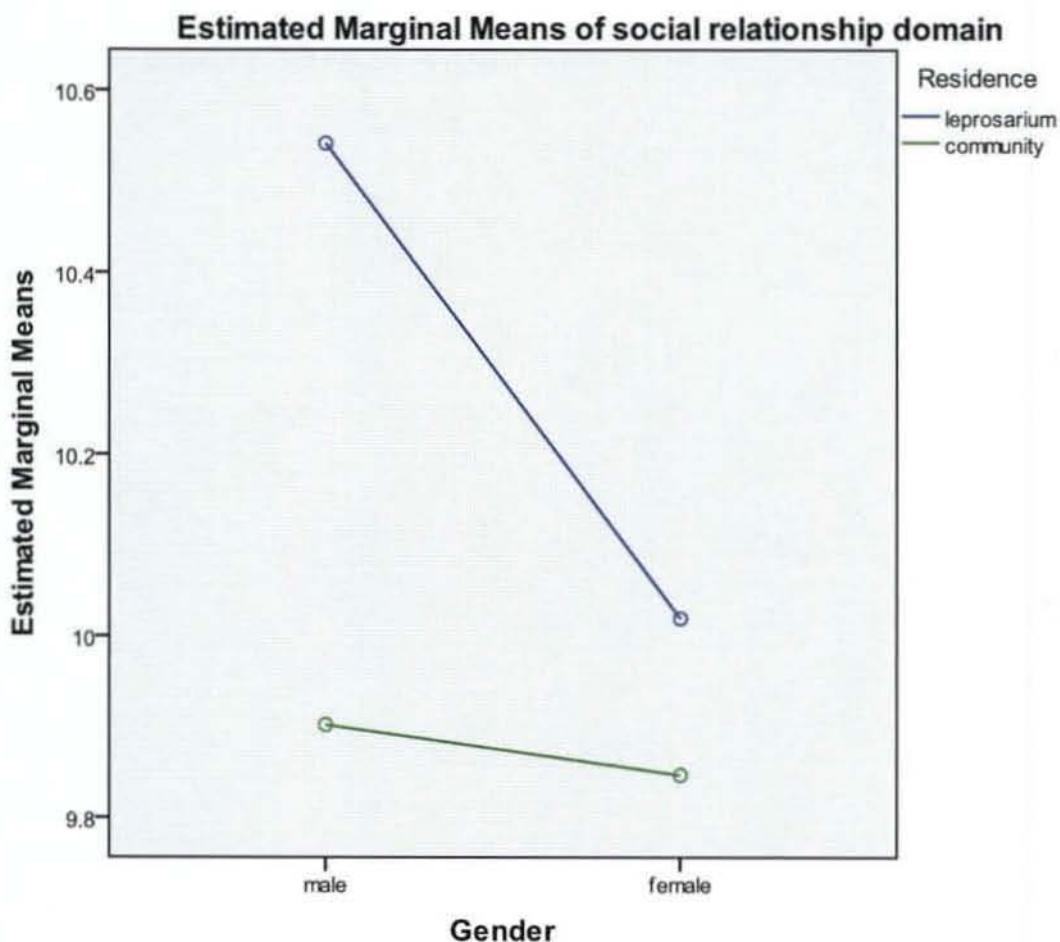


Using tests of interaction, the findings indicate that there was statistically significant interaction effect between residence and gender on the psychological domain. Males in the communities had a lower psychological mean score than males in the leprosarium ($p= 0.003$). This result shows that men in the leprosarium had on average a higher quality of life score in the psychological domain than male survivors of leprosy in the community. This implies that gender had a positive impact on the quality of life of

the male survivors living in the leprosarium than on the quality of life of the the male survivors re-integrated in their communities.

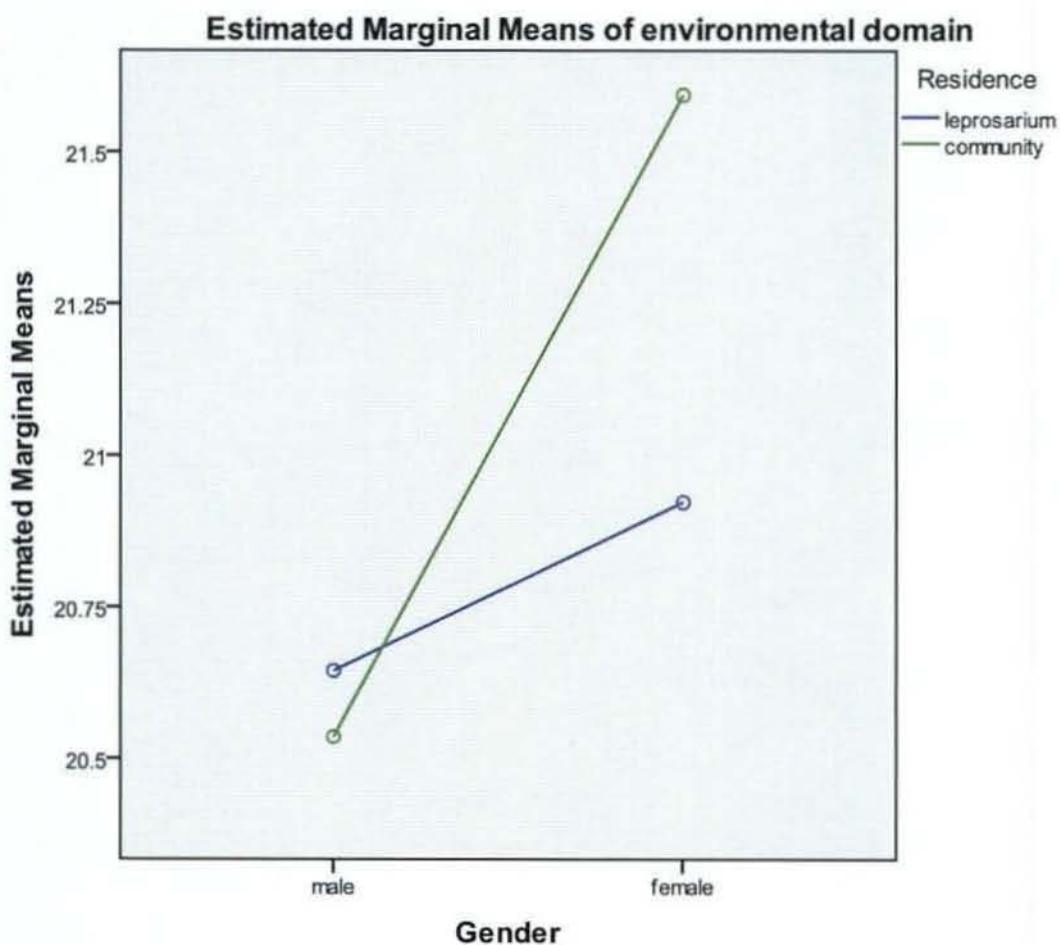
Female survivors in the communities had a better psychological mean score than those in the leprosarium($p=003$). This suggests that gender had a positive impact on the quality of life of female survivors re-integrated in their communities than the ones living in the leprosarium.

Figure 4.9 Mean score of social relationship domain of the survivors of leprosy living in the leprosarium and those re-integrated in the communities by gender



Using the tests of interaction between residence and gender, results show that there was no statistical interaction effect between residence and gender on the social relationship domain for male and females survivors of leprosy in both residences ($p = 0.437$). The evidence suggests that survivors of leprosy were maintaining normal interaction within their residences. This implies that gender did not have any impact on the quality of life on male and female survivors of leprosy in both study sites.

Figure 4.10 Mean score of environmental domain of the survivors of leprosy living in the leprosarium and those re-integrated in the communities by gender



Using the tests of interaction between residence and gender, results showed that there was no statistical interaction effect between residence and gender on the environmental domain in both residences ($p=0.519$). The mean score for the environmental domain was similar for both genders in both residences. This indicates that gender did not have any effect on the environmental quality of life of the survivors of leprosy living in the leprosarium and the ones re-integrated in their communities.

4.5 Conclusion

There were no significant differences in the mean scores of WHOQOL-BREF between survivors of leprosy living in the leprosarium and those reintegrated in the communities. However, there was a significant difference in mean age of the survivors of leprosy in the leprosarium and those reintegrated communities. Survivors of leprosy living in the leprosarium reached an older age than those living in the communities.

Farming was the main occupation in which the survivors from both research locations were engaged in. Some worked as farm laborers as their productive occupation, respectively. The survivors also pursued a different range of work related occupations in the 2 locations apart from farming activity.

Survivors from both locations had spouses. The morbidity rate of spouses of survivors of leprosy in both locations was similar. The findings revealed that male survivors living in the leprosarium had a better quality of life than female survivors in the same setting. Female survivors who had been reintegrated in their communities had a better quality of life than female survivors in the leprosarium. Male survivors living in the leprosarium had a better quality of life than males in the community. When age was used as a confounding factor on residence, the results indicated that survivors aged 70 years and older living in the leprosarium had better scores in the total WHOQOL-BREF mean scores in the physical, psychological and environmental domains than the elderly survivors who were reintegrated in their communities.

CHAPTER 5
DISCUSSION

5.1 Introduction

The aim of this study was to describe the quality of life being experienced by survivors of leprosy living in the one remaining leprosarium and those reintegrated into their communities in the southern region of Malawi. This could be the first such a study to directly compare the quality of life among leprosy survivors in the country. The results indicate that there was no difference in the quality of life experienced by the two groups. Age and gender however emerged as confounding factors in the quality of life that residents experienced in the two locations. Statistically significant differences existed between the quality of life experienced by men and women and by survivors older than 70 years in the various domains that were measured. This difference may be attributed to the fact that leprosy is not only a medical condition but also affects the psychological and socio-economic part of an individual if the person is not properly cared for (Rafferty, 2005:119).

A description of the demographic data will be presented first as guided by the results established in chapter 4. Thereafter, differences between the survivors of leprosy living in the leprosarium and communities that were statistically significant will be discussed with regards to the identified differences in the scores of the domains. Lastly, the conclusion and limitations of the study will be outlined.

5.2 Demographic profile and quality of life

5.2.1 Age

Survivors of leprosy living in the leprosarium reached an older age than those reintegrated in their communities. This could be attributed to the social support which is available in the leprosarium from the church and well wishers in terms of food, housing and clean water. Cassel (2001:36), in a study on age related disabilities, reported that some of the social and medical factors that have impact on longevity include provision of food, clean water and good housing. The author notes that the social and medical care has contributed to the longevity of participants in her study. The provision of these

factors in the leprosarium could make the survivors to have longer life expectancies. In addition, survivors in the leprosarium have access to a health facility and rehabilitation services. This could provide them with an opportunity to get treated for infections and age related health problems contributing to their longevity (Cassel, 2001:36).

On the other hand, survivors reintegrated in the communities could have less opportunity to access health facilities in Malawi (Loebe & Eide, 2004:9). This could be explained by the fact that because most of the communities are in the remote areas where there are few health facilities, clean water and better food (Braathen & Kvan, 2008:462).

Furthermore, aging is associated with a decline in function and quality of life because of age related diseases and deformities due to leprosy (Horowitz & Stuen, 2003:6). Survivors at Utale were provided with free assistive devices such as wheel chairs, photo chromic spectacles, prosthesis, gloves and clutches. The provision of assistive devices had a positive impact on the declined functional abilities of the survivors.

According to Hedsstrom and Blomstrand study, (2003:252), the provision of assistive devices has a positive impact on an individual's quality of life that has developed a disability by relieving pain and restoring function. Therefore the availability of rehabilitation services in the leprosarium helped the survivors to accomplish Activities of Daily Living (ADL) such as bathing, dressing, toileting and mobility. Independent engagement in activities of daily living by survivors of leprosy in the leprosarium, could have contributed active aging. This could have led the survivors older than 70 to live a better quality life than their counterparts in the communities (discussed later).

The notion that rehabilitation as a profession is committed to enhancing the quality of life for people with disabilities, has been acknowledged by Clark et al(2004:60). The author states that the role of rehabilitation is to provide interventions that improve the self-esteem and wellbeing of an individual (Clark et al., 2004:60). Advancements in age

cause general decline in health and functioning. Therefore, it may be inferred that occupational therapy rehabilitation plays a role in promoting longevity.

5.2.2 Education

Levels of education have been linked to quality of life and play a role in the type of occupations which people with disabilities are able to pursue (Loebe & Eide, 2004:9). There were similarities in the educational status among the survivors of leprosy in both contexts. This could be attributed to the literacy and numeracy levels of the average rural Malawian citizen. The literacy level is 62.7 % (National Statistical Office (NSO) [Malawi], & ORC Macro, 2005:12). On average, the Malawian based in the rural area only attains primary level education. It must be noted that the leprosarium is located in a rural area of southern Malawi. Equally those survivors who are reintegrated into communities return to their original homes in rural areas of the country. Living in rural areas is a common denominator for those living in leprosarium as well as those reintegrated in communities. According to Loebe and Eide's study, (2004:9) people with disabilities in Malawi are doubly disadvantaged because of their low level of education and also have reduced opportunities in accessing employment.

The low levels of education amongst the study population could be understood in the context of the restricted access to education which they may have experienced. The school authorities may have been unwilling to admit them because of their deformities or because of limitations that were placed on them based on their perceived abilities when they were young (Rafferty, 2005:119). As a result of limited opportunity to education, Rafferty (2005:120) reported that young people affected by leprosy were not able to make informed choices of what they wanted in life. This was a limitation on employment opportunities later in life and had adverse consequences on their ability to earn income resulting in living in a poor quality of life when in adulthood.

5.2.3 Access to occupational opportunities

Survivors of leprosy in both research locations engaged in farming activities as their primary productive occupation. This could be attributed to the fact that Malawi is basically an agro – based economy with 90% of the population living in rural areas and depending on agricultural activity for their livelihoods, regardless of the area of their residence (National Statistical Office (NSO) [Malawi], & ORC Macro, 2005:22). Other survivors from the communities were able to secure paid jobs such as working as farm laborers, a guard, builder and cook. This range of occupations could be understood in the context that survivors in the communities have broken the barriers of isolation through reintegration (Rafferty, 2005:122), such that they have the opportunity to be employed.

From the perspective of an occupational therapy lens, by engaging in a range of paid jobs of their choice, the survivors proved that they were also capable of performing any task despite physical impairments. This idea is echoed by Abrahams (2008:188) who observes that the ability to do things provides an affirmation of competence and enhanced feelings of self worth through a sense of being valuable and capable. While the survivors in the leprosarium could have less opportunity to compete with a wider range of occupational choices in the outside world, they nevertheless engaged in small businesses such as selling crafts, baskets, brooms and dolls from crocheting.

5.2.4 Marital status

The results of the study indicate that there were more married couples among leprosy survivors reintegrated in communities than those still living in the leprosarium. This could be attributed to more social contacts for those reintegrated in communities, as opposed to those still living in leprosarium whose social contacts were somewhat limited. Parker (1992:83), writing about disability and marriage in the American context, states that some marriages break up soon after the onset of disability. This perspective may not apply in an African context such as Malawi where traditional views on marriage

as an institution of identity and belonging (Koyana, Mwambene & Bekker, 2007:35). A limitation of the study is that the questionnaire did not capture the gender of the partner who had leprosy. It is therefore not possible to speculate about gender differences amongst the married people in this study.

The results of the study indicate a higher divorce rate for survivors of leprosy still living in leprosarium than those reintegrated in their communities. This could be attributed to a higher rate of rejection for those still living in the leprosarium because of the stigma attached to the disease (Arole, Premkumar, Arole, Maurym &Saunderson, 2002:186). The stigma could have been increased by visible physical deformities, such as loss of a limb or blindness, making the survivor unattractive for marriage (Lesshafft et al., 2010:73).

5.2.5 Contact with relatives

According to the results of this study, a higher percentage of survivors of leprosy still living in the leprosarium (58%) had no contacts with their relatives, as opposed to only 21% of those re-integrated in communities, who reported that they had absolutely no contacts with their relatives. Similar findings were shown in a former colony in Brazil where some survivors did have any contact with their family (Lesshafft et al., 2010:73).

The reasons for this disparity may be two-fold. In the first instance, the existence of relatives is higher in the community than in the leprosarium. The community accommodates all types of people whereas the leprosarium only hosts those that are affected by the disease. Secondly, this could be attributed to the social stigma attached to the disease. This could lead to a higher rejection rate and reduced contact with relatives for those still living in the leprosarium, than those reintegrated in the communities (Arole, Premkumar, Arole, Maurym &Saunderson, 2002:186). In contrast, those reintegrated in communities were more or less accepted by their relatives.

Try, (2006:58) reports that stigma exists where people have a phobia that they can contract the disease through touch or contact although the person has been clinically

cured. Survivors of leprosy would experience rejection and exclusion from society based on such phobias.

According to (Bajunirwe, et al., 2009; 272) the extent of social support and social relations acts as a key component for a good quality of life. Contrary to this literature, results from this study show that survivors living in the leprosarium reported much less contact with relatives than those in the community, their quality of life was similar in the social relationship domain with survivors reintegrated in the community. This suggests that the community within the leprosarium provides the necessary social relations required for a good quality of life as a substitute for contact with relatives. Mkize, (2004:47), writing about communal life and personhood in the African worldview, states that a person does not exist alone rather he or she belongs to a community of similar constituted selves.

5.3 Impact of gender on quality of life

5.3.1 Gender and total WHOQOL-BREF scores

Results of the mean scores of WHOQOL-BREF domains did not show any significant gender difference between survivors of leprosy living in the leprosarium and those reintegrated into their communities. The justification for such similar mean scores could be the fact that leprosy and its associated deformities is the common denominator for those still living in leprosarium and those re integrated in their communities. Statistically significant gender differences surfaced within the four quality of life domains: physical, psychological, social relations and environment. While literature suggests that the quality of life of women is more affected by leprosy than men (Shale, 2000: 6), the findings from this study introduces a new perspective. It indicates that men and women are affected similarly but that where they live (location) and their age accounts for difference.

5.3.2 Gender roles and Psychological quality of life for women

The results show a significant difference in the mean score of psychological quality of life domain among female survivors of leprosy in the leprosarium and those in the communities. The women in the communities reported a higher psychological quality of life than those in the leprosarium. This could be attributed to the fact that those who had been reintegrated in communities were able to exercise their social roles such as being care givers for their families, preparing food and doing other house hold chores that has been prescribed and influenced by culture. The cultural roles according to Adams (2009:8) could be being a mother and care giver. The opportunity to engage in their natural cultural roles may have a positive impact on the mental strength among the female survivors reintegrated in the communities.

Women survivors in the communities were able to network with others. Braathen and kvam(2008:463), writing about female experiences of disability in Malawi, found that although some women experienced discrimination, the majority of them were well taken care of and treated equally by their family members and friends. This experience of belonging could have a positive impact on their emotions. The higher score on quality of life could also be attributed to the social contacts they developed in the community. A study by Ohaeri, Awadalla & Farah (2009:16) has echoed that happiness can spread from person to person within social networks, such that people's happiness depends on the happiness of others with whom they are connected.

While women in the leprosarium clean their houses, they have meals prepared for them and unless they are married, they do not have family members to care for. Their social roles may be restricted and the psychological quality of life adversely affected as a result. They may be reduced to a situation of helplessness and apathy because their social and occupational roles are restricted. Isolation in a leprosarium may mean that women survivors do not experience social networks and are therefore vulnerable to psychological poor quality of life. It is interesting to note that the women in the leprosarium had a statistically significant lower quality of life than men. Similar findings

were reported by Varkevisser et al., (2009:68) in a study which found that when women are isolated from their society, they are deprived of an opportunity to engage in domestic roles like cooking, breast feeding their children, sleeping in the same room along with the other family members and mixing with them. These findings therefore, point to the importance of occupational therapy rehabilitation being much more than the provision of assistive devices. It must focus on woman as an occupational and social being and on the consequences of not engaging in occupations that their culture prescribes (Hocking, 1994:36).

5.3.3 Psychological quality of life of male and female survivors living in the leprosarium

There were statistically significant differences between males and females in the community. However, the difference in scores between the genders within the leprosarium could be attributed to the different roles that males and females play in a typical African society (Braathen & Kaaven, 2008: 464). In Malawi, females play a number of social roles but the main role is being care giver for their families. Males are providers of material needs for their families (Nyirenda et al., (2006:75)

It has already been discussed that females who are confined to leprosarium may have adverse psychological consequences. These could arise from their inability to play their cultural roles. Varkevisser et al., (2009:68) observe that women suffer more isolation and rejection from the society than men. For example women may suffer rejection by their husbands, children and relatives. The rejection experienced by the women, deprives them of an opportunity to engage in domestic roles like cooking, breast feeding their children, sleeping in the same room along with the other family members and mixing with them. This negates the role of the woman as a natural care giver in the home.

Zodney, Tiwari and Salodkar (2000:509) observe that such isolation from domestic roles degrades and dehumanize the self, projecting an image of being a less valued member.

On the other hand, for the males in the leprosarium, their role of providers has been taken over by the church which is providing for their basic needs, thus relieving them of a responsibility. Nyirenda et al., (2006:75) in a study conducted in Malawi, provides evidence that women's work is centered around the household, whereas men's role as primary income earners increases their values to and within the family, reducing the impact of stigma on their status. However, it is interesting to note these differences in the quality of life between the male and female survivors. Therefore, further research needs to be conducted to investigate why it appears as if being relieved of a responsibility makes a woman unhappy and a man happy.

5.3.4 Psychological quality of life of males in the communities and males in the leprosarium

Males in the communities had a lower psychological mean score than males in the leprosarium. This could be attributed to the fact that those who were reintegrated in their communities may subconsciously feel the pressure of having to compete with able bodied people in finding basic needs to provide for their families to fulfil their role as a provider (Nyirenda et al., (2006:75). On the other hand, male survivors in the leprosarium, had their role as providers taken over by the church and other wellwishers.

The social support provided in the leprosarium may contribute to a better quality of life being experienced by male survivors. Studies have shown that social support is significantly associated with better QOL scores although most such studies were conducted in industrialized countries (Bajunirwe et al., 2009:275). An example of a social support programme discussed in the above mentioned literature proved that HIV patients who received nutritional supplements through Home Based Care and community services expressed better quality of life than those who received less social support. Further research is needed to investigate the gender differences in the appreciation and psychological response to the social support provided in the leprosarium.

5.4 Ageing, continuity of care quality of life

5.4.1 Age and total WHOQOL-BREF mean score

Survivors aged between 70 and 90 years living in the leprosarium had a better score of WHOQOL-BREF than survivors in the same age band, living in the communities. It can be inferred that the care and support that those still living in the leprosarium receive from the church such as food, clean water and good housing may have a positive impact on their quality of life, hence an increase in longevity. Those who were reintegrated in communities may be lacking the above mentioned needs since they do not get an support and have to fend for themselves. This may have a negative impact on their quality of life. According to Adrin(1989:163), the transition from a public institution to a community residential may be difficult for elderly individuals who have spent most of their adulthood living in a state facility. Difficulties to adapt to the community may have an adverse effect on the quality of life of the survivors aged 70 and above (Adrin,1998:163).

The poor quality of life in the community could also be contributed due to the diseases of old age and leprosy related deformities such as vision and hearing impairment. According to a study by Horowitz(2003:53), depression, vision and hearing impairments in later life, had a negative impact on quality of life on the older population. The reason for this was the loss of functional abilities. Old people depend on the support of others to walk around their environments. According to Joseph and Rao (1999:516), the impairments lead to progressive physical, psychological and social disabilities. This leads to a decline in the overall quality of life of survivors. These findings suggest that occupational therapy rehabilitation in the elderly is essential to meet their physical, psychological and social needs.

5.4.2 Age and impact on physical quality of life

There was a significant decrease in the physical quality of life mean score of the survivors of leprosy living in the community at the age category between 80 and 90

years. This difference in scores could be understood in the context that those still living in leprosarium do receive assistive devices which help them participate in activities of daily living. A study by Toiten, Fredriksson and Kamwendo(2008:146) showed that age related disabilities that come due to injuries and illnesses affect the physical health of the elderly. This results in the limitation to participate in daily activities.

In contrast, survivors who were reintegrated in communities do not receive assistive devices to help with their mobility. As such, they are restricted from accessing their environments. Additionally, those living in the leprosarium are confined to a smaller area, requiring shorter walking distances, whilst those re integrated in communities could be facing the strain of walking long distances to their gardens. It should also be borne in mind that deformities in their feet which are caused by leprosy would make it difficult for them to walk long distances.

Furthermore, such deformities could prevent participation in church activities, attendance at weddings, farming and other activities of daily living. People with deformities experience barriers that may be physical, in the form of reduced accessibility to local services such as schools and hospitals. Additionally, they may be socially discriminated against by society at large. These are problems that can be avoided, or at least reduced. This could be done through the development of policies targeted towards inclusion and addressing the specific needs of people living with disabilities. Such an approach is being proposed for governments, donor organisations and development agencies.

5.4.3 Age and psychological quality of life

Survivors aged 70 years and above living in the leprosarium had a better psychological quality of life than survivors of leprosy of the same age living in the community. Horowitz' study(2008:32) has shown that depression is probably the most pervasive mental health problem among older adults. It can be assumed that the care and support that those still living in the leprosarium receive from the church, relieves them of worries

of having to fend for themselves. On the other hand, those reintegrated in communities have to struggle to fend for themselves, competing with young and strong bodied people in the process. This could lead to frustration resulting to mental health, in particular depression. The loss of drive to participate in daily activities of living could contribute to the a negative impact on the quality of life. The restriction of the social participation could be attributed to visible deformities, that cause the society to have negative attitudes towards the affected people (Ganapati, Pai & Kingsley, 2003:369).

5.4.4 Age and environmental quality of life

The older age groups of survivors of leprosy living in the community showed a marked decrease in environmental domain scores than survivors of leprosy in the leprosarium. It could be assumed that those who were reintegrated in communities were exposed to environmental barriers such as having to walk long distances, cross rivers and rough terrains. On the other hand, those still in the leprosarium are confined to a smaller area with comparatively less environmental barriers. Furthermore, literature shows that infiltration of *Mycobacterium leprae* into Schwann cells results in inflammation of the nerves. This leads to a progressive loss of nerve fibre function (defined as neuropathy) mostly in the eyes, hands, and feet (Slim et al., 2010:1).

Nerve dysfunction can lead to more severe impairments, such as wounds, clawing and shortening of digits, and visual impairments. As a consequence of impairments, very old people affected by leprosy may experience worse limitations and restrictions in activities of daily living. This poses a challenge for the individual to interact with the environment in a healthy way (Bakker, 2003:47). The basic activities that leprosy patients experience participation restriction could be farming, brushing hair, bathing, washing and eating. The combination of old age and accessibility of environment could be improved by providing assistive devices.

5.5 Conclusion

The findings have revealed that the quality of life being led by survivors of leprosy in the leprosarium and those reintegrated in their communities in Malawi is similar. However, gender and age impact differently on quality of life domains depending on residence. Female survivors of leprosy resident in the community have a better quality of life than those in the leprosarium while the opposite is true for males. Survivors of leprosy who are older than 70 years resident in a leprosarium have a better quality of life than survivors of a similar age living in the community. The findings of this study have added to the body of evidence in which occupational status, contact with relatives, social support, gender and age could be determinants of quality of life among survivors living in the leprosarium and those reintegrated in the communities.

5.6 Limitations of the study

There are some limitations that have been identified in the study.

- The first such limitation has to do with the fact that limited information was obtained from the participants because of the design of the study which is quantitative.
- Secondly, the translators had problems to directly translate the standardized questionnaire. This is because some of the concepts do not exist in the local language (Chichewa). As a result, the translators had to rephrase some of the questions to obtain the information required and this may ultimately affect the accuracy of some answers and the questionnaire was not back translated.
- In the social relationship domain, the private nature of some of the questions asked, for example sexual activity may have resulted in some participants hiding what they perceived to be sensitive and confidential information.
- Lastly, the married survivors did not indicate whether the spouse was a fellow survivor of leprosy or not.

CHAPTER 6
Conclusion and Recommendations

6.1 Conclusion

The study has revealed that the quality of life of survivors of leprosy is influenced by gender, age and location. These findings show that males and the elderly have a better quality of life residing in the leprosarium than in the communities. This could mean that integration process may have a negative impact on the quality of life of the elderly. In addition, the findings may mean that the elderly are being neglected by their relatives and neighbours in the communities. Therefore, there is need to have strategies that would consider lifelong unfulfilled and unsatisfied needs and wants of the elderly in the communities of Malawi. The Ministry of People with Disabilities and the Elderly, Community Based Organizations and families in collaboration with the elderly themselves need to have a shared responsibility in addressing these needs.

The closure of leprosaria by the Malawi Government is recommendable. However, survivors of leprosy need to be provided with quality care that addresses both physical and psychosocial needs and within the contexts which they live. This could be done by training health professionals in programs to work with survivors of leprosy and the elderly. The programmes would address cultural and psychosocial needs through occupations that improve the sense of wellbeing. This could be done through the inclusion of the survivors of leprosy in the disabled people's organizations and adoption of a multi sectoral approach. An inclusive focus where survivors of leprosy would be seen as any other person with disability would enable them to access the resources that are available in their communities from government and non governmental agencies. Examples of such resources would be health, education and social participation, which would go a long way in improving their sense of wellbeing. The multi faceted approach is aligned with the principles of community based rehabilitation recommended by the World Health Organization (WHO) (WHO, 2010:25). Furthermore, the Occupational Therapist's core belief is that every human being is a social and occupational being. Therefore Occupational Therapist, who promotes social and occupational justice for the survivors of leprosy, will be an important human resource in the Malawian sector.

This study has provided evidence of the need for disability policies in Malawi that address the factors such as gender, age and location in the quality of life in persons with disabilities. This could be achieved by advocating in collaboration with the survivors of leprosy in mobilizing services that meet their needs. This is in keeping the disability slogan “Nothing for us without us”.

6.2 Recommendations

The findings of this study indicate that the physical medical needs of the leprosy survivors constitute a fraction of the challenges they face. The study therefore recommends:

- LCAs as a human resource in Malawi should be trained to address more than just giving drugs to the leprosy patients. For example they could introduce self care groups both in the leprosarium and the communities. The group could consist of all people with skin problems with or without disabilities. This would help to remove the prevailing social barriers between the leprosy sufferers and non sufferers.
- Policy makers especially in the agricultural sector should enable the people living with disabilities related to leprosy to benefit from the fertilizer subsidy programme. The findings indicated that both groups were involved in farming as their primary occupation making this an important focus for occupational therapists who are concerned with occupational justice.
- Program managers need to be trained in the theory of disability so that they recognize that the quality of life of survivors of leprosy is more than just providing them with drugs. A shift in the paradigm from medical to social view will enable the managers to develop and implement policies that are aligned with the community based rehabilitation principles.
- The government should ensure that anti-discriminatory measures are put into practice where appropriate to protect survivors of leprosy.
- Self help projects that are responsible in the distribution of loans should adopt policies to promote full representation of survivors of leprosy with disabilities.

- Government should integrate disability dimensions into Millennium Development Goals (MDGS) baseline data collection and analysis. This will enable it to allocate a certain percentage of the total rural development/ poverty alleviation funds towards persons with disabilities because these are the people who are most likely to be marginalized by society.
- Inclusive community based rehabilitation is adopted as a policy frame work in Malawi. This will help in self empowerment, and to overcome social exclusion and to restore dignity of survivors of leprosy living in the leprosarium and those reintegrated in their communities.
- The Ministry responsible for Persons with Disability and the elderly in Malawi need to formulate policies that will enable communities to have knowledge on the care of the elderly and disabled.

6.2.1 Further Research

For a wider understanding of the experience of the survivors of leprosy in Malawi, there is need to conduct

- An ethnographic documentation of how leprosy survivors are viewed by people who live around the leprosarium and those reintegrated in the communities. Such information would help to inform policy makers to make changes that would improve the service delivery among survivors living in the leprosarium and those reintegrated in their communities.
- A research to investigate why it appears as if being relieved of a responsibility makes a woman unhappy and a man happy.
- Further research is needed to investigate the gender differences in the appreciation and psychological response to the social support provided in the leprosarium.

CHAPTER 7
REFERENCES

Abrahams, T (2008) Occupation, identity and choice: a dynamic interaction. *Journal of Occupational Science*, 15(3): 186-189.

Adrin, M (1989) Older adults with developmental disabilities and chronic mental illness. In Reichel, W (ed). *Care of the elderly, clinical aspects of the aging (4th ed)*., William & Wilkins, 428, East Preston Street, Baltimore, Maryland 212002, USA.

American Journal of Occupational Therapy Association (1995) Position paper: *Occupation. American Journal of Occupational Therapy*, 49(10):1015:1018.

Arrehag, L, Vyllder, S, Durevall, D & Joblom, S., M (2006) *The impact of HIV/AIDS/ on livelihoods, poverty, and the economy of Malawi*, 33-77, Art.nr.SIDA31461EN.

Arole,S, Premkumar, R. Arole, R, Maury, M & Saunderson, P(2002) Social stigma: a comparative qualitative study of integrated and vertical care approaches to leprosy. *Lepr Rev*, 73:180-196.

Awadalla, W., A, Ohaeri, U.,J, Gholoum, A, Khalid, O.,A.,A., Hamad, M.,A.,H, and Jacob, A(2007) Factors associated with quality of life of outpatients with breast cancer and gynaecological cancers and their family caregivers: a controlled study. *Biomedical Central Cancer*, 7:102-117.

Bajunirwe, F, Tisch, J.,D, King, H.,C, Arts, J.,E, Debanne, M.,S and Sethi, K.,A (2009) Quality of life and social support among patients receiving antiretroviral therapy in Western Uganda. *AIDS Care*, V 21(3):271-279.

Bakker, R (2003) Sensory loss, Dementia, and Environment. *Spring*, 46:51.

Bechelli, L., M (1997) Prospects of global elimination of leprosy as a public Health problem by the year 2000. *International Journal of leprosy and Other Mycobacterial Diseases*, V62: 282-284.

Braathen, H., S & Kvan, H., M (2008) 'Can anything good come out of this mouth?' Female experiences of disability in Malawi. *Disability & Studies*, V 23(5): 461-474.

Brandsma, J., W & Brakel, W., H (2003) WHO disability grading: operational definitions. *Lepr Rev*, 74:366-373.

Brakel, W., H & Officer, A (2008) Approaches and tools for measuring disability in low and middle- income countries. *Lepr Rev*, V 79:50-64.

Brakel, W., H (2003) Measuring leprosy stigma – a preliminary review of the literature review. *Int. J Lepr Other Microbact Dis*, 71:190-197.

Braveman, B., & Bass-Haugen, J., D (2009) From the Desks of the Guest Editors— Social justice and health disparities: An evolving discourse in occupational therapy research and intervention. *American Journal of Occupational Therapy*, 63:7–12.

Brown, W (2006) Can Social Marketing approaches change community attitudes towards leprosy. *Lepr Rev*, 77:89-98

Burns, N & Grove, S., K (2007). Clarifying Research Designs in *Understanding Nursing Research, Building an Evidence –Based Practice* (4th Ed.). Missouri, Saunders.

Calcraft, J., H (2006) The effect of the stigma of leprosy on the income generation of leprosy affected people in Terai Area of South East Nepal. *Asia Pacific Disability Rehabilitation Journal* 17(2):73-89.

Canadian Association of Occupational Therapists (1997, 2002) Enabling occupation: An occupational therapy perspective. [Online]. Available: <http://www.caot.ca/pdfs/positionstate/universaldesign.pdf>. [Accessed on 12th February, 2010].

Cassel, K., C (2001) Successful ageing: How increased life expectancy and medical advances are changing geriatric care. *Geriatrics*, V 56(1):35-40.

Chapel, P & Wirz, S (2003) Quality of life following spinal cord injury for 20-40 year old males living in Sri Lanka. *Asia Pacific Disability Rehabilitation Journal*, 14(2):162-178.

Chen, S, Chu,T & Wang, Q (2005) Qualitative assessment of social, economic and medical needs for the ex-leprosy patients living in leprosy villages in Shandong Province, the People's Republic of China. *Lepr Rev*, 76:335:347.

Chinguo, D (2005).Assessment of needs and concerns of leprosy survivors at Utale leprosarium in Balaka (unpublished).

Chisi,J., E., Nkhoma, A, Zvere, Y., Misiri, H, Komolafe, O., O (2003) Leprosy in Nkhotakota District Hospital. *East African Medical Journal*, 12:635-639.

Clark F, Stanley P, Azen R, Zemke R, Jackson J, Carlson M, Mandel D, Hay J, Labree L, Lipson L (2001) Embedding health promoting changes into the lives of independent living older adults: long term follow up of an occupational therapy intervention. *Journal of Gerontology: Psychological Sciences*, 56B (1), 60-63.

Creek J & Hughes, A (2008) Occupation and Health: a Review of Selected Literature. *British Journal of Occupational Therapy*, 77(1):456-468.

Cross, H (2006) Interventions to address the stigma associated with leprosy: A perspective on the issues. *Psychology, Health & Medicine*, 11(3):367-373.

Cross, H & Choundhary, R (2005) STEP: an intervention to address the issue of stigma related to leprosy in Southern Nepal. *Lepr Rev*, 76: 316-324.

Duarte, M., T., C & Ayres, J., A (2007) Socioeconomic and demographic profile of leprosy carriers attended in nursing consultations. *Rev Latino-am Enfermagem*, 15:774-779.

Ebenso, B, Fashona, A, Ayuba, M, Idah, M, Adeyeni, G & Fada, S ,S(2007) Impact of socio-economic rehabilitation on leprosy stigma in Northern Nigeria: Findings of a retrospective study. *Asia Pacific Disability Rehabilitation Journal*, 18(2): 98-119.

El Hassan, A.,L, Khalil, A.,G & El Hassan, A.,M(2002) Socio cultural aspects of leprosy among Masalit and Hawsa tribes in the Sudan, *Lepr Rev*, 73:20-28.

Ganapati, R, Pal, V., V, Kingsley, S (2003) Disability and prevention and management in leprosy: A field experience. *Indian J Dermatol. Leprol*, 69(6): 369:374.

Girdhar, B.K, Girdhar, A & Kumar, A (2000) Relapses in multibacillary leprosy patients: effects of length of therapy. *Lepr Rev*, 71(2):144:153.

Hedstrom, G., G & Blomstrand, C (2003) Dependence and health related quality of life in elderly people using assistive devices after acute stroke. *Technology and Disability*, 15:247-257.

Hocking, C (1994) A model of interaction between objects, occupation, society and culture. *Journal of Occupational Science*, 1(3):28:44.

Horowitz, A & Stuen, C (2003) Aging and the senses. *Spring*, 6-7.

Horwitz, S (2006) Leprosy in South Africa: A case Study of Westfort Leper Institution, 1898-1948. *African Studies*, 65(2):271-295.

International Labour Office (2006) *Malawi Country profile: Promoting the Employability and Employment of People with Disabilities through Effective Legislation* (Southern Africa). ILO, Geneva.

Izutsu, T, Tsutsumi, A, Akramul Islam, A, Yusuke Matsuo, M, Helena Sayuri Yamada, S.,H, Hiroshi Kurita, H & Susumu Wakai, S (2005) Validity and reliability of the Bangla

version of WHOQOL-BREF on an adolescent population in Bangladesh. *Quality of Life Research*, 14: 1783–1789.

John, S., A, Rao, P., S., S & Das, S (2010) Assessment of needs and quality care issues of women with leprosy. *Lepr Rev*, 81:34-40.

Joseph, A., P & Rao, P., S., S (1999) Impact of leprosy on the quality of life. *Bulletin of the World Health Organization*, 77(6):515-517.

Kaur, H & Brakel, W (2002) Dehabilitation of leprosy affected people- a study on leprosy affected- beggars. *Lepr Rev*, 73: 346-355.

Kerr-Pontes, R.,S.,L, Barreto, L.,M, Evangelista, M.,N.,C, Rodrigues, C.,L., Heukelbach ,J, & Feldmeier, H(2006) Socioeconomic, environmental, and behavior risk factors for leprosy in North-east Brazil: results of a case-control study. *International Journal of Epidemiology*, 35:994-1000.

Koyana,D.,S, Mwambene, L& Bekker, J.,C(2007) *Customary marriage systems in Malawi and South Africa*. East London, University of Fort Hare.

Leekassa, R,Bizuneh, E & Alem, A (2002) Prevalence of mental distress in the outpatient clinic of a specialized leprosy hospital, Addis Ababa. Ethiopia. *Lepr Rev*, 75:367-375.

Lesshafft, H, Heukelbach, J, Barbosa, C., J, Rieckmann, N, Liesenfeld, O & Feldmeier, H (2010) Perceived social restriction in leprosy-affected inhabitants of a former leprosy colony in Northeast Brazil. *Lepr Rev*, 81:69-78.

Liddle, J & McKenna, K (2000) Quality of life: An overview of issues for use in Occupational therapy outcome measurement. *Australian Occupational Therapy Journal*, 47:77–85.

Lockwood, N., J., D & Suneetha, S (2005) Leprosy: too complex a disease for a simple elimination paradigm. *Bulletin of the World Health Organization*, 83:230-235.

Lockwood, N., J.,D (2002) Leprosy Elimination – a virtual phenomenon or a reality? *British Medical Journal*, 324: 1516-1518.

Loebe, M., E & Eide, A., H (2003) *Living among people with Activity Limitations in Malawi, A National Representative study*, STF78A044511. Oslo: SINTEF Health Research [On line]. Available: <http://www.sintef.no/10>[Accessed on 20th January 2011].

Malawi National Leprosy Skin Programme (1994) *Field Workers' Manual Guide lines for Multi Drug Regime*. Government Print, Zomba: Malawi.

Mayo, E., N, Dauphinee, W., S, Cote, R, Durcan, L & Carlton, J (2002) Activity, Participation, and Quality of Life 6 Months Post stroke. *Arch Phys Med Rehabil*, 83:1035:1042.

Meima, A., Veen, H., J., N & H. Richardus, J., H (2008). Future prevalence of WHO grade 2 impairments in relation to incidence trends in leprosy: an exploration. *Tropical Medicine & International Health*, V13 (2):241-246.

Meima, A, Saunderson, P.R, Gebre, S., Desta, K, Van Oorrtmarsssen, G, J, &Habbema J., D., F (1999) Factors associated with impairment in new leprosy patients: The AMFES cohort. *Lepr Rev*, 70:142-158.

Mkhize N (2004) Psychology: An African Perspective. In Hook, D, Mkhize, N, Kiguwa, P, Collins, A, Burman, E& Parker, I. *Critical Psychology*. UCT Press, Lansdowne 7779.

Moore, W., M (1996) *Feminist Perceptive on Development: Why Leprosy is a feminist issue?* Occasional paper No 9. Department of Anthropology, CAPI Research Fellow, University of Victoria, April, 1995-96.

Molyneux, H., D (2004) "Neglected "diseases but unrecognised successes- Challenges and opportunities for infectious disease control. *Lancet*, 364:380-383.

Muldoon M., F, Barger S., D, Flory J.,D, Manuck S.,B(1998) What are quality of life measurements measuring? *BMJ* 316:542-545.

Murithi, T (2006) Practical Peacemaking wisdom from Africa: Reflection on Ubuntu. *The Journal of Pan African Studies*, V1 (4): 25-34. NJ: Slack.

Nagata, K., K (2003) Gender and Disability in the Arab Region: The challenges in the New Millennium, *Asia Pacific Disability Rehabilitation*, V14(1):10-17.

Naidoo, P & Mwaba, K (2010) Helplessness, Depression and social support, among people being treated for Tuberculosis in South Africa. *Social Behavior and Personality*, 38(10):1323-1334.

Nash, J (2007) Leprosaria - a continuing social change. *Lepr Rev*, 78:193-196.

National Statistical Office (2008) *2008 Populations and Housing Census, Preliminary of final census results*. Zomba, Malawi: National Statistical Office.

National Statistical Office (NSO) [Malawi] & ORC Macro, 2005. *Malawi Demographic and Health Survey, 2004*. Calverton, Maryland: NSO and ORC Macro.

Nicholls, P.,G, Bakirtzief, Z, Brakel, W.,H, Das-Pattanaya, R.,K, Raju, M, Norman, G, Mutatikar, R.,K(2005) Risk factors for participation restriction in leprosy and development of screening tool to identify individuals at risk. *Lepr Rev*, 76:305-315.

Nienhuis, A., W, Brakel, H., W, Butlin, C., R & Werf S., T (2004) Measuring impairment caused by leprosy: inter-tester reliability of the WHO disability grading system. *Lepr Rev*, 75: 221-232.

Nyirenda, L, Makwiza, I, Bongololo, G & Theobald, S (2006) A gender perspective on HIV treatment in Malawi: a multi-method approach. *Gender & Development*, 14(1):69-79.

O'Carroll, E., R., K, Smith, K., M, Couston M., Cossar, A., J & Hayes, C., P (2000) A comparison of the WHOQOL-100 and the WHOQOL-BREF in detecting change in quality of life following liver transplantation. *Quality of Life Research*, 9: 121-124.

Odawara, E (2010) Occupation for Resolving Life Crises in Old Age. *Journal of Occupational Science*, 17(1):14-19.

Ogbeiwi, O & Nash, J (1999) What would make your life better? A needs analysis of leprosy settlements in middle belt region of Nigeria. *Lepr Rev*, 70 (3): 295-304.

Ohaeri JU, Awadalla AW, Farah AA(2009) Quality of life in people with epilepsy and their family caregivers. An Arab experience using the short version of the World Health Organization quality of life instrument. *Saudi Med J.*, 2009:1328-1335.

Owolabi, O.M (2008) Determinants of health-related quality of life in Nigerian stroke survivors. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 102:1219-1225.

Parker G (1992) *With this body: Caring and disability in marriage*. Open University Press. Buckingham. Philadelphia.

Polit, F.D. & Beck, T.C. (2008). *Generating Research Evidence Ethically in Nursing Research, Generating and Assessing Evidence for Nursing Practice* (8thed.), Lippincott Williams &Wilkins, London.

Puri, K., S, Suresh, K., R, Gogtay, N., J, & Thathe, U., M (2009) The Declaration of Helsinki, 2008: Implications for stakeholders in research. *Journal of Postgraduate Medicine*, V 55(2):131-134.

Rad, F, Ghaderl, E, Morad, G, Salimzadeh, H (2007) The study of disability status of live leprosy patients in Kurdistan Province of Iran. *Pak Med Sci* (part-11) V 23(6):857:861.

Rafferty, J (2005) Curing the stigma of leprosy. *Lepr Rev*, 76:119-126.

Rankin, H., S, Lindgren, T, Rankin, W., W & Ng'oma, J (2005) Donkey Work: Women, Religion and HIV/AIDS in Malawi. *Health Care for Women International*, 26:4-16.

Rawcliffe, C (2006) *Leprosy in Medieval England*. Woodbridge: Boydell Press

Republic of Malawi Ministry of Health (2008) *Central Hospital Reform Programme*. Government Print, Zomba: Malawi.

Richardus, J., H & Habbema, J., D., F (2007) The impact of leprosy control on the transmission of *M Leprae*. Is elimination being attained? *Lepr Rev*, 78: 330-337.

Rosebaum, P & Stewart, D (2004) The world health organization international classification of functioning, Disability and health; a model to guide clinical thinking, practice and Research in the field of cerebral palsy. *Seminars in pediatric Neurology* V 11(1):5-10.

Sandqvist, G & Eklund, M. (2008) Daily occupations--performance, satisfaction and time use, and relations with well-being in women with limited systemic sclerosis. *Disability and rehabilitation*, 30(1), 27-35.

Scaffa, E., M, Slyke, N & Brownson, A., C (2008) Occupational Therapy Services in the Promotion of Health and the Prevention of Disease and Disability. *The American Journal of Occupational Therapy*, V 62(6):694-703.

Schatz, E (2005) 'Take your mat and go!' Rural Malawian women's strategies in the HIV/AIDS era. *Culture, Health & Sexuality*, 7(5):479-492.

Seddon, D & Seely, J (2006) Leprosy and stigma. *Asia Pacific Disability Rehabilitation Journal*, 17(2):3-7.

Shale, H., J., M (2000) A woman with leprosy is in double jeopardy. *Lepr Rev*, 71(1):5-17.

Shen, J., Liu, M & Zhou, M (2007) Current situation of leprosy colonies/leprosaria and their future in P.R. China., *Lepr Rev*, 78: 281–289.

Shieh, C, Wang, H., H & Lin, F., C (2006) From contagious to chronic: a life course experience with leprosy in Taiwanese women. *Lepr Rev*, 79:99-113.

Shumin, C., Diangchang, L., Bing, L., Lin, Z & Xoiulu, Y (2003) Assessment of disability, socio and economic situations of people affected by leprosy in Shandong Province, People's Republic of China, *Lepr Rev*, 74: 215-221.

Shumin, C, Lin, Z, Zhaozi, W, Jiyang, Z, Yingwei, L & Chengyu, M (2001) Experiences from a collaborative project on the prevention of disability in leprosy patients in Shandong Province, the People's Republic of China. *Lepr Rev*, 72:330-336.

Slim, J.,F, Schie, H., C, Keukekamp, R, Faber, R., W and Nollet F (2010) Effects of impairments on activities and participation in people affected by leprosy in the Netherlands. *J Rehabilitation Med Preview*, 42:1-8

Somba, W (2009) History of leprosy in Malawi. Personal communication, September 2009.

Susinos, T (2007) 'Tell me in your own words': disability barriers and social exclusion in young persons. *Disability & Society* V22 (2):117-127.

Thomas, G (1997) Inclusive schools for an inclusive society. *British Journal of Special Education*, V24 (3):103:107.

Try L (2006) Gendered experiences: Marriage and the stigma of leprosy. *Asia Pacific Rehabilitation Journal*, 17(2): 55-72.

Tolten, A, Freddrickson, C & Kamwendo, K (2008) On elderly persons with disability in Sweden: their experiences of everyday life. *Occupational Ther, Int.*, 15(3):133-149.

Tsutsumi, A., Izutsu, T., Kaso, S., Islam, A., Sayuri, Y., H., Kato, H., Wakai, S (2007) The quality of life, mental health and perceived stigma of leprosy patients in Bangladesh. *Social Science and Medicine*, 64:2443-2453.

Tsutsumi, A., Izutsu, T., Kaso, S., Islam, A., Sayuri, Y., H., Kato, H., Wakai, S (2006) Reliability and validity of the Bangla version of WHOQOL-BREF in an adult population in Dhaka, Bangladesh. *Psychiatry and Clinical Neurosciences*, 60: 493–498.

Varkevisser, M., C,Lever, P, Alubo, O, Burathoki, K, Idawani, C, Moreira, M., A., T, Patrobas, P & Yulizar, M (2009) Gender and leprosy: case studies in Indonesia, Nigeria, Nepal and Brazil. *Lepr Rev*, 80:65-80.

Veen, N, .H, Meima, A, Richardus, J., H (2006) The relationship between detection delay and impairment in leprosy control: a comparison of patient cohorts from Bangladesh and Ethiopia. *Lepr Rev*, 77: 356-365.

Velema, J., P (2008). Best practices in the socio-economic rehabilitation of persons affected by leprosy and other marginalized people in their communities: Findings from

nine evaluations in Bangladesh, India and Africa. *Asia Pacific Disability Rehabilitation Journal*, V19 (1):319.

Vrankrijker, K.,W.,M (2003) The long way from the International Classification of Impairments, Disabilities and Handicaps (ICIDH) to the International Classification of Functioning, Disability and Health(ICF). *Disability and Rehabilitation*, V25 (11-12):561-564.

Walker, A (2002) A strategy for active ageing. *International Social Security Review*, V55 (1):121-139.

Werntoft, E, Hallberg, R.,Ingalill and Edberg, K.,A (2006) Prioritization and resource allocation in health care: The views of older people receiving continuous public care and service. *Health Expectations*, 10:117–128.

Whiteford, G (2000) Occupational deprivation: Global challenge in the new millennium. *British Journal of Occupational Therapy*, 63(5): 200-2004.

Wilcock, A., A (2003) Occupational Science: The study of Humans as Occupational Beings. In Kramer, P, Hinojosa, J, Royeen, C. *Perspectives in Human Occupation*. Baltimore: Lippincott Williams and Wilkins: 156-180.

Wilcock, A., A & Townsend, E. (2000) Occupational terminology interactive dialogue: Occupational justice. *Journal of Occupational Science*, 7(2), 84-86.

Wilcock, A., A (1998) Occupation for Health. *British Journal of Occupational Therapy*, 61(8):340-345.

World Federation of Occupational Therapists (2006) World Federation of Occupational Therapists Position Statement on Human Rights [On line].Available: [http://www.wfot.org/office/Human%20rights%](http://www.wfot.org/office/Human%20rights%20) [Accessed on 6th February, 2010].

World Health Organization (2010) Principles of the convention on the Rights of the persons with disabilities. WHO Press, World Health Organization 20, Avenue Appia 1211, Geneva 27.

World Health Organization (2002) International Classification and Functioning [On line]. Available: <http://www.who.int/classification/icf/en/> [Accessed on 6th February, 2010].

World Health Organization (1996) WHOQOL-BREF Introduction, Administration, Scoring and Generic Version of the Assessment [On line]. Available: http://www.who.int/mental_health/media/en/76.pdf [Accessed on 12th February, 2009].

WHOOQL group (1998) Development of world health organization WHOQOL-BREF quality of life assessment. *Psychol. Med*, 28: 551–558.

World Health Organization Quality of Life Group (1995) The World Health Organization Quality of Life Assessment (WHOQOL): Position paper from the World Health Organization. *Social Science and Medicine*, 41:1403-9.

Yao, G., Chung, C., W., Yo, C., F., & Wang, J.,D (2002) Development and verification of validity and reliability of the WHO QOL BREF Taiwan version. *Journal of the Formosan Medical Association*, V101:342 -351.

Zodpey,S., P, Tiwari, R., R, Salodkar, A., D (2000) Gender differentials in the social and family life of leprosy patients. *Lepr Rev*, 71:505-510.

Chapter 8
Appendices

APPENDIX 1: WHO QOL BREF ADAPTED QUESTIONNAIRE (1996)

A. Demographic data

ID NUMBER

Sex

Male	Female
------	--------

Age (years)

Residence

Leprosaria	Community
------------	-----------

Religion

Christian	Moslem	Tradition	Other(specify)
-----------	--------	-----------	----------------

Level of formal education

None at all	Primary school	Secondary school	Tertiary
-------------	----------------	------------------	----------

Marital Status

Single	Married	Divorced	Widow/Widower
--------	---------	----------	---------------

Number of children

Do you have any relations?

Father/Mother	Sister/brother	Uncle/Aunt	Any(specify)	None
---------------	----------------	------------	--------------	------

What is your occupation?

Farming	Business	Begging	Any(specify)	unemployed
---------	----------	---------	--------------	------------

Are you currently ill? Yes No

At what age did you suffer from leprosy?

If something is wrong with your health what do you think it is?
Illness/problem

INSTRUCTIONS

This assessment asks you how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

		Very poor	Poor	Neither poor nor good	Good	Very good
1	How would you rate your quality of life	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last four weeks

		Not all	A little	A moderate amount	Very much	An extreme amount
3	To what extent do you feel that the physical pain prevents you from	1	2	3	4	5

	doing what you need to do?					
4	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5
6	To what extent do you enjoy life to be meaningful	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7	How well are you able to concentrate	1	2	3	4	5
8	How safe do you feel in your daily life	1	2	3	4	5
9	How health is your physical environment	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks

		Not all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for	1	2	3	4	5

	everyday life?					
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	Have you enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day- to- day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspect of your life over the last four weeks

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5

17	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity to work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the help you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied	1	2	3	4	5

	are you with your access to health services?					
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

APPENDIX II: WHO QOL- BREF translated questionnaire (Chichewa version)

Demographic data

ID NUMBER

Sex

Mwamuna	Mkazi
---------	-------

Zaka

Kudera kochokera

Leprosaria	Mmudzi
------------	--------

Tchalitchi

Mkhristu	Msilamu	Chamakolo	China (tchulani)
----------	---------	-----------	-------------------

Sukulu

Sindinaphuzilepo	Pulayimale	sekondale	Koleji
------------------	------------	-----------	--------

Marital status

Wosakwatira/ wosakwatiwa	Wokwatiwa	Wosudzulidwa	Wamasiye
-----------------------------	-----------	--------------	----------

Nambala ya ana anu

Muli ndi achibale?

Mayi/ Bambo	Mchimwene/Mchemwali	Amalume/ Azakhali	Ena (Palibe tchulan)
-------------	---------------------	----------------------	--------------------------

Mumagwira ntchito yanji?

Ulimi	Bizinesi	Kupempha	Ina (tchulani)	Sindigwira ntchito
-------	----------	----------	-----------------	-----------------------

Mukudwala?

Eya

Ayi

Munadwala khate muli ndi zaka zingati?

Ngati china chake chavuta pamoyo wanu mukuganiza kuti ndi chani?

Matenda/Mavuto

MALANGIZO

Mafunso otsatirawa akufufuza za ubwino wa moyo wanu malinga ndi mmene mwaonera inuyo. Wochita kafukufuku akuwerengani funso lirilonse bwinobwino kudzanso mayankho a mafunsowo inu musankhe yankho limodzi lomwe mukuona kuti ndi loyenera. Ngati mukukayika ndi yankho lanu dziwani kuti loyambirira lomwe limabwera m`maganizo koyambirira ndi lomwe limakhala lolondora. Manambala omwe ali kutsogolo kwa mayankho akuwonetsa kukhoza kwa mayankho anu.

Tikukupemphani kuti muwunguze za moyo wanu pa sabata zinayi zapitazi poganzira za ubwino wa moyo zikhulupiliro, zisangalalo komanso nkhwana zanu. Ubwino wamoyo ndi thanzi la moyo wanu

Kodi mungauyike pa mulingo wanji ubwino wa moyo wanu

		Woyipa kwambiri	Woyipa	Siwoyipa komanso siwabwino	Wabwino	Wabwino kwambiri
1	Kodi mungauyike pa mulingo wanji ubwino wa moyo wanu?	1	2	3	4	5

		Sindimak hutitsidwa kwambiri	Sindikh utitsidwa	Ndili pakati ndimakhuti tsidwa komanso sindikhutitsidwa	Ndimakhu titsiddwa	Ndimakhu titsidwa kwambiri

2	M'makhutitsid wa bwanji ndi thanzi lanu?	1	2	3	4	5
---	--	---	---	---	---	---

Mafunso otsatirawa akufunsa za zinthu zimene mwakumana nazo pamasabata anayi apitawo

		Ayi sundileph eretsa mpang'on o pomwe	Umandil epheret sa pang'on o	Pakati	Kwambiri	Kwambiri zedi
3	Kodi ululu wa mthupi mwanu umakulepher etsani kupanga zomwe mukufuna kuchita motani	1	2	3	4	5

		Sindimafu na chithandi zo chamakh	Pang'on o	Pang'ono kwambiri	Chambiri	Chambiri zedi

		wala chilichons e				
4	Kodi m'mafuna chithandizo chamakhwala chotani kuti muthe kugwira bwino ntchito m'moyo wanu	1	2	3	4	5

		Sindisang alala	Pang'on o	Momverera ko	Kwambiri	Kwambiri zedi
5	M'masangala la ndi moyo wanu bwanji	1	2	3	4	5

		Ayi sindiona konse	Pang'on o	Pang'ono kwambiri	Kwambiri	Kwambiri zedi
--	--	--------------------------	--------------	----------------------	----------	------------------

6	M'maona kuti moyo wanu uli ndi tanthauzo lotani	1	2	3	4	5
---	---	---	---	---	---	---

		Palibe	Pang'ono	Pang'ono kwambiri	Kwambiri	Kwambiri zedi
7	Mumatha kutsatira ntchito kwa mphindi yayitari bwanji	1	2	3	4	5

		Palibe	Pang'on o	Pang'ono kwambiri	Kwambiri	Kwambiri zedi
8	Chitetezo chanu pamoyo wanu watsiku ndi tsiku m'chotani	1	2	3	4	5

		Kulibe	Pang'on o	Pang'ono kwambiri	Kwambiri	Kwambiri zedi
9	Kumalo komwe mumakhala kuli moyo wabwino motani	1	2	3	4	5

Mafunso otsatirawa akufunsa za m`mene munachitira zina zomwe mumakumana nazo m`moyo wanu kapena m`mene mumathera kupanga zinthu zina ndi zina zomwe mwakumana nazo m`moyo wanu pasabata zinayi zapitazi.

		Ayi	Pang'on o	Pang'ono kwambiri	Masiku ambiri	Nthawi zones
10	Kodi m'makhala ndi mphamvu zokwanira pamoyo wanu watsiku ndi tsiku	1	2	3	4	5

		Ayi	Pang'on o	Pang'ono kwambiri	kwambiri	Kwambiri zedi
11	Kodi m'mavome reza mmene thupi lanu limaoneker a	1	2	3	4	5

		Ayi	Pang'on o	Pang'ono kwambiri	kwambiri	Nthawi zonse
12	Muli ndi ndalama zokwanira zodzithand izira pamoyo wanu	1	2	3	4	5

		sizindipeza	Pa ng' on o	Pang'ono kwambiri	Nthawi zambiri	Nthawi zonse

13	Kodi nkhani zolengezedwa zofunika pamoyo wanu watsiku ndi tsiku zoyenera kuti inu mudziwe zimakupezani motani	1	2	3	4	5
----	---	---	---	---	---	---

		Palibe	Pang'on o	Pang'ono kwambiri	Nthawi zambiri	Nthawi zonse
14	M'makhala ndi mwayi wotani wopanga nawo masewera ena ndi ena omwe mungapan ge nawo panthawi yanu yopuma	1	2	3	4	5

		Movutiks kwambiri	Movutik a	Simovutika komanso simwabwin o	Mwabwin o	Mwabwin o kwambiri

15	Kodi mungathe kuyendera anzanu?	1	2	3	4	5
----	---------------------------------	---	---	---	---	---

Mafunso awa afunsa mmene mwakhala mukunvera kapena kukhutitsidwa paumoyo wanu masaba anayi apitawa

		Sindikhuti tsidwa kwambiri	Sindikh utitsidw a	Ndilli pakati pokhutitsid wa komanso oskhutitsid wa	Ndimakhu titsidwa	Ndimakhu titsidwak wambiri
16	Kodi m'magona mokwanira ?	1	2	3	4	5

		Sindikhuti tsidwa kwambiri	Sindikh utitsidw a	Ndilli pakati pokhutitsid wa komanso oskhutitsid wa	Ndimakhu titsidwa	Ndimakhu titsidwak wambiri
17	M'makkhut itsidwa ndi m'mene m'magwirir a ntchito zanu za tsiku ndi tsiku	1	2	3	4	5

		Sindikhuti tsidwa kwambiri	Sindikh utitsidw a	Ndilli pakati pokhutitsid wa komanso oskhutitsid wa	Ndimakhu titsidwa	Ndimakhu titsidwak wambiri
18	M'makkhut itsidwa bwanji ndi kuchuluka kwa ntchito yomwe m'magwira	1	2	3	4	5

		Sindikhuti tsidwa kwambiri	Sindikh utitsidw a	Ndilli pakati pokhutitsid wa komanso oskhutitsid wa	Ndimakhu titsidwa	Ndimakhu titsidwak wambiri
19	M'makhutit sidwa bwanji ndi inu nokha eni ake pamoyo wanu	1	2	3	4	5

		Sindikhuti tsidwa kwambiri	Sindikh utitsidw a	Ndilli pakati pokhutitsid wa komanso osakhutitsi dwa	Ndimakhu titsidwa	Ndimakhu titsidwa kwambiri
20	M'makhuti tsidwa bwanji ndi ubwenzi wanu ndi anzanu	1	2	3	4	5

		Sindikhu	Sindikhut	Ndilli	Ndimakhutit	Ndimakhutits
--	--	----------	-----------	--------	-------------	--------------

		titsidwa kwambiri	itsidwa	pakati pokhutit sidwa komans o osakhut itsidwa	sidwa	idwakwambir i
21	Mumak hutistid wa bwanji ndi moyo wanu pogona na ndi akazi kapena amuna anu	1	2	3	4	5
		Sindikhuti tsidwa kwambiri	Sindikh utitsidw a	Ndilli pakati pokhutitsid wa komanso osakhutitsi dwa	Ndimakhu titsidwa	Ndimakhu titsidwak wambiri

22	M'makhutit sidwa bwanji ndi chithandiz ozo chimene m'malandir a kuchokera kwa anzanu	1	2	3	4	5
----	--	---	---	---	---	---

		Sindikhu titsidwa kwambiri	Sindikh utitsidw a	Ndilli pakati pokhutitsid wa komanso oskhutitsid wa	Ndimakhu titsidwa	Ndimakhu titsidwak wambiri
23	M'makhutits idwa bwanji ndi makhalidwe a pamalo pamene mumakhala	1	2	3	4	5

		Sindikhuti tsidwa kwambiri	Sindikh utitsidw a	Ndilli pakati pokhutitsid wa	Ndimakhu titsidwa	Ndimakhu titsidwak wambiri
--	--	----------------------------------	--------------------------	---------------------------------------	----------------------	----------------------------------

				komanso oskhutitsid wa		
24	M'makhutit sidwa bwanji ndi mwayi umene m'malandir a nawo pachithand izo cha makhwala	1	2	3	4	5

		Sindikhuti tsidwa kwambiri	Sindikh utitsidw a	Ndilli pakati pokhutitsid wa komanso oskhutitsid wa	Ndimakhu titsidwa	Ndimakhu titsidwak wambiri
25	M'makhutit sidwa ndi mayended we anu atsiku ndi tsiku?	1	2	3	4	5

Mafunso otsatirawa akukhudza za milingo umene mwamvera kapena kukumana ndi zinthu zina ndi zina pa milungu inayi yapitayi

		Palibe	Pafupipafupi	Pafupipafupi kwambiri	Nthawi zonse
26	Mkangati? Kamene m'mamva mthupi kunyong'o nyeka, kukhumudwa, mantha, kapena kusowa mtendere	1	2	3	4

APPENDIX III: Research consent form

Study title: A Comparison of quality of life of leprosy survivors living in the leprosaria and those reintegrated in their communities in the Southern region of Malawi.

Researcher: Dorothy Chinguo (occupational therapy masters student)

Ethics Approval Institutions: University of Cape Town REC REF: 495/2009

: University of Malawi, College of Medicine:P.11/09/839

Funded by: Ministry of Health

Contact Address: Queen Elizabeth Central Hospital, P.O.BOX 95, Blantyre.

Telephone: 0888514639

Introduction

You are asked to participate in a research study as part of minor master's dissertation. This consent form gives detailed information about the research study that will be discussed with you. Once you understand what would be involved you will be asked to sign or thumb print this form if you choose to participate in the study.

Little is known about the outcomes of the deinstitutionalization process of leprosy patients in Malawi. The aim of this research study is therefore to determine the differences between the quality of life being led by leprosy survivors living in the one remaining leprosaria and of those integrated in surrounding communities in the southern region of Malawi. The leprosy survivors living in the leprosaria and those living in the community will be invited to participate in the study. The leprosy Control Assistant will ask questions using the already set questionnaire which has been translated in Chichewa.

Procedure If you agree to be in the study, the following will occur:

- You will be asked about your quality of life using the pre-set instrument on quality of life.
- The interview will take 30-45 minutes and will be conducted by Leprosy Control Assistant. Examples of the kind of information that will be asked are: your age, health status, any pain, if you are able to use transport that is available in your community and if you get some support from relatives and friends.
- The setting will be at your home or any other place you may prefer.
- You will be allowed to ask questions for any clarification.

Participation Terms

Participation in this research is voluntary. You are free to decline to participate and withdraw from the study at any point without any negative consequences to yourself. If you require any assistance, the Leprosy Control Assistant will refer you to the appropriate agencies that can address your needs. There are no risks to you for participating in this study

Confidentiality

The information that you provide will be handled in confidence. Your name will not appear on any forms. Data will be identified by code numbers.

Benefits to the participants

The information obtained will assist with care and support of the leprosy survivors by ensuring appropriate referral if needed. There will be no remuneration for participating in this study.

Costs

There will be no costs for you as a result of participating in the study. The study will be funded by the Ministry of Health.

Contact details

Participants may contact any of the below individuals if they may have any queries regarding the study:

Project supervisors:

Madeleine Duncan

Senior lecturer, Division of Occupational Therapy

School of Health & Rehabilitation Sciences

Faculty of Health Sciences

University of Cape Town

Tel: +2721406601

Fax: +27214066323

Seyi Ladele Amosun (PhD)

Professor, Division of Physiotherapy

School of Health & Rehabilitation Sciences

Faculty of Health Sciences

University of Cape Town

Tel: 27214066444

Fax: 27214066323

Ethics (UCT)

Prof. Marc Blockman,

Faculty of Health Sciences

Research Ethics Committee

Room E52-24 Groote Schuur hospital, Old main Building, Observatory 7925

021-4066338

I accept to participate in the study. I understand that my application is voluntary and withdrawing from participating will not affect me in any way. I therefore give my consent to participate in this study.

Participant's signature /thumb print

Date

Researcher's signature

Date

Appendix IV: Research Consent form (Chichewa)

Fomu yobvomeleza kutenga nawo mbali mukafukufuku wosiyanitsa amene ali ndi umoyo wabwino pakati pa amene anadwalapo khate womwe akukhala pa chipatala cha akhate ndi omwe anasamutsidwa kupita kwao monga ku Balaka, Thyolo ndi ku Chikwawa.

Muli kupemphedwa kutenga nawo mbali mukafukufuku. Mukanvetsa bwino za kafukufukuyu mudapemphedwa kudinda chidindo ngati muvomereza kutenga nawo mbali.

Pamene zipatala zina zakhate zinatsekedwa, odwala ena anabwelera kwao. Koma sizikudziwika bwino kuti odwalawo akukhala bwanji. Tsono ndi cholinga chake chakafukufuku amenewu kuti tisiyanitse moyo wa odwala amene akukhala pachipatala cha akhate ndi amene anabwelera kumudzi kwawo. Mufunsidwa mafunso pakafukufuku ameneyi amene atha kutenga kwa nthawi. Muli ndi danga lofunsa mafunso pamene simunamvetse.

Kutenga mbali kukafukufuku ameneyu ndikufuna kwanga ndipo nditha kusiya kutenga nawo mbali mukafukufuku nthawi ina iliyonse popanda kupeleka chifukwa china chili chonse komanso sindidzakhudzidwa mwa njira ina iriyonse nditasiya kutenga mbali pakafukufuku ameneyu.

Palibe chiwongola dzanja chinachilichonse chomwe chidzalandiridwe chifukwa chotenga nawo mbali pakafukufuku ameneyu.

Chidindo cha wotenga mbali

Tsiku

Chidindo cha wofufuza

Tsiku

APPENDIX V: Letter requesting permission

University of Cape Town
School of Health and Rehabilitation Sciences
Division of Occupational Therapy

The District Health Officer
Thyolo/Balaka/Chikwawa District Hospitals

Dear Sir

RE: PERMISSION TO CONDUCT A RESEARCH STUDY

I am a Postgraduate student registered with the Division of Occupational Therapy, School of Health and Rehabilitation Sciences, University of Cape Town, South Africa. I hereby request permission to conduct a research project as partial requirements for the Msc. degree in Occupational Therapy. I intend to investigate the quality of life of leprosy survivors at Utale leprosaria and those integrated in the community using a measurement tool developed by the WHO (2004). The study will help in the development of services of the leprosy survivors in the region.

Description of study:

The study will be comparative descriptive design.

Proposed number of participants:

200 participants from will be recruited for the study from the Leprosy survivors living in the leprosaria and those integrated in the community.

Recruitment methods:

The participants will be selected using the criteria as stipulated in the protocol. I include a copy of the research protocol for your perusal. Two leprosy Control Assistants will be used to collect data in each district. They will be on a one week holiday for two days training on a pilot study and five days for data collection.

I would be grateful if you could permit me to conduct the study in the community/leprosarium. The project has been approved by the University of Cape Town

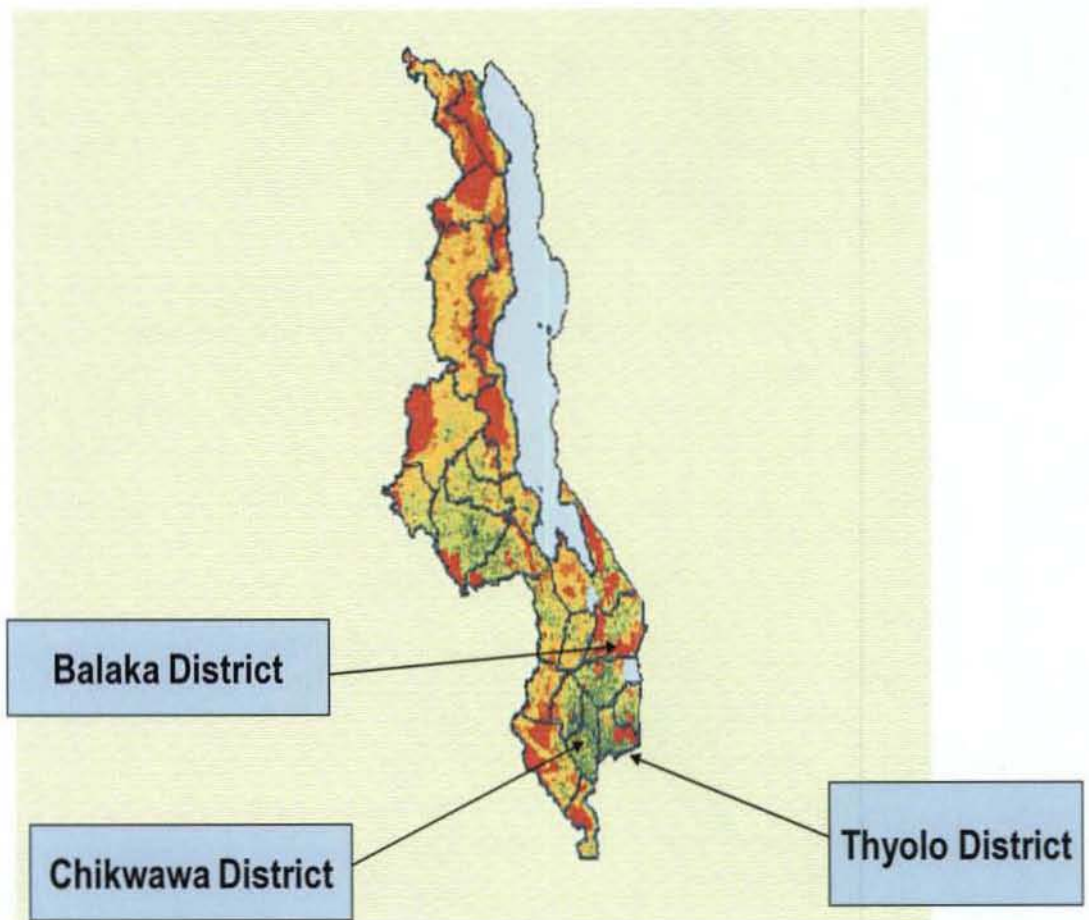
and University of Malawi (reference numbers are UCT 495/2009 and P.11/09/839 respectively).

I undertake to provide feedback on my findings to you and relevant role players.

Yours faithfully

Dorothy Chinguo

Appendix VI: Map of Malawi



Appendix VII: WHOQOL BREF Measuring Tool domains

Physical Health	Activities of daily living, Dependence on medical substances and aids, energy and fatigue, mobility, pain and discomfort, sleep and rest, work capacity.
Psychological	Bodily image and appearance, negative feelings, positive feelings, self esteem, spirituality/religion/personal beliefs, Thinking/Learning/memory/concentration
Social Relationships	Personal relationships, social support, sexual activity
Environment	Financial resources, freedom, physical safety and security, Health and social care, accessibility and quality, home environment, opportunities for acquiring new information and skills, participation in and opportunity for recreation, physical environment/pollution/noise/traffic/transport

Appendix VIII: WHO disability grading

Hands and feet

Grade 0: No anesthesia, no visible deformity or damage.

Grade 1: Anesthesia present, but no visible deformity or damage

Grade 2: Visible deformity or damage present

Eyes

Grade 0: No eye problem due to leprosy, no evidence of visual loss

Grade 1: Eye problem due to leprosy present, but vision not severely affected (Vision 6/60 or better, can count fingers at 6 meters.

Grade 2: Severe visual impairment (Vision worse than 6/60, inability to count Fingers at 6 meters. Also includes lagophthalmos, iridocyclitis, and Corneal opacities

Appendix IX: Approval letter (University of Malawi)



UNIVERSITY OF MALAWI

Principal

Prof. R.L. Broadhead, MBBS, FRCP, FRCPC, DCH

Our Ref.:

Your Ref.: P.11/09/839

College of Medicine

Private Bag 360

Chichiri

Blantyre 3

Malawi

Telephone: 01 877 245

01 877 291

Fax: 01 874 700

Telex: 43744

2nd February 2010

Mrs Dorothy Chinguo
Kamuzu College of Nursing
Blantyre Campus
Blantyre 3

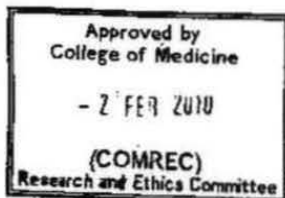
Dear Mrs Chinguo,

P.11/09/839 – A comparison of quality of life between Leprosy Survivors living in the Leprosarium and those integrated in the communities in the Southern region of Malawi

I write to inform you that COMREC reviewed your proposal which you resubmitted for expedited review. I am pleased to inform you that your proposal was approved on 27th January 2010 after considering that you addressed all the queries which were raised during the previous review.

As you proceed with the implementation of your study I would like you to take note that all requirements by the college are followed as indicated on the attached page.

Yours sincerely,



Dr. S. Kamiza

For: CHAIRMAN – COMREC.

Appendix X (University of Cape Town)

UNIVERSITY OF CAPE TOWN



Health Sciences Faculty
Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: sumaysh.arietfilien@uct.ac.za

16 November 2009

REC REF: 495/2009

Mrs D Chinguo
Occupational Therapy

Dear Mrs Chinguo

PROJECT TITLE: A COMPARISON OF THE QUALITY OF LIFE BEING LED BY LEPROSY SURVIVORS LIVING IN THE LEPROSARIA AND THOSE INTEGRATED IN THE COMMUNITIES IN THE SOUTHERN REGION OF MALAWI

Thank you for submitting your study to the Research Ethics Committee for review.

It is a pleasure to inform you that the Ethics Committee has formally approved the above-mentioned study.

Approval is granted for one year till the 30th November 2010.

Please submit an annual progress report if the research continues beyond the expiry date. Please submit a brief summary of findings if you complete the study within the approval period so that we can close our file.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

Yours sincerely

PROFESSOR M. BLOCKMAN
CHAIRPERSON, HSE HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

Attachment