

**THE HEALTH RELATED QUALITY OF LIFE OF REFUGEES WITH
DISABILITIES IN ZAMBIA**

BY

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The logo of the University of the Western Cape, featuring a classical building facade with columns and a pediment, with the text "UNIVERSITY of the WESTERN CAPE" below it.

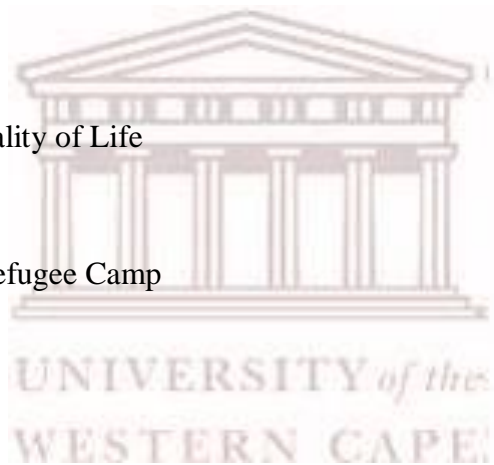
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**Supervisor: Prof Julie Phillips
(University of the Western Cape)**

KEYWORDS

1. Refugees
2. Health
3. Disabilities
4. Physical Disabilities
5. Quality of Life
6. Health-Related Quality of Life
7. Mayukwayukwa Refugee Camp
8. Zambia
9. Impairments
10. World Health Organization



ABSTRACT

Forced immigration in most cases is compounded by unprecedented human health problems as a result of traumatic life experiences. Atrocities affect both the mental and the physical wellbeing of refugees. Physical disability is one of the health problems faced by refugees more especially in post-war circumstances. The pathway to becoming a refugee is marked by significant personal hardship, which includes experiences of war and civil unrest, torture and other trauma, loss of family members and displacement from ones original home. Hence, quality of life becomes compromised by these experiences. There are about 16 million refugees worldwide with Zambia being home to 175,584. The study aimed to determine the health-related quality of life of these refugees with physical disabilities living in Mayukwayukwa refugee camp in Zambia. Furthermore, the physical functional status among refugees with physical disabilities was determined and the association between socio-demographic factors, level of physical function and health-related quality of life was established. A cross-sectional, descriptive study design using quantitative methods was conducted. Structured self-administered questionnaires were used to collect data on health-related quality of life and level of physical functioning using a study sample of 314 randomly selected participants. The sample included males and females between 18-65 years of age with physical disabilities. The WHOQOL-BREF and the Functional Status Questionnaire (FSQ), internationally validated questionnaires, were used to collect data. Analysis of data was done using the Statistical Package for Social Sciences (SPSS). Since the variables of interest are ordinal in nature, Spearman Rank Correlations or Kruskal-Wallis test were used to compare groups. Chi-square tests were also used to check for significant associations between quality of life, physical function and selected socio-demographic variables. The majority of the participants (68.8%) had a lower limb disability. Gunshots, landmines and

bomb explosions were the main causes of disabilities for 88.9 % of the participants. More than half (54.8 %) of the participants rated their quality of life as either very poor or poor, while 37.3 % rated it as neither poor nor good. The mean score for physical health, psychological, social relations and environmental domains were 41.4, 49.4, 70.1 and 37.7 respectively. Education was significantly related to the psychological domain ($p=0.0022$) and social relations ($p=0.0324$) domains. This study attests to the fact that disability is an issue in conflict-affected populations, in particular refugees. Refugees with disabilities living in Mayukwayukwa refugee camp also have poor HRQOL similar to other studies. Education was the only variable significantly correlated to the psychological and social domains of the HRQOL. The study highlighted that environmental and personal variables played a role in the determination of health related quality of life among refugees with disabilities.



DEDICATION

This thesis is dedicated to my wife, my son and daughter. To my parents, **Geoffrey and Joyce Mulenga** who loves me unconditionally and always prays for me on a daily basis.



DECLARATION

I declare that **“the health related quality of life of refugees with disabilities in Mayukwayukwa refugee camp Kaoma, Zambia”** is my own work, which has never been submitted before for any degree or examination at any other university, locally or internationally. In addition all information I have mentioned and phrase are displayed and acknowledge as complete references.

Mulenga Davie

November 2010

Signature:

Witness

Prof Julie Phillips



ACKNOWLEDGEMENTS

The foundation of this work was inspired by the work experience I had 7 to 8 years ago while working on an ICRC/U.T.H refugee rehabilitation project. The project embarked on rehabilitation of refugees with disabilities from Angola. At that time, I served as a physiotherapist for the project dealing with assessment and rehabilitation of refugees with traumatic amputations. Having secured a scholarship from the Ministry of Health to pursue my MSc in Physiotherapy at the University of Western Cape, South Africa, I set off on an academic and challenging journey in South Africa. Thus, the historical background to this work is that it contains my personal experiences and feelings towards refugees with disabilities. The project for the rehabilitation of refugees was conducted in 2002/03 at the University Teaching Hospital under the auspices of the International Committee of the Red Cross through the Prosthetics and Orthotics Centre.

I would like to say: All the worship and praise to God because above all, He made the impossible possible and has opened more doors for me. My deepest thanks go to the Physio colleagues at the UTH for their morale support. Prof Madsen of Missouri University as well as Abu Elgasim A.A.Osman for their statistical input. More so, I would like to say thank you very much to my supervisor, Prof Julie Phillips for her commitment and kindness towards my work despite her busy schedules. My writing coach, Dr. Abidemi Kappo for his commitment towards my work. Thanks, to the Zambian Government and in particular, the Ministry of Health and selected hospitals for allowing me to complete data collection. I would be failing in my endeavors, if I do not mention UNHCR Zambia members of staff for providing transport, accommodation and access to Mayukwayukwa, one of the oldest refugee camps in Africa. Thanks to my research assistants and participants for their commitment and diligence during data collection in that blazing sun. Many thanks to my best friend Kate Clerick for being there for me in times of need.

TABLE OF CONTENTS

KEYWORDS	ii
ABSTRACT	iii
DEDICATION	v
DECLARATION.....	vi
ACKNOWLEDGEMENTS	vii
TABLE OF CONTENTS.....	viii
LIST OF TABLES	xi
LIST OF FIGURES.....	xii
APPENDICES.....	xiii
CHAPTER ONE	1
INTRODUCTION.....	1
1.1 INTRODUCTION	1
1.2 BACKGROUND TO THE STUDY	1
1.3 STATEMENT OF THE PROBLEM	6
1.4 RESEARCH QUESTIONS	6
1.5 RESEARCH OBJECTIVES.....	6
1.6 SIGNIFICANCE OF THE STUDY.....	7
1.7 DELINEATION/SCOPE OF THE RESEARCH.....	8
1.8 DEFINITION OF TERMS	8
1.9 LIST OF ABBREVIATIONS USED IN THE STUDY.....	10
1.10 OUTLINE OF THE CHAPTERS	11
CHAPTER TWO	13
LITERATURE REVIEW	13
2.1 Introduction	13
2.2 Global situation of refugees.....	13
2.3 Refugees in Africa	14

2.4 Refugees in Southern Africa	16
2.4 Refugees and Health	19
2.4.1 Refugees and Disabilities	22
2.4.3 Quality of life of refugees with disabilities	26
2.5 Health-related quality of life of refugees with disabilities	29
CHAPTER THREE.....	34
METHODOLOGY	34
3.1 Introduction	34
3.2 Research setting	34
3.3 Research design	35
3.4 Study population and sample.....	36
3.5 Data Collection Methods	36
3.5.1 Research Instruments	37
3.5.2 Reliability and validity of the instruments.....	38
3.6 Procedure.....	39
3.7 Data analysis.....	40
3.8 Ethical Considerations.....	41
CHAPTER FOUR.....	43
RESULTS	43
4.1 Introduction	43
4.2 Profile of refugees with disabilities.....	43
4.3 Physical function of study sample.....	46
4.4 The health related quality of life of refugees with physical disabilities.	48
4.5 Summary	52
CHAPTER FIVE.....	53
DISCUSSION	53
5.1 Introduction	53
5.2 Profile of refugees.....	53
5.3 Level of physical function of study sample.....	55

5.3	Health related quality of life of study sample	57
5.4	Summary	61
CHAPTER SIX		62
CONCLUSION, LIMITATIONS AND RECOMMENDATIONS		62
6.1	Conclusion.....	62
6.2	Limitations of the study.....	63
6.3	Recommendations	63
REFERENCES.....		65



LIST OF TABLES

Table 4.1	Profile of study sample (n=314)	43
Table 4.2	Types of disabilities among study sample (314)	44
Table 4.3	Causes of disabilities among study sample (n=314)	44
Table 4.4	Mean (SD) physical function score of study sample (n=314)	45
Table 4.5	Mean (SD) physical function score by level of disability (n=314)	46
Table 4.6	Bivariate correlations between physical function and HRQOL (n=314)	46
Table 4.7	Mean (SD) raw domain scores of WHOQOL-BREF for the study sample (n=314)	47
Table 4.8	Mean (SD) transformed domain scores of WHOQOL-BREF for refugees with disabilities (n=314)	48
Table 4.9	Factors associated with HRQOL of the study sample (n=314)	49

LIST OF FIGURES

- Figure 4.8.1** Box plots association between Psychological domain and Education 50
- Figure 4.8.2** Box plots association between Social domain and Education 51



APPENDICES

- Appendix A:** Letter of approval to conduct research by ethics committee and senate of the University of the Western Cape
- Appendix B:** Request to the Ministry of Health to conduct the research in Mayukwayukwa refugee camp.
- Appendix C:** Request to the Director of Kaoma District Hospital to conduct research in Mayukwayukwa refugee camp
- Appendix D:** Letter from the Ministry of Health
- Appendix E:** Letter from the director of Kaoma District Hospital
- Appendix F:** Participant information sheet (English)
- Appendix G:** Participant information sheet (Mbunda)
- Appendix H:** Participant consent form (English)
- Appendix I:** Participant consent form (Mbunda)
- Appendix J:** The World Health Organization Quality of life, short form (WHOQOL-BREF) (English)
- Appendix K:** The World Health Organization Quality of life, short form (WHOQOL-BREF) (Mbunda)
- Appendix L:** The physical function status questionnaire (English)
- Appendix M:** The physical function status questionnaire (Mbunda)
- Appendix N:** Certificate of incorporation for professional translators

CHAPTER ONE

INTRODUCTION

1.1 INTRODUCTION

In this chapter the refugee crisis in the world, with special emphasis on Africa, is highlighted. Furthermore, the health problems experienced by refugees, especially physical disability, are highlighted. The research objectives and significance of the study are also stated.

1.2 BACKGROUND TO THE STUDY

The world today is faced with refugee crisis in astronomical proportions. According to the United Nations High Commission for Refugees (UNHCR) Annual Global Trends Report (2009), the number of people forcibly uprooted by conflict and persecution worldwide stands at 42 million as of 2008. This is as a result of a sharp decline in repatriation and more prolonged conflicts resulting in protracted displacements (UNHCR, 2009). The UN Refugee agency, the UNHCR, distinguishes between refugees and the internally-displaced persons as follows: both groups often leave their homes for similar reasons. Civilians are recognized as 'refugees' when they cross an international frontier to seek sanctuary in another country, however, the internally-displaced, for whatever reason, remain in their states (UNHCR, 2007). The total numbers of displaced persons include 16 million refugees and asylum seekers, while 26 million internally-displaced people were uprooted within their own countries.

Refugees experience various life transitions as a result of armed conflicts and civil wars that lead to emergency displacement in their normal everyday lives. Wars and armed conflicts remain one of the major causes of forced immigration leading to the creation of refugees and

internally-displaced persons. These are people who have been subjected to so much violence or persecution in their home land that the only option left for them is to flee what is comfortable and familiar (UNHCR, 2008) . In an effort to rebuild their lives in a new country, many end up living in tents in crowded camps, without sufficient food, water, healthcare and education. In addition, violence and fighting continue to threaten their lives even in exile as in the case of xenophobic attacks in South Africa (Sowetan, 2008).

The UNHCR Annual Report (2009) showed 80 % of the world's refugees and internally-displaced people are in the developing nations. These are people who have been uprooted for years with no end in sight. The alarming part of the whole situation is that this number is increasing from time to time as a result of continued social upheavals in different parts of the world especially in the developing countries.

Africa remains one of the main contributors to the world refugee population due to war, poverty and organized crime on the continent. It is estimated that Africa has the largest number of refugees (more than 15 million) compared to other regions (Stebleton, 2007). The horn of Africa is a 'hotspot' for conflicts with the area repeatedly hit by natural and man-made disasters resulting in millions of people having to flee their homes to spare their lives. Somalia still remains a country without proper government while the situation between Eritrea and Ethiopia; Eritrea and Sudan remain tense especially in Darfur region (Internal Displacement Monitoring Centre, 2009). War and violence still threatens Africa, thus leading to mass killings and displacements. The recent bomb blast in which scores of soccer fans were killed and many others wounded in Uganda during the recently concluded Soccer World Cup attests strongly to this fact (BBC News, 2010). Another example is the recent trial of the former Liberian President, Mr Charles Taylor at the International Court of Justice in Hague over his involvement in the war in Sierra Leone in which civilians were either killed or

maimed and his use of child soldiers in prosecuting the Liberian civil war which left thousands of people dead and a lot more homeless (Open Society and Justice Initiative, 2010).

The United Nations High Commission for Refugees (UNHCR) created in 1950, is the world's largest organization with the sole responsibility of protecting and assisting refugees. Analyzing the refugee phenomenon, the UNHCR found out that forced migration is always associated with political, ethnic or violent conflict which is accompanied by intensive human rights abuses (UNHCR, 2004). Hence, the mandate given to this organization has been carried out in 110 countries of which Zambia is no exception and has helped some 50 million people "restart their lives" (The UN Refugee agency, 2010).

In her attempt to alleviate the suffering of thousands of refugees and asylum seekers who continually flock its shores, Zambia enjoys an outstanding record with the world refugees commission (UNHCR, 2008). The UNHCR started operating in Zambia in 1967, three years after the country's independence with the sole purpose of providing initial assistance to refugees running away from persecution as a result of the struggle for independence in neighboring countries like Angola, Mozambique, Namibia, South Africa and Zimbabwe. Even now, Zambia being in a strategic geographical location in Southern Africa has not been spared by the influx of refugees running away from civil wars, political instability, organized crime and poverty (Congressional Record, 2003).

Zambia has been a citadel of peace for many, from far and wide fleeing from well founded fears of persecution. The refugees' phenomenon in Zambia is divided into three main phases. The first occurred in 1943 during the Second World War when Northern Rhodesia hosted Polish refugees. The second was in the 1960s after independence when Zambia opened its newly recognized borders to Angolan refugees fleeing from conflict. This phase also includes

Zambia's hosting of those that fled colonial persecution and the policy of apartheid in South Africa. The final phase which begun in the 1990s is Zambia's response to the conflict in the Great Lakes Region, the major conflicts being the Rwandan genocide of 1994 and the Congo DR conflict that intensified in 1996 and has now gained a reputation as "Africa's world war" for its involvement of about seven countries (Times of Zambia, 2005). Perhaps one of the worst catastrophes of modern times that have sculptured an indelible scar on the conscience of humanity is the 1994 Rwandan genocide, which led to many Rwandese refugees fleeing to the peace haven which is Zambia (Times of Zambia, 2005). UNHCR operations have continued ever since, expanding and contracting as the situation demanded. At its peak in 2001, Zambia hosted over 280,000 refugees which were mainly from the Democratic Republic of Congo (DRC) and Angola (UNHCR, 2010).

Above all, the impulse to migrate is inherent in human nature as an instinctual and inborn disposition and inclination to wander in search of new opportunities and new horizons (Adler & Gielen, 2003). This is, however, a stressful process (Bhugra & Jonnes, 2001) which in post-conflict situations, research revealed that people of a refugee background suffer a high incidence of physical and mental problems (Refugee Health and Wellbeing Action Plan, 2004). The refugee crisis has indeed evolved with it a plethora of health problems implicating the refugee's quality of life. Researchers have highlighted that refugees experience a considerable stressful events that are associated with adverse health outcomes (Holyfield *et al.*, 2008).

Both qualitative and quantitative methods have been used to assess quality of life among refugee populations with chronic diseases living in developed countries but few studies have assessed quality of life among refugees living in camps and how they are affected by chronic illnesses (Preedy & Watson, 2010). Aggarwal (2007) shared his experiences with displaced

refugees and their sufferings in a camp settlement in India, while the work of Halab (2005) work revealed the health status and life experiences of Palestinian refugees in Jordan. Elsewhere, Shoeb and co-workers (Shoeb *et al.*, 2007) explored the experiences of the refugee populations in Detroit, Michigan, while Eljedi and colleagues (Eljedi *et al.*, 2006) conducted a study on the health-related quality of life of refugees with diabetes living in camps in the Gaza strip, Palestine.

According to the World Health Organization (WHO), approximately 7-10 % of the total world population today lives with disabilities. Based on this figure, the WHO further assumes between 2.5 and 3.5 million of the world's 35 million displaced people also live with disabilities (Women's Commission, 2008). It is further suggested that this number might even be higher among refugees who have fled conflicts and civil wars, since these refugees suffer various degrees of disablement due to injuries carried over from different stages of conflicts leading to impairment, disability and being handicap (Boyce *et al.*, 2002).

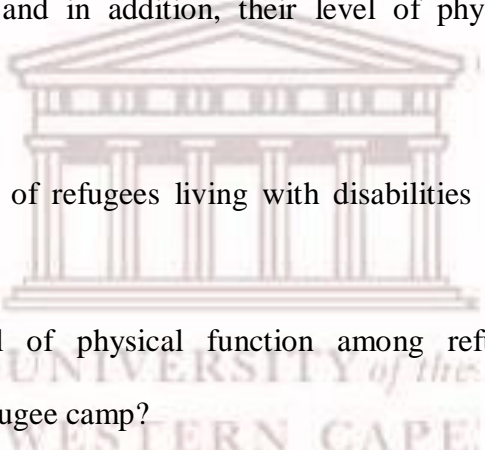
Although the UNHCR has the sole responsibility for protecting and assisting the world's refugees, a major distinction ought to be made between refugees with disabilities living in developed countries and refugees with disabilities living in camps, predominantly located in developing countries. While both groups share past experiences of trauma and displacement, the living conditions and problems affecting their health-related quality of life differ (Preedy & Watson, 2010). Refugees with disabilities are not only affected by this traumatic displacement they experience, but also by the fact that the camp conditions predisposes them to additional challenges of obtaining optimal treatment and adhering to treatment regimens. As a result, their quality of life is synergistically reduced due to both chronic disease and the camp conditions (Preedy & Watson, 2010).

1.3 STATEMENT OF THE PROBLEM

A number of studies have been done on refugees and their mental wellbeing but little attention has been paid to injuries including disabilities sustained in the course of torture or trauma and their impact on the quality of life of an already vulnerable group. Until now, no study has been done on the health-related quality of life of refugees with disabilities in Zambia.

1.4 RESEARCH QUESTIONS

The purpose of the study is to examine the **Health-Related Quality of Life (HRQL)** of refugees living in camps and in addition, their level of physical functions and factors affecting them.

- 
- What is the profile of refugees living with disabilities in Mayukwayukwa refugee Camp?
 - What is the level of physical function among refugees with disabilities in Mayukwayukwa refugee camp?
 - What is the health-related quality of life of refugees with disabilities in Mayukwayukwa refugee camp?
 - What are the factors that are associated with health-related quality of life and levels of physical function among refugees with physical disabilities in Mayukwayukwa refugee camp?

1.5 RESEARCH OBJECTIVES

The specific objectives of the study are as follows:

- To establish the demographic profile of refugees with physical disabilities in Zambia.

- To determine the level of physical function among refugees with disabilities in Zambia;
- To determine the health-related quality of life among refugees with disabilities in Zambia;
- To establish the factors associated with health-related quality of life and levels of physical function among refugees with disabilities in Zambia.

1.6 SIGNIFICANCE OF THE STUDY

The United Nations agency estimates that there are almost 33 million refugees in the world, with about one third in Africa and faces serious challenges for their displacement (Karanja, 2009). Asylum seekers and refugees frequently present to physiotherapy with symptoms arising from the physical trauma or emotional distress related to being dislodged from their countries of origin (O'Shaughnessy & Tilki, 2007; Gard, 2007), and physiotherapy may be provided in settings outside of the hospital. In refugee situations, people with disabilities are particularly more vulnerable as they may be exposed to more health and safety risks which reduce their chances of survival. The situations in the refugee camps often give rise to an increase in impairment (Karanja, 2009). It is therefore important to prepare physiotherapists and physiotherapy students to meet these responsibilities.

'The Women's Commission for Refugees, Women and Children (2008) highlighted that of all the programs surveyed in their report, the collection of reliable and accurate data on the numbers and profile of displaced persons/refugees with disabilities was one of the weakest aspects. The present study will thus be able to provide policy makers and Non-Governmental Organizations (NGOs) with information on health-related quality of life of refugees with disabilities.

1.7 DELINEATION/SCOPE OF THE RESEARCH

The present study will focus on refugees based at Mayukwayukwa refugee camp which is located at the Western Province of Zambia. Mayukwayukwa refugee camp consists of both genders although males account for the biggest number of the population. The scope of the present research is on refugees and not internally-displaced population or asylum seekers and more so, refugees with disabilities living at the Mayukwayukwa refugee camp. The emphasis of this research will be on the health-related quality of life with disabilities and not any other quality of life.

1.8 DEFINITION OF TERMS

Disability: The World Health Organization in 1976 came up with the definition of disability which draws a three-fold distinction between impairment, disability and handicap. “An impairment is any loss or abnormality of psychological, physiological or anatomical structure or function; a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being; a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that prevents the fulfillment of a role that is considered normal (depending on age, sex and social and cultural factors) for that individual” (WHO, 1976). Putting the above definitions into context, the World Health Organization sees disability as an umbrella term, covering impairments, activity limitations, and participation restrictions. Therefore, impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus, disability is a

complex phenomenon, reflecting an interaction between features of a person's body and features of society in which he or she lives (WHO, 1976).

Health: The World Health Organization (WHO, 1948) defined health as “a complete physical and mental social well-being, and not merely the absence of disease and infirmity”.

Health-related quality of life: This is defined as a subset of the overall quality of life that encompasses an individual's health state, functioning status (both physically and mentally), as well as the individuals overall well-being (Tarlov *et al.*, 1989).

Physical Functioning: This defined as the ability to conduct a variety of activities ranging from self care to more challenging and vigorous activities that require increasing degrees of mobilization, strength, or endurance (Hays *et al.*, 2007).

Quality of life: This is defined as an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships and their relationships to salient features of their environment (Lipton *et al.*, 2001; The WHOQOL Group, 1994a).

Refugee: According to the 1951 United Nations Convention relating to the status of refugees, a refugee is a person who owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion, is outside the country of their nationality, and is unable to or owing to such fear, is unwilling to avail himself of the protection of that country (UNHCR, 2007).

1.9 LIST OF ABBREVIATIONS USED IN THE STUDY

ADL	Activities of daily living
DRC	Democratic Republic of Congo
ICF	International Classification of Functioning
GO	Governmental Organization
HRQOL	Health Related Quality of Life
MDG	Millennium Development Goals
NGO	Non Governmental Organization
UNDP	United Nations Development Programs
UNHCR	United Nations High Commissioner for Refugees
UN	United Nations
PWD	People with Disabilities
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life
WHOQOL-BREF	World Health Organization Quality of Life Brief

1.10 OUTLINE OF THE CHAPTERS

Chapter One: This chapter provides an introduction to the issue of forced migration and the rationale for this research. Africa has been hit by refugee crisis in astronomical proportions due to ethnic conflicts, civil wars, poverty and violence. In the event of war these people lose their beloved ones, their income and their health and as such these circumstances have profound implications on their quality of life. One of the major tragedies is that they are faced with health issues among them disabilities and are forced to live in foreign countries as refugees. The development of a case study in Zambia will provide a context and understanding of the refugees with disabilities and their health- related quality of life and level of physical function and factors determining them. The present study will thus be able to provide policy makers and Non-Governmental Organizations (NGOs) with information on health-related quality of life of refugees with disabilities.

Chapter Two: Literature pertaining to refugees are reviewed and discussed in this chapter. Literatures regarding refugees worldwide with specific reference to Africa are outlined. Furthermore, the health challenges and HRQOL of refugees with disabilities are highlighted in this in this chapter.

Chapter Three: This chapter focuses on various aspects relating to the research methods of this empirical study. Included in this chapter are the methods used, descriptive of the study population and the sample, the appropriate analysis of the data and the ethical considerations applied in the study.

Chapter Four: This chapter presents the results of the data analysis. The results are complimented with graphs and tables.

Chapter Five: This chapter provides a discussion of the results of the study. The results of the study are also compared with relevant literature.

Chapter Six: Provides a summary of the study. Furthermore, the limitations of the study are outlined and recommendations offered.



CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

Literature pertaining to refugees will be reviewed and discussed in this chapter. The literature will include the refugee situation worldwide with specific reference to Africa, the health challenges of refugees and specifically the HRQOL of refugees and disabilities.

2.2 Global situation of refugees

The history of migration has its roots in population movements as one of the fundamental factors in human survival. Derived from the British Parliaments International Development Sixth Report on Development of July 2004, this is conceptualized as the history of peoples struggle to survive and to prosper, to escape insecurity and poverty, and to move in response to opportunity (Juss, 2006). This has resulted in the mass evolution of 175 million people worldwide living outside their country of birth (Juss, 2006). While migration is viewed from a broader perspective, definitions must be considered cardinal to the issue of forced migration (Abedi *et al.*, 2010). The 1951 convention regarding the refugee status and its definition which is the international legal definition is used in this review: A person who is outside his or her country of nationality or habitual residence; has a well founded fear of persecution because of his or her race, religion, nationality, membership of a particular social group or political opinion and is unable or unwilling to avail himself to the protection of that country, or to return there, for fear of persecution (UNHCR Media Services, 2007).

The world today has been engulfed with refugee populations standing at 125 million currently (Juss, 2006). The number which is significantly growing is already immense as a

result of the refugee-producing and migration-facilitating conditions. This has largely been due to contributing factors such as political repression, armed conflict, civil strife, environmental disaster, famine, social and economic disintegration, wretched government policies, and improvements in communication and transportation opportunities (Juss, 2006).

Since the early 1990s, the United Nations and the international aid community have focused on refugee emergencies, delivering humanitarian assistance to refugees and war-affected populations, and encouraging large-scale repatriation programs in high-profile regions such as the Balkans, the Great lakes and recently, Darfur and Chad. Almost two thirds of the world's refugees, however, are trapped in protracted refugee situations. Such situations often characterized by long periods of exile, stretching to decades for some groups- occur on most continents in a range of environments to which Zambia is no exception, such as camps, rural settlements and urban centers (Loesch & Milner, 2005).

According to Loesch & Milner (2005), long-term refugee scenarios are a growing challenge. Not only are their consequences being more keenly felt by host nations and regions of origin, but their total number has increased dramatically in the past decade. More significantly, protracted refugee problems now account for the vast majority of the global refugee population, demonstrating the importance, scale and global significance of the issue.

2.3 Refugees in Africa

Political violence in civil war and ethnic conflicts has generated millions of refugees across the African continent with unbelievable pictures of suffering and unnecessary death (Kallipini & Oppong, 1998). Indeed, contemporary migration in Africa (voluntary or forced, internal or international) is best understood in the context of the political and the historical

evolution of African societies, and of the current economic crises, ecological disasters and the ongoing political events in the region. The combination of wars, civil unrest and the way both super powers (the former USSR and USA) pursued their global interests in Africa generated both economic migrants and refugees including internally displaced persons. This literature review focuses on the political experiences of post-independence sub-Saharan Africa and how these have triggered various movements and displacements of persons.

Displacement is a common story in many African countries. According to Cohen (1995), in addition to the normal, seasoned cross border movements of people, post independence Africa has triggered mass flows of two kinds. The first one arose from what he calls 'the era of mass expulsions', when the newly assertive nationalist politicians responded to populist demands to put nationals ahead of 'foreigners'. In situations where claims to citizenship and nationality were in any case poorly documented this often resulted in unjust attacks and roundups of peaceable, long-standing residents. The second form of mass migration resulted from political destabilization and civil war which have afflicted, inter alia, Ethiopia, Uganda, Sudan, Angola, Mozambique, Liberia and Somalia. It is difficult to see anything positive about these events, as so many people have been forced to abandon their livelihoods and flee for food and shelter. The only positive aspect is that most African countries bordering the refugee-generating areas have been conspicuously generous in their admission, recognition and settlement policies of which Zambia is no exception (Cohen, 1995). African countries have shown very high rates of internal, regional and international migration from slave-raiders and colonial butchers not for economic opportunity, but for mere survival (Cohen, 1995).

Mass movements of people across borders are often classified as economic and political migration. Economic migrants are seen as having left their homes voluntarily to earn better wages while those affected by political migration: often referred to as 'refugees' are seen to

have been forced to leave their countries for their safety (Oneworldguides, 2008). The refugee concept as expanded by further conventions of the United Nations includes persons who had fled war or other violence in their home country. A person who is seeking to be recognized as a refugee is an asylum seeker (UNHCR, 2007).

The causes of the refugee problem in Africa are many and varied but unending wars usually fuelled by repressive governmental regimes seem to be the major cause, followed by natural disasters. Refugee crisis has been part of mankind for quite some time now. However, exodus of refugee and their traumatic experiences have grown significantly over time due to numerous factors. Political instability, civil unrest and regional conflicts in many parts of the world have led to people being displaced from their homes and livelihood (Chitereka, 2008). In Africa, most especially, displacement is as a result of struggle for political and economic power between different factions and/or ethnic groupings. Struggle for power coupled with poverty have been the contributing factors to the refugee crisis in Africa e.g. the current conflicts in Darfur, Sudan; Somalia and Cote d'Ivoire lends credence to this fact. Furthermore, Zimbabwe's current political problem has resulted in a large number of its population becoming refugees in other African countries like South Africa (Chitereka, 2008).

2.4 Refugees in Southern Africa

Much of the recent history of Southern Africa revolves around migration, which became a major force both integrating the region, and reflecting its integration and uneven incorporation into a changing world order. Southern Africa witnessed for the best part of the century the world's largest and most coercive regional labour migration network and the largest forced displacement of rural populations. These refugee flows in Southern Africa are shaped by several distinct periods: pre-colonial, colonial, independence struggles and post-

colonial (Makhema, 2009). The focus is on independence struggles and post-colonial situations as these have significant impact on the refugee flows in Zambia.

Southern Africa's independence struggles continued for a protracted period, with the first country gaining independence and majority rule being the Congo (then renamed Zaire and now the Democratic Republic of Congo) in 1960, with South Africa being the last in 1994. The decolonization process led to large-scale displacement in the region. While some countries such as Lesotho and Swaziland were never fully colonized and others (such as Botswana, Tanzania, Malawi, Zambia, and Mauritius) had peaceful transitions to self-rule, many countries in the region, especially those with settler colonies fought bloody wars before gaining independence. These countries included Angola and Mozambique (1975), Zimbabwe (1980), Namibia (1990) and South Africa (1994) (Makhema, 2009).

Conflicts in Southern Africa did not end with independence, and Angola (1975-2002), the DRC (Zaire) (most recently from 1997-2002 and ongoing), and Mozambique (1976-1992) became embroiled in civil wars soon after independence, which lasted for decades. Since 1994, refugee flows in the region have changed once again, with democratic South Africa becoming a host for refugees from around the continent, including within the region from Angola and DRC. While the Mozambican and Angolan conflicts were resolved in 1992 and 2002 respectively, that of DRC, continues to produce refugees to date. Since 2000, the political instability and economical collapse of Zimbabwe have also led to a new flow of Zimbabweans into the region (especially South Africa and Botswana, with increasing numbers in Mozambique and Zambia since 2005) (Makhema, 2009). Angola has been a refugee producing country for decades. Since the end of the civil war in 2002, Angolan refugees have been returning to the country, spontaneously and through organized repatriation programs from neighbouring countries. About 1.4 million still remained displaced as of 2002 within Angola (Makhema, 2009).

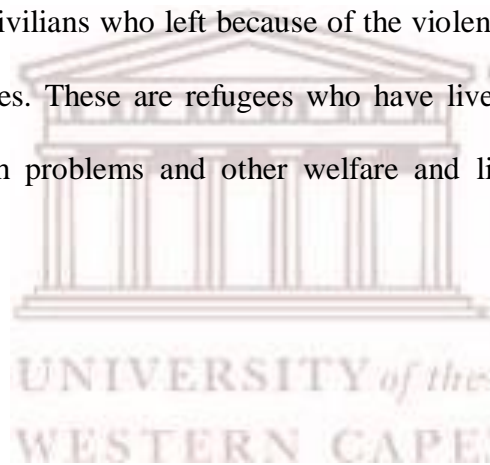
Zambia began hosting refugees fleeing wars in nearby countries just two years after becoming independence in 1964. UNHCR operations have continued ever since, expanding and contracting as the situation demanded. At its peak in 2001, Zambia hosted over 280,000 refugees-mainly from the Democratic Republic of Congo (DRC), and Angola. At the end of June 2009, Zambia was hosting some 78,000 refugees and asylum-seekers. By mid 2009, Zambia was hosting approximately 18,700 Angolan refugees in two settlements of Mayukwayukwa (10,000) and Maheba (8,800), while another 8,200 are settled among local communities. More than 25,200 Congolese refugees are living in Kala, Mwanze and Maheba camps. The government estimated that 15,000 Congolese are settled spontaneously within host communities. Mayukwayukwa and Meheba settlements host some 4,500 refugees of various other nationalities while another 2000 in this category are settled among the local communities. Almost 4,800 urban refugees are residing in Lusaka (UNHCR-Zambia, 2010).

Zimbabwe has historically hosted refugees from Mozambique as well as providing sanctuary for South African liberation fighters. More recently, the country has provided refuge to people from the DRC, Angola and Somalia. In 2006, there were 3800 refugees and asylum seekers registered in Zimbabwe. With political unrest and economic collapse of Zimbabwe in 2002, most of the refugees in the country have since moved elsewhere, especially South Africa (Makhema, 2009).

Refugees and asylum-seekers in South Africa have freedom of movement, the right to work and the right to avail themselves of basic social services. Consequently, they reside mainly in urban areas amongst migrants, foreigners and the local population. Government statistics indicate that more than 207,200 individual asylum claims were registered in South Africa in 2008, making the country the largest single recipient of asylum-seekers in the world. There were some 227,000 asylum applications pending at the end of December 2008. The majority

were from Zimbabwe (122,600), Malawi (18,160), and Ethiopia (11,350), as well as from other African countries and from Bangladesh, China, India and Pakistan. There are also some 43,500 refugees recognized by the Government, mainly from Burundi, the Democratic Republic of the Congo (DRC) and Somalia (UNHCR Global Appeal, 2009).

Southern Africa's recent decades of conflict have since generated some of the world's highest per capita levels of refugees and internal displacement. The first round of refugees in Southern Africa's history is associated with its ant-colonial wars and political strife in Angola, Mozambique, Namibia and Zimbabwe. Refugees from these conflicts were both combatants and political cadres who chose to leave their homes with the aim of joining the armed struggle, and also civilians who left because of the violence of the counter insurgency operations in the war zones. These are refugees who have lived in rural camps and many experienced serious health problems and other welfare and livelihood problems (Cohen, 1995).



2.4 Refugees and Health

The impact of conflict-related, complex emergencies on human health is widely documented, but poorly quantified, as most data collection and registration systems ceases to function in conflict affected situations. Modern conflict, which in increasing degrees, affects the civil populations and is estimated to be one of the top ten causes of global mortality (Rockhold, 2010). The direct effects of war and conflict on health are due to landmines, exploded remnants of war, active combat, small arms, forced amputations, forced military recruitment, sexual and gender based violence, and other violent acts. The indirect effects of war impact health through a myriad of ways including social, political insecurity, environmental degradation, and human rights violations. Conflicts are a major cause of injuries, violence,

and disability and place a large economical burden on the individual, the family and the society (Rockhold, 2010).

Human rehabilitation is an essential investment that minimizes the healthy and disability consequences of conflict and enables people to live healthy and economically productive lives (Rockhold, 2010). Forced human migration poses a significant public health challenge. The United Nations High Commissioner for Refugees estimates that one in every thirty persons in the world will be a formal or informal refugee at some point in his or her life. Furthermore, 95 % of all refugees are estimated to come from, and reside in, developing countries such as Asia, Latin America, and Africa, where health status is already compromised (Yehieli and Mukeshimana, 2002).

Refugee health is also a critical mother-and-child issue, as approximately 80 % of all refugee populations around the world are comprised of women and children, with children accounting for 50 % of these groups (Yehieli and Mukeshimana, 2002). The refugee crisis has brought with it challenges with implications for global health. Migration is an old phenomenon that is associated with a lot of health issues. Carballo & Nerukar (2001) observed there are number of health issues that can be associated with migration and this is inevitably broad. It is recognized that refugees and displaced people are some of the most vulnerable populations in the world. In general, the major health problems of refugees and internally displaced persons are similar in nature, however, the health status of the internally displaced maybe worse because access to these populations by international relief agencies is often difficult and dangerous. However, despite their different backgrounds, most refugees share common experiences related to wars, extreme poverty, and other disruptions-such as physical and psychological health problems prior to and during their resettlement (Yehieli & Mukeshimana, 2002). Furthermore, internally displaced persons may suffer more injuries because they are usually located closer to zones of conflict than are refugees; however, both

refugees and internally displaced are often victims of landmines, particularly as they cross international borders (Toole & Waldman, 1997).

Sturchio (2007) highlighted that added to refugees losing the security of their homes, their employment and social networks; they are also at a very high risk of poor health, nutrition and human rights violations. The UN High Commission of Human Rights (2005) has further added that due to the loss of basic necessities such as clean water and stable living conditions, in addition to the devastated health services, refugees are highly susceptible to diseases. Not only are refugees unable to return to their country of origin voluntarily, but, in many of these cases, refugees languish in camps, dependent on humanitarian assistance and food aid, with limited or no opportunities for self reliance or local integration. Densely populated refugee camps with limited opportunities become the home and the community of those who have been forcibly displaced for decades. As a result, significant portions of today's refugees have severe psychosocial and physical health concerns of which disability is one of them (Presse & Thomson, 2008).

Furthermore, the health of refugees and other forcibly displaced people is a key component of protection and a priority for UNHCR. Based on the 1951 Refugee Convention, refugees should enjoy access to health services equivalent to that of the host population, while everyone has the right under international law to the highest standards of physical and mental health (UNHCR, 2010). Although there has been a number of health problems regarding immigrants, relatively little attention has been given to the impact migration and resettlement have on the health of immigrants. Even less attention has been paid to conditions possibly linked to poor health in the context of migration. National Health Statistics rarely reflect the process or its implications, and there has been relatively little interest in the phenomenon by health and social scientists. The data available tend to be from small studies and anecdotal reports. They nevertheless indicate that the health circumstances that characterize uprooting

and migration merit more consideration (Carballo & Nerukar, 2001). Merck and colleagues (2007) is of the opinion that responding to the health challenges of the refugees is not just a humanitarian necessity but also a strategic imperative. It is estimated statistically that a population of about 3.5 million refugees and internally-displaced people live with disabilities in refugee camps and urban slums. These are people who are excluded from and unable to access mainstream assistance programs as a result of attitudinal, physical and social barriers and whose potential to contribute and participate is seldom recognized (Merck *et al.*, 2007).

2.4.1 Refugees and Disabilities

The United Nations Convention on the Rights of Persons with disabilities defines “Persons with disabilities as follows: include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”. It further stated that persons with disabilities do not constitute a homogenous group. They come from all ages, ethnicities, gender, religious and economic classes. Impairments may be congenital or result from birth, accidents, physical or psychological traumas, violence and abuse, disease, psychiatric disorders, poor access to health care, bad nutrition. Resulting disabilities can be transitory or permanent, but they tend to be magnified in situations of emergence and movements of populations (UN Enable, 2009).

In 2002, the WHO estimated a total of 57 million deaths worldwide out of which 700.000 were as a result of violence being inflicted on individuals, including conflict related deaths (WHO, 2004). More than 80 % of these deaths were in males and the mortality rate was higher in low income countries compared to high-income countries (Payne, 2006). Globally, conflict caused an estimated 310,000 deaths in the year 2000, more than half occurred in Sub-

Saharan Africa and about 20 percent in South East Asia (WHO, 2001). In 2002 WHO (WHO, 2004) estimated the global burden of disease (including years of life lost and years of life lived with disability directly due to conflict to be 0.7 %, compared to 2.8 % due to road traffic injuries; 1.31 % due to self inflicted injuries; and 1.09 % due to homicide. Modern conflicts are on the increase, affecting the civil population. More civilians are dying or acquiring a conflict-related disability in recent times than during the times of the world wars (Rockhold, 2010).

According to the United Nations (UN) (2006), about 10 % of the world's population, approximately 650 million people, live with a disability. It is further estimated by the UN Development Programme (UNDP) that 80 percent of persons with disabilities live in developing countries while the World Bank says among the world's poorest people, 20 % are living with disabilities. However, between 2.5 and 3.5 million of the world's 35 million displaced persons live with disabilities. Among displaced persons who have fled civil conflict, war or natural disasters, the number with disabilities may be even higher (UNHCR, 2008). The United Nations High Commissioner for Refugees (UNHCR) in partnership with the Protection Cluster Working Group (PCWG) has recognized persons with disabilities (PWD) as a population of concern. Historically, the unique needs of PWD have not been fully identified or addressed. In order to remedy this predicament proactive steps are being taken by the United Nations (UN), Non Governmental Organizations (NGO), and Governmental Organizations (GO) to assess the needs, analyze findings and develop appropriate programming for PWD.

“Too often invisible, too often forgotten and too often over looked, refugees with disabilities are among the most isolated, socially excluded and marginalized of all displaced populations...Yet refugees with disabilities

possess valuable skills, knowledge and experience, and they wish and deserve to be given the opportunity to use them.” Antonio Guterres (UNHCR, 2009).

According to the global burden of disease, it is estimated that by 2030, injury from war and civil conflict, particularly among adults will account for 0.63 to 1.04 % of disability-adjusted life years (DALYs) globally (Pringle & Cole, 2009). These are persons who will continue to face barriers to their participation in their communities and are often forced to live on the margins of society. They often face stigma and discrimination and are routinely denied basic rights such as food, education, employment, access to health and reproductive health services. Many persons with disabilities are also forced into institutions, a direct breach of the rights to freedom of movement and to live in their communities (UN Enable, 2009).

Persons with disabilities represent key target groups in all the Millennium Development Goals (MDGs), yet disability and the concerns of persons with disabilities still remains to be included in MDG processes and mechanisms. Progress made in the achievement of the MDGs could be negatively impacted if people with disabilities are under-represented (Lennox, 2005). Although, governments, global leaders, policy-makers and other stakeholders acknowledge the need for disability-inclusive development, they must be supported in their efforts and be reminded to keep their promises. This can be fully reaffirmed on the International Day of Persons with Disabilities to be held on 3rd December, 2010 and advocated for this purpose to further ensure the full and effective participation of persons with disability in all aspects of societal life and development (Kirsten, 2008) and that disabled persons who have to leave their countries find themselves in particularly disadvantaged situations. Disabled refugees are an extremely vulnerable group and are, therefore, in need of special attention. However, there are no legal instruments at an international level, as such, to protect the rights of disabled refugees. Disabled refugees can

only refer to scattered provisions of conventions, instruments and international humanitarian law (UN Enable, 2003/4).

Humanitarian aid and development discussions often focus on persons of concern. Persons of concern exist in high, middle, and low-income countries. These persons of concern are often delineated as: the poor, children, orphans, older persons, and/or women. Disability is not always manifested in an easily identifiable physical dimension. It can either be physical, sensory, intellectual, and/or mental. It must be realized that a person with a birth injury resulting in spastic athetoid cerebral palsy, a traumatic amputation from a land mine, anxiety disorders associated with posttraumatic stress disorders, the genetic condition Down's syndrome, a spinal cord injury from road traffic accident, or a vitamin A deficiency resulting in blindness are all disabilities and equal in their rights to protection. The United Nations High Commissioner for Refugees (UNHCR) in partnership with the Protection Cluster Working Group (PCWG) has recognized persons with disabilities (PWD) as a population of concern. Historically, the unique needs of PWD have not been fully identified or addressed. In order to remedy this predicament, proactive steps are being taken by the United Nations (UN), Non Governmental Organizations (NGO), and Governmental Organizations (GO) to assess the needs, analyze findings and develop appropriate programming for PWD (Kirsten, 2008).

The ability of refugees to meet the basic needs, such as food, water, and shelter, can be compromised by physical disability, mental or social impairments and loss of support mechanisms especially in the early stages of humanitarian emergency when resources are most scarce (Burton & Breen, 2002). However, their ability to meet basic needs is dependent on their level of physical function after disability. There are many reasons why a person may not be functioning at the optimal level. Subjective complaints are an important component of a general health measure because they relate dysfunction to a specific problem (Kaplan &

Anderson, 1988). Disability is a universally used, yet ambiguous term. Categorizing the level of functional limitation, impairment or disability is confounded by the availability of assistive devices, personal help, cultural expectations and environmental modifications and adaptations (Rockhold, 2010). According to the International Classification for Functioning Disability and Health (ICF), individual's functionality, disability and health are assessed and classified at three levels: impairment of the body function and structures (e.g. missing a leg), activity limitations and participation restriction (e.g. unable to dress oneself or difficulties with interpersonal relations) and the environmental factors (e.g. attitudes or systems and policies (Rockhold, 2010). Refugees from conflict situations are vulnerable to potentially disabling disease because of the conditions during their journeys and in camps (Elwan, 1999). However, the quality of life of these refugees can be assessed not only by the degree of function loss, but also by the level of health care interventions they receive, and the rehabilitation of the physically disabled persons among them.

2.4.3 Quality of life of refugees with disabilities

The conceptualization of health and disability is moving away from diagnosis alone towards a more holistic understanding of the determinants and the consequences of health conditions, framed in terms of disabilities that are experienced at the level of the body, person and the overall social context. A number of approaches have been used to ascertain the quality of life of PWDs but distinct among these are those based on objective characteristics and those based on individuals' perception and experiences (Leduc & Lepage, 2002). Subjective health experiences (quality of life) occur in specific contexts and cannot be divorced from personal and environmental factors, which may differ from one geographical and cultural setting to another (Rockhold, 2010).

The World Health Organization Quality of Life Group (WHOQOL) (1996; 1993) defined quality of life as follows: Individuals perceptions of their position in life in the context of their culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. This is a broad ranging concept, incorporating in a complex way a person's physical health, psychological state, level of independence, social relationships, personal beliefs and relationships to salient features of their environment.

The term 'quality of life' is great in speeches, but when it is given the stature of a research concept; it becomes an uncertain tool unless it is controlled by a precise definition and rigorous discipline in thought and word (Wolfensberger, 1994). This is a concept that has been very difficult to define in the last decade though different researchers have tried to explore its definition based on individual's experiences and expectations following chronic diseases (Abu-El-Noor, 2010). It is in this context that the term 'quality of life' and more specifically "health related quality of life" refer to the physical, psychological, and social domains of health and describes the individual's sense of well being (Preedy & Watson, 2010). It is conceived that although there are different factors that affect quality of life (QOL) (Khawaja *et al.*, 2006; Almedom *et al.*, 2007), patients with similar disease profiles can experience different quality of life (Preedy & Watson, 2010). Quality of life in people with chronic diseases may be reduced because of psychological aspects and, but also because of insufficient treatment or lacking medical care that can lead to the development of complications. Some of the chronic diseases have little debilitating effects themselves, but their complications can be very serious and can reduce QoL substantially (Preedy & Watson, 2010). It is believed that exposure to violence has a direct impact on the quality of life of refugees. Health-related quality of life is strongly reduced as a result of disease or impairment (Elijedi *et al.*, 2006).

There has been a significant number of studies assessing QoL that have been conducted in developed countries, but few studies have assessed QoL among refugees living in camps and how they are affected by chronic illnesses (Disabilities) (Preedy & Watson, 2010). According to Abu-El-Noor (2010), the concept of QoL is a general concept that can be applied to evaluate several dimensions of life. To distinguish between QoL in its more general sense and the requirements of clinical medicine and clinical trials, the term health related quality of life (HRQoL) is frequently used to avoid ambiguity; therefore a major distinction is made between QoL and HRQoL. Although QoL embraces the broader aspects of health such as social, economic and environmental factors, the focus of the study is on the more specific health related quality of life related to the physical health of refugees in refugee camps. Following the various definitions of QoL it can only be concluded that the concept of QoL has a subjective nature since it reflects ones individuals feelings towards his/her own life and that disabilities sustained by refugees reflects experiences and challenges that are personal (Abu-El-Noor, 2010).

According to UNHCR (2006) there are over 1,100 different locations hosting refugees and people in refugee-like situations which were identified in 2006. These included 305 camps with an average population size of 4,800 (UNHCR, 2006). The living conditions in unofficial camps are largely unknown, but are generally characterized by overcrowding, lack of heating and ventilation, lack of piped water and, limited access to toilets and cooking facilities (Zabaneh *et al.*, 2008). Not only have these deplorable conditions in refugee camps led to a lot of chronic diseases due to insufficient water and sanitary services (Cronin *et al.*, 2008). The treatment and management of chronic disease has sometimes been neglected in camp settings (Hafeez *et al.*, 2004). The QoL among refugees is not only affected by living conditions of the refugees, but also by continuing political conflicts and outbursts of war (Giacamen *et al.*, 2007). These are people who can be assisted in coping with past

experiences of trauma that result from war and sometimes torture, and this forms an important aspect of medical care in refugee camps (Stepakoff *et al.*, 2006).

2.5 Health-related quality of life of refugees with disabilities

Literature pertaining to refugees, disabilities and their quality of life will be reviewed in this section. Both qualitative and quantitative approaches have been utilized to assess QoL in refugees. Qualitative studies have recorded experiences of single persons (Aggarwal, 2007). They have also conducted group observations, focus group sessions, narrative studies, and in-depth interviews with refugees (Pavlish, 2007; 2005). Other research has stressed the importance of qualitative approaches in order to capture the very specific situation of refugees (Halabi, 2005). Qualitative approaches also prove useful considering the lack of quantitative instruments validated in these specific populations (Almedom *et al.*, 2007, Makhoul & Nakkash, 2007). However there have been some authors who have defended the use of instruments that have only been validated in non refugee groups and have applied them in their research on refugees (Araya *et al.*, 2007; Shoeb *et al.*, 2007; Willis & Gonzalez, 1998). Most of these quantitative studies were conducted among refugees living in developed countries, with several studies conducted in either Nordic countries or in North America (Blight *et al.*, 2006; Carlsson *et al.*, 2006; Fenta *et al.*, 2004; Lindencrona *et al.*, 2008). A recent systematic review identified 183 studies; among these a total of 125 different quantitative instruments were used to assess health in refugee populations (Holyfield *et al.*, 2002) and these have since been published. Many recent studies use the WHOQOL-BREF, a QoL questionnaire developed under the World Health Organization (WHO) umbrella (The WHOQOL-Group, 1998). The WHO-BREF, which includes 26 items, is a shortened version of WHOQOL-100(100 items). The items are used to construct scores in four domains related

to quality of life (OoL): physical health, psychological health, social relationships, and environmental (WHO, 1996).

Quality of life is one of the most widely used terms in modern vocabulary of health professions (Draper, 1997), research methods (Brown, 1998), health economics (Revicki *et al.*, 1998) and health services management (Kernick *et al.*, 2000). It refers to a person's holistic evaluation of satisfaction with his own life in areas (domains) that one considers to be important (Swigris *et al.*, 2005). It is a broad concept affected in a complex way by the person's physical health, psychological state, and level of independence, social relationships and relationships to salient features of his/her environment (WHO QOL Group, 1993). According to Fisch *et al.*, (2003), this is a multidimensional concept that focuses on how disease and its treatment affect the individual. It has evolved to become an important concept in refugee health issues. HRQoL questionnaires (or instruments) characterize and measure what subjects experience as a result of their receiving medical care (Staquet *et al.*, 1998). Quantitative research methods involving clinical trials are used in the measurements of quality of life to evaluate the effectiveness of the various forms of medical interventions. This is an approach that generates numerical data and tends to favour research methods as it relies on physical characteristics rather than qualitative well-being of the participants (Draper, 1997). Furthermore in addition to relieving clinical symptoms and prolonging survival, a primary objective of any healthcare interventions is the enhancement of quality of life and well being. Circumstances which contribute to this premise include the ageing of the population and the increasing prevalence of chronic diseases. However for those individuals diagnosed with a chronic condition where cure is not attainable and therapy may be prolonged, quality of life is likely to be the essential outcome (Staquet *et al.*, 1998).

There has been a significant interest in measuring health status from the patient's point of view (Jenkinson & McGee, 1998). Health-related quality of life represents the effects of an

illness and its treatment as perceived by patients. The concept is being used in treatment effectiveness research as a primary outcome measure to provide insights into the subjective aspects of health, as well as clinical practice. Health-related quality of life is applied to patients with clear cut manifestation of disease and that a minimum of five attributes need to be considered: physical function, social functioning, emotional and mental status, burden of patients of symptoms and perception of well being (Draper & Thompson, 2001). Hence, this patient-based instrument provide assessment of important aspects of the patient's experience of his/her health problems in areas such as physical function (e.g. mobility, self care); emotion function, social function (e.g. social contacts, social support); role performance (e.g. work, house work), pain and fatigue. The most important is that assessment covers those areas considered most relevant to the patient and the illness (Guyatt *et al.*, 1993). HRQoL can be assessed with health profile (descriptive) questionnaires that are either generic or specific. A health profile instrument denotes a health status questionnaire that which measures by means of similar metric, different aspects of health related quality of life and well being defined across multiple health domains or areas (for example physical function, emotional distress, social well being) that the patient has identified as being important. Generally, each domain is represented by a separate scale and the calculation of data from each scale produces a separate numerical value (or score) that usually is unweighted. Both generic and specific health profile instruments have advantages and disadvantages and must be evaluated within the context of the needs of the particular study. Generic instruments allow comparisons to be made across conditions and interventions, but may not focus adequately on the area of interest for a specific intervention. Specific instruments are likely to be more responsive to change, but are not comprehensive, do not allow across-condition comparisons and may not be available for certain populations or interventions. These measures are designed to assess specific disease states, areas of function or patient populations. Specific

measures continue to be generated (Staquet *et al.*, 1998). The World Health Organization (WHO) has identified immigrants living in stressful situations as one of the five priority groups in an international Quality of life (QOL) assessment and has developed a WHOQOL instrument (Orley & Kuyen, 1994).

De Vries and Van Heck (1994) posited that the perceived quality of life of refugees has not been assessed adequately and that essential disabilities suffered by refugees can be grouped under the following categories: Powerlessness as a result of being alien to social and economic environments (Khawaja *et al.*, 2006), physical and psychological toll on individuals, which has immediate and long term consequences for their capacity of the subgroups to re-establish viable production units and loss of property (Mikolajczyk *et al.*, 2010).

Many studies have assessed health including mental health and QoL of life, among refugees living in developed countries, after having received asylum. Most of these studies were conducted in specific populations, assessing a single group of refugees from a given country. For example several studies in Sweden have focused on refugees from Bosnia, after the war in former Yugoslavia in the early 1990s. Earlier studies were conducted among refugees living in the USA, after the war in Vietnam. But what many population based-studies on adult refugees and asylum seekers living in Western countries have highlighted is so much on the report concerning the prevalence of mental health problems, which mainly concern symptoms of PTSD, depression and anxiety but only a few have investigated the general health status and or physical problems of the refugees (Gerritsen *et al.*, 2006), more especially disabilities sustained during trauma and the impact they have on their quality of life. The health of refugees and other displaced people is a priority for UNHCR. Article 12 of the International Convention on Economic, Social and Cultural Rights (WHO, 1966), stipulates that everyone has a right to the highest standards of physical and mental health.

People seeking refugee status are not a homogeneous population but coming from different countries and cultures, they have had in their own and other countries, a wide range of experiences that may affect their health (Health Needs of Asylum Seekers, 2008). The Ottawa Charter for Health Promotion (1986) advocates that good health is a major resource for social, economic and personal development and an important dimension to the 'quality of life'. Post traumatic experiences of refugees are so immense that it is only advisable that the impact on their quality of life is measured (Eisenman *et al.*, 2003).



CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter outlines the methods used to carry out the present study. A description of the research setting, study population and sample are given. The chapter also describes the research instrument used and the procedure followed. Finally the ethical considerations are also outlined.

3.2 Research setting

Zambia is a landlocked country surrounded by eight neighbouring countries: Angola, Botswana, Congo Democratic Republic (DRC), Malawi, Mozambique, Namibia, Tanzania and Zimbabwe. Refugee settlements in Zambia are found in six of the nine provinces of the country and these include Mayukwayukwa and Mayeba in North-Western province, Kala in Luapula province, Mwanze in the Northern Province, Nangweshi in the Western province and Ukwimi in the Central province. Only Copperbelt, Eastern and Southern provinces are not populated by refugees. Approximately 54 % of the refugees live in refugee settlements and 5 % in urban areas, while the rest have settled spontaneously in different parts of Zambia (UNHCR, 2008). The total number of refugees in Zambia is 88,457. These refugees are of different nationalities: 18,932 refugees from Angola, 517 refugees from Burundi, 36,114 refugees from Congo Democratic Republic, 2,883 refugees from Rwanda, 107 refugees from Somalia and 17 refugees from Uganda. The total number of encamped refugees in Zambia is 58,585. Kala camp has 15,598 refugees, Mayukwayukwa has 10,395 refugees, Maheba has

15,372 refugees, Mwanze has 17,220 refugees and urban refugees are reported at 4,539 (Zambia Refugee Population, 2008).

The research setting is Mayukwayukwa refugee camp which is one of the oldest refugee camps in Zambia. It was established in 1966 and it is 72 km away from Kaoma district in the Western Province of Zambia. The settlement is divided into three zones consisting of fifty three sectors. In each sector there is a chairperson, secretary and committee members. They are elected through a ballot and the elections are organized by UNHCR office. The term of office is two years. Most of the refugees in this area are subsistence farmers but as the soil conditions in the area are less favourable, many refugees have to walk some distance to their plots. The settlement features a basic school, clinic, a well-equipped workshop, and two guest houses. According to UNHCR (2008), the Mayukwayukwa camp has the highest prevalence of refugees in Zambia with physical disabilities. On the whole, an estimated 2,500 refugees in this camp have disabilities accounting for 25 % of the total number of refugees.

3.3 Research design

A cross-sectional descriptive study design using a quantitative approach was employed to carry out the research. This is an approach that generates numerical data and tends to favour research methods as it relies on physical characteristics rather than qualitative well-being of the participants (Draper, 1997). The design is normally a non-experimental but rather one which makes enquiries about individuals, groups or situations, natural tendencies and the rate at which these are repeated (Polit & Hungler, 2001). Therefore, enquiries were made about the health-related quality of life of refugees with disabilities and how these compromise their health-related quality of life and levels of physical function. Manasseh (2001) highlighted the

delivery of care services such as health and education, and further evaluated the benefit of these services from a descriptive study perspective.

3.4 Study population and sample

The study population comprised of male and female refugees with disabilities with an average age range of 18-65 residing in Mayukwayukwa refugee camp. Out of the six refugee camps, Mayukwayukwa refugee camp was chosen as the best possible camp to carry out the research study because it has been reported by the UNHCR office in Zambia as the camp with the highest number of refugees with disabilities. The required sample size was calculated with Yamane's formula, $n = N / (1 + N(e)^2)$ where N = Study population; n = Study sample; e = constant which is given as 0.05 (Israel, 1992). A sample size of 340 participants was deemed to be appropriate according to the above formula.

In Mayukwayukwa refugee camp, the UNHCR local office uses the food ration register as the population register which specify the age, gender, country of origin and refugee numbers throughout the fifty three sectors. However, refugees who do not collect food are omitted from the ration list. Therefore, to ensure that all refugees had an equal opportunity to participate in the study, the assistance of chairpersons of the 53 sectors were sought. The chairpersons informed and invited all refugees with disabilities in their respective sectors about the study. All interested refugees met at a particular point in each sector. Approximately 400 refugees attended the meeting and were approached to participate in the study. Of these 345 voluntarily agreed to participate in the study. Due to language barriers, 31 were excluded, thus the final sample consisted of 314 refugees with disabilities.

3.5 Data Collection Methods

Data was collected by means of self-administered or interview administered questionnaires.

3.5.1 Research Instruments

Two different self-administered instruments were used to collect data. The first instrument, WHOQOL-BREF which is an abbreviated version of the WHOQOL-100 was developed by the World Health Organization (WHO) to assess quality of life (WHOQOL, 1998). This is an instrument whose psychometric properties were evaluated using cross-sectional data from 23 countries (n = 11,830) (Laban *et al.*, 2008). This instrument is available in 19 different languages and is self-administered if participants have sufficient ability but can also be interviewer-assisted or interview-administered. The instrument is made up of two sections: in the first section, information such as gender, age, educational level and marital status are required while the second section is made up of twenty-six items assessing perceived health-related quality of life. Four domains assessed with the instrument include physical health, psychological, social relationships and the environment. These domains were assessed with Likert-type questions ranging from not at all (1) to an extreme amount (5).

The second instrument, the FSQ measures the level of function and it is a brief, standardized, self-administered questionnaire designed to provide a comprehensive and feasible assessment of physical function. Physical function or activities of daily living (ADL) can be divided into two: basic and intermediate. Under basic ADL, the ability to carry out physical functions like eating, dressing and bathing; moving in and out of a bed or chair; and walking around the house are considered. However, the intermediate ADL involves being able to carry out activities such as walking several blocks; climbing one flight or one flight of stairs; doing maintenance work around the house; errands such as grocery shopping; and driving a car or being able to use public transport (Jette *et al.*, 1986).

3.5.2 Reliability and validity of the instruments

Validity is the capacity of the assessment tool to measure what it is intended to measure (Silverman, 2000) while reliability is the ability of the assessment tool when repeated measurements are taken under constant conditions to give same results (Bless & Higson, 2000). The WHOQOL-BREF instrument has undergone extensive field testing. This instrument's cross-cultural validity and reliability has been tested and retested by WHO in several studies (Skevington *et al.*, 2004). Analysis of internal consistence, item-total correlations, discriminant validity and construct validity indicate that the WHOQOL-BREF has good to excellent psychometric properties and performs well in preliminary tests of validity and results show that overall, the WHOQOL-BREF is a sound, cross-culturally valid assessment of QoL (Laban *et al.*, 2008). The Functional Status Questionnaire (FSQ) is an internationally used instrument and translated into Swedish, French and German. This is an instrument whose reliability and validity has been tested and retested in different populations including assessment of the impact of variations in hospital practice patterns, the study of relationships between hospital process of care and outcomes, and randomized controlled trials of pharmaceuticals (Cleary & Jeff, 2000). The scales testing basic and intermediate ADL had internal consistence reliabilities of 0.79 and 0.82 respectively (Jett *et al.*, 1986)

For a better understanding of the instrument, the WHOQOL-BREF was translated into the targeted language maintaining as far as possible the conceptual, semantic and technical equivalence between the target language and the source language (English) version of the instrument (Sartorius and Kuyken, 1994). In situations where versions are not the same as the original questionnaire, translations were redone to ensure that all versions are the same and hence, possible loss of content validity was eliminated. For the purpose of this study and considering the fact that participants are from Angola who are Mbunda speaking, the WHOQOL-BREF and FSQ were translated from English to Mbunda for both research

assistants and participants. Furthermore these were then back –translated into English to make sure that the content is the same. To further ensure validity of the instrument, a pilot study was conducted among ten refugees with disabilities from the Lusaka District Refugee Centre and more especially, those receiving services from the orthopedic centre at the University Teaching Hospital, Lusaka. These were refugees being referred for prosthetic fitting and rehabilitation from refugee camps hence, had the same characteristics to those of the main study. The pilot study was done to ensure there was no possible loss of content validity after possible translations of the instruments and to measure the length of time participants required to complete the questionnaire. Thereafter, the participants were then invited to give feedback on their understanding and clarity of the questionnaire.

3.6 Procedure

After obtaining ethical clearance from the University of the Western Cape Senate Research Grants and Study Leave Committee, ethical approval was also sought from the Zambian Ministry of Health and the University of Zambia’s Research ethics committee (APPENDIX B). In addition, permission to conduct the study was obtained from the Director of Kaoma General Hospital. A meeting was held with UNHCR officials and respective chairpersons in charge of various sectors on how to recruit participants. Nine social workers were recruited and trained as research assistants, their role in the study; the aim and the nature of the study as well as the ethical issues were explained. The study sample consisted of refugees with disabilities from the different sectors (52) of the refugee camp. The refugees were introduced to the study through various chairpersons of the camp. They were approached and invited to take part in the study at a meeting convened by the chairpersons of the sectors. The aims and objectives of the study were explained. All subjects who volunteered to participate in the

study provided written informed consent. The researcher and research assistants completed the FSQ and WHOQOL-BREF with participants either on the day of the meeting or arranged times afterwards.

3.7 Data analysis

Descriptive statistics was used to analyze data which were expressed as frequencies, percentages, means and standard deviations. Inferential statistics was employed to check for associations between socio demographic variables, quality of life and level of function. The WHOQOL BREF (1996) has four domains and results in a raw score for each domain. Using the WHO guideline, these scores can be transformed or rescaled on a 0-100 scale. The scaled variables are denoted by WHO1-WHO4. The raw scores were then used for analysis exploring the question of relationships among variables since it has a larger set of possible outcomes (e.g. 29 different outcomes on the raw score scale 1 gets modified to 17 different outcomes on the transformed scale). The factors that were assessed included gender, age, educational level, and marital status, diagnosis (types of disabilities and level of physical function). Marital status was condensed to two levels (married/living together or single/divorced/separated/widowed). These factors' associations with HRQOL was assessed one at a time by examining associations and thereafter, were assessed via a multiple predictor setting. This was only necessary in the event of evaluating more than one significant factor singly.

Since the variables of interest were ordinal in nature, using non-parametric methods such as Spearman Rank Correlations or Kruskal-Wallis test to compare groups was deemed appropriate. The analyses were done using the Statistical Package for Social Sciences Version 18 software (SPSS). The four domain scores denote individual's perception of

quality of life in each particular domain. The domains scores are scaled in a positive direction i.e. higher score denote high quality of life. The mean score of items within each domain was used to calculate the domain scores. Chi-square was used to check for significance while α -level was set at 0.05. As earlier noted, the FSQ physical function instrument's two subscales were used: the basic ADL (3 items) and the intermediate ADL (6 items). These are scaled up according to response rates ranging from 0 point (usually did not do for other reasons) to 4 points (usually with no difficulty). In cases where the scores are transformed, transformed scale values range from 0 to 100, with a score of 100 indicating maximum functional ability. The items were scored by using an algorithm and summarized into disability index scores (Jette *et al.*, 1986). Scores falling below 88 on the basic ADL and below 78 on the intermediate ADL were considered to fall in the warning zones, i.e. reduced ability to perform ADL.

3.8 Ethical Considerations

Ethical clearance was obtained from the Senate Research Grants and Study Leave Committee at the University of the Western Cape and the Ethics Committee at the University of the Zambia. Permissions were also granted by the Ministry of Home Affairs for the involvement of refugees through the Commissioner for refugees, the Ministry of Health for welfare of the refugees and the World Health Organization for using the research instrument. Participants gave their informed consent to participate in this study. The study was conducted in the following manner: all participants received the information sheet and consent form. The information sheet explained the purpose and nature of the study, gave assurance of anonymity, confidentiality and the right to withdraw from the study if they wished, without any consequences. Counseling services were made available to participants if needed. A

final copy of the research report will be distributed to the University of the Western Cape, the
Zambian Ministries of Health and the Department of Home Affairs.

3.9 Summary

In this chapter the methods used to meet the research objectives were outlined. The procedure
and an explanation of the research instruments used were given. A brief explanation of the
data analysis procedure was also given. In the next chapter the results of the data analysis will
be presented.



CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter will present the analysis and contextualize the demographic profile of the participants. The health related quality of life as well as level of physical function and factors predictive of them are also presented. The results are complimented with graphs and tables.

4.2 Profile of refugees with disabilities

The study sample consisted of 314 participants who took part in the study. The minimum age of the participants was 18 while the maximum age was 80. The mean age of the study sample was 49.45 (SD=11.73). The study population comprises of 83% males (n=252) and 16% females (n=52) as outlined in table 4.1. The highest level of education attained by most participants was primary school education (59.7%) and no education at all (30.7%). More than half (58.3%) were either married or lived with a partner.

Table 4.1 Profile of study sample (n=314)

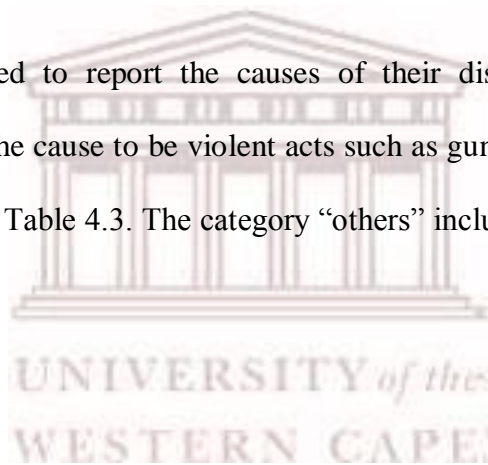
Variables	Frequency (n)	Percentage (%)
Gender		
Male	262	83.4
Female	52	16.6
Education		
None at all	96	30.7
Primary school	187	59.7
Secondary school	29	9.2
Tertiary	1	0.32
Marital status		
Married/living with partner	183	58.3
Single/living alone	126	40.1
Missing	5	1.6

Participants also reported on their level or type of disability. Most of the participants (68.8%) had a lower limb disability as illustrated in table 4.2. The category “other” included hip and ankle disarticulations and dropped foot.

Table 4.2 Types of disabilities among study sample (n=314)

Type of disability	Males	Females	Total
U/L Disability	27	3	30 (9.6%)
L/L Disability	187	29	216 (68.8%)
Both U/L & L/L	20	4	24 (7.6%)
Peripheral neuropathies	4	2	6 (1.9%)
Others	24	14	38 (12.1%)
Total	262	52	314 (100%)

Participants were requested to report the causes of their disability. The overwhelming majority (88 %) reported the cause to be violent acts such as gun shots, landmines and bomb explosions as illustrated in Table 4.3. The category “others” included stroke, tuberculosis and road traffic accidents.

**Table 4.3** Causes of disabilities among study sample (n=314)

Causes	Frequency (n)	Percentage (%)
Gunshots	42	13
Landmines	181	60
Bomb explosions	54	17
Others	37	10

4.3 Physical function of study sample

The physical function score for the study sample was determined. These included physical function related to basic ADL and intermediate ADL. The standard deviations of the mean overall transformed scores for the study sample were 43.9 (basic ADL) and 26.6 (intermediate ADL). These transformed scores for each domain are illustrated in table 4.4. Males had slightly better scores for basic ADL than females but these differences were not statically significant ($p>0.05$).

Table 4.4 Mean (SD) physical function score of study sample (n=314)

Physical function	Males	Females
Basic ADL	44.1 (23.6)	42.9 (24.9)
Intermediate ADL	26.0 (13.8)	29.5 (13.5)

The mean physical function score for each type of disability was also determined. The highest scores for basic ADL was found for “others” types of disabilities and for intermediate ADL was found for peripheral neuropathies. No significant differences was found between types of disability ($p>0.05$). These scores are summarized in Table 4.5.

Table 4.5 Mean (SD) physical function score by level of disability (n=314)

Level of Disability	Basic ADL	Intermediate ADL
U/L Disability	44.3 (23.4)	27.8 (13.4)
L/L Disability	43.7 (23.9)	25.5 (13.5)
Both U/L and L/L disability	44.4 (21.2)	30.6 (15.3)
Peripheral neuropathies	44.4 (34.4)	33.3 (14.9)
Others	45.6 (25.0)	28.5 (13.4)

A significant relationship was found between the basic ADL scores and the physical health (domain 1) of the health related quality of life of the study sample ($p < 0.05$) as highlighted in table 4.6.

Table 4.6 Bivariate correlations between physical function and HRQOL (n=314)

Variable	Physical Domain	Psychological Domain	Social Domain	Environmental Domain
Basic ADL	0.114*	0.106	0.068	0.050
Intermediate ADL	-0.006	0.070	0.010	-0.064

* Significant at $p < 0.05$

4.4 The health related quality of life of refugees with physical disabilities.

As part of the HRQOL instrument, participants were requested to rate their quality of life. More than half (54.8%) of the participants rated their quality of life as very poor or poor, while 37.3% rated it as neither poor nor good.

Furthermore, the mean (SD) for the 4 domain scores of the WHOQOL-BREF were calculated for the study sample. These scores (raw) for each domain are illustrated in table 4.7.

Table 4.7 Mean (SD) raw domain scores of WHOQOL-BREF for study sample (n=314)

Domain	Mean (SD)
Physical health	18.6 (3.4)
Psychological	17.8 (3.2)
Social relationships	11.4 (2.4)
Environment	19.5 (3.9)

The raw scores of the HRLQOL were then transformed to a 0-100 scale as recommended by the WHO guidelines and these scores are illustrated in table 4.8.

Table 4.8 Mean (SD) transformed scores of WHOQOL-BREF (n=314)

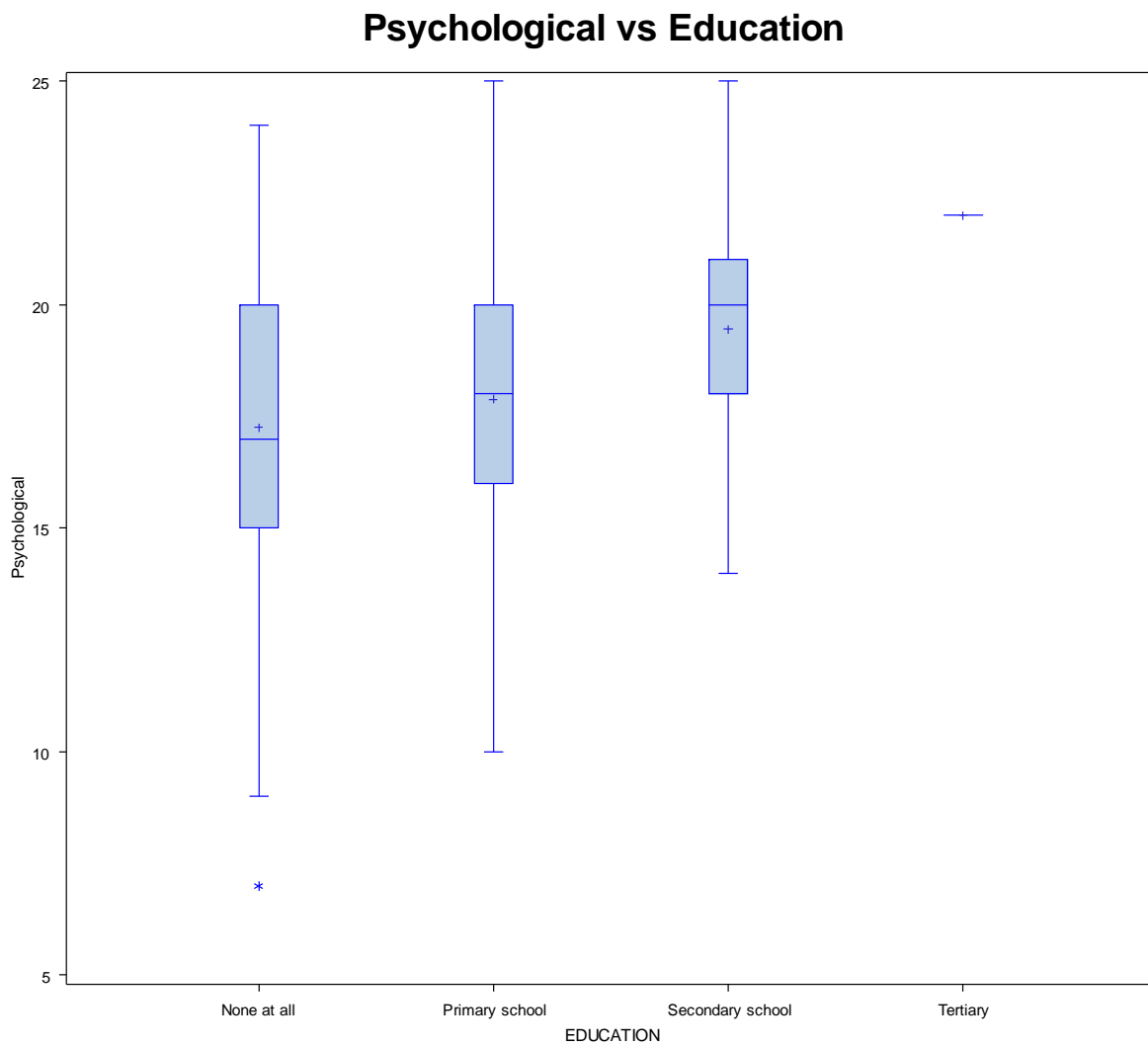
Domain	Means (SD)
Physical health	41.4 (12.3)
Psychological health	49.4 (13.6)
Social relationships	70.0 (20.6)
Environment	37.7 (12.4)

The impact of various factors on HRQOL such as gender, marital status, education and level of disability was examined. Since the variables are ordinal in nature, Spearman Rank Correlation and Kruskal-wallis tests were used to compare groups. Table 4.9 summarizes the results of these analyses. The only relationships of significance was found to be between education and domain 2 (psychological domain) and 3 (social domain) and between gender and domain 3 (social domains). After combination of secondary and tertiary education for further analysis, a weak relationship was found between domain 3(social domain) and education too as illustrated in table 4.9.

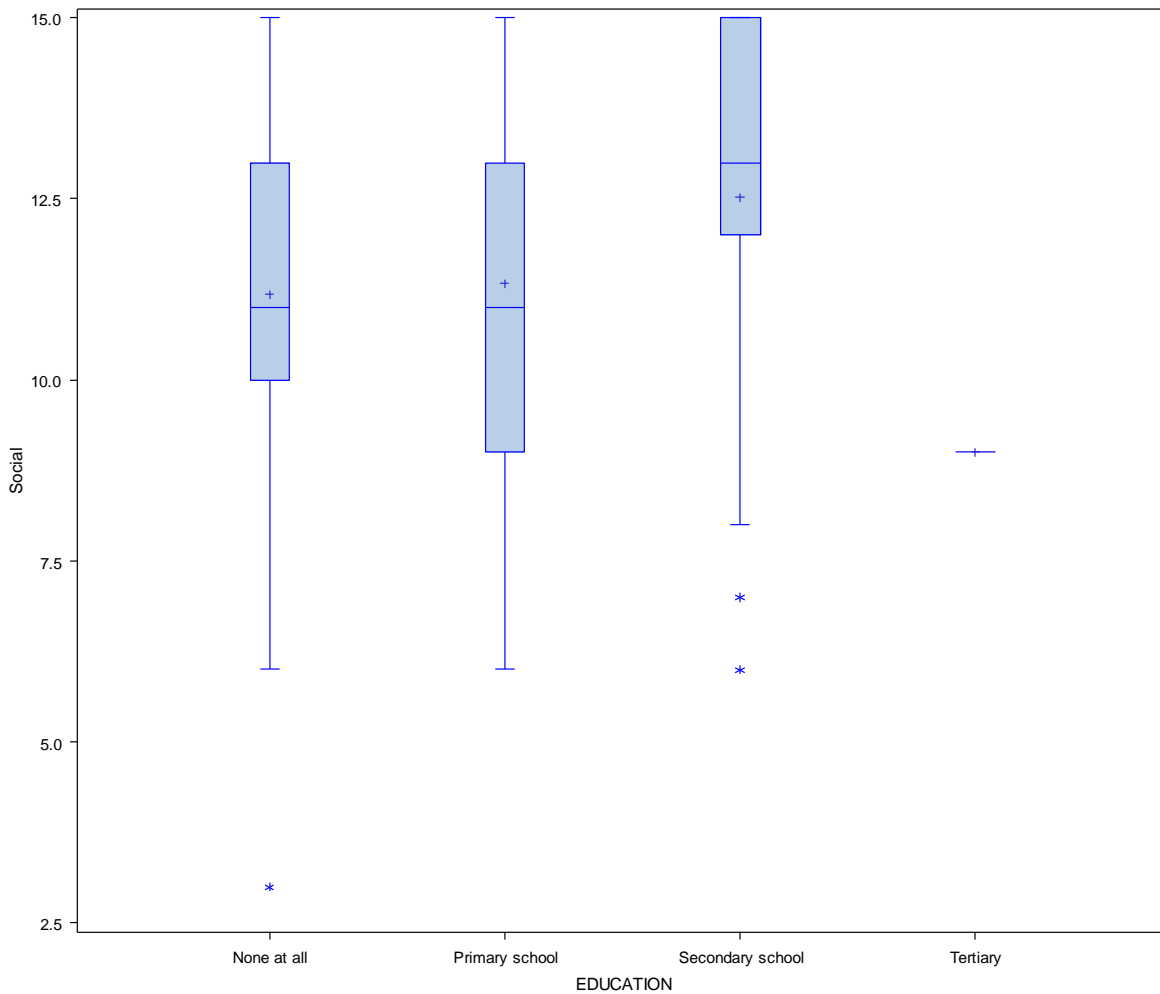
Table 4.9 Factors associated with HRQOL of the study sample (n=314)

Variable	Physical Domain	Psychological Domain	Social Domain	Environmental Domain
Gender				
Male	18.6 (3.4)	17.9 (3.1)	11.5 (2.3)	19.6 (3.8)
Female	18.0 (3.6)	17.5 (3.6)	10.5 (2.9)	19.1 (4.5)
p-value	0.327	0.628	0.032	0.518
Marital status				
Living alone	18.7 (3.4)	17.7 (3.2)	11.2 (2.4)	19.6 (4.1)
Living with partner	18.4 (3.4)	17.8 (3.2)	11.4 (2.4)	19.5 (4.1)
p-value	0.414	0.627	0.475	0.874
Education				
None at all	18.5 (3.5)	17.2(3.2)	11.1 (2.4)	19.3 (3.7)
Primary school	18.4 (3.3)	17.8 (3.1)	11.3(2.3)	19.4 (4.1)
Secondary school	19.6 (3.4)	19.5(2.9)	12.4 (2.5)	20.1(3.3)
p-value	0.637	0.0022	0.032	0.262
Levels of disability				
U/L disability	18.9 (2.9)	18.1 (2.5)	11.7 (2.2)	19.1 (3.9)
L/L disability	18.7 (3.4)	17.8 (3.2)	11. (2.36)	19.6 (3.9)
Both U/L and L/L	17.9(3.4)	17.7 (3.1)	11.4 (2.1)	18.9 (3.7)
Peripheral neuropathies	18.0 (5.0)	18.5 (2.8)	11.8 (2.6)	22.8 (4.5)
Others	18.0 (3.6)	17.5 (3.4)	10.6 (3.1)	19.1 (4.2)
P-value	0.803	0.909	0.597	0.317

Box plots to further illustrate the association between education and the psychological domain (fig 4.1) and education and the social domain (fig 4.2) are shown below.



Social vs Education



4.5 Summary

This study aimed to describe the profile of refugees with disabilities living in a refugee camp in Zambia. It further aimed to determine the physical function and health related quality of life of these refugees. Physical function of the sample was found to be low. Education was significantly associated with the psychological and social domain of HRQOL. The next chapter will discuss these findings.

CHAPTER FIVE

DISCUSSION

5.1 Introduction

The purpose of the study was to describe the profile of refugees with physical disabilities living in Mayukwayukwa refugee camp in Zambia. The study further aimed to establish the levels of physical function, HRQOL and the factors associated with these among these refugees. This chapter discusses the findings of the current study and compares the findings with similar published studies.

5.2 Profile of refugees

Various researchers and organizations have alerted to the huge refugee crisis and the associated public health concerns (UNHCR, 2009; Stebleton, 2007; Wills & Levy, 2000). Furthermore, researchers have highlighted the high levels of exposure to violence and the related mental health problems among this group (Marshall *et al.*, 2005; Eisenham *et al.*, 2003). The present study is evidence to the high levels of exposure to violence as almost 90 % of the study sample reported the cause of their physical disability as an act of violence, such as gun shots, landmines and bomb explosions. This is a cause of concern as it is well documented in literature that post traumatic stress disorder is common among refugees who have been exposed to violence (Marshall *et al.*, 2005). These problems of violence are common among poor countries including Africa (Karunakara *et al.*, 2004). Mussi (2004) indeed stated that many communities; especially in Africa, Asia and Middle East continue to be afflicted by chronic war-conflicts with massive traumatization among various populations.

Rasmussen *et al* (2007) asserts that post traumatic stress disorders are experienced among refugees in African refugee camps. Stalnacke and Ostman (2010) highlighted the major symptom clusters associated with post-traumatic stress. Some of the other symptoms frequently experienced highlighted by these authors included tiredness, dizziness, irritability and lower ability to concentrate. Health care professionals dealing with refugees and more specifically those that have been exposed to severe violence should take cognizance of these facts as it will influence the rehabilitation progress of these individuals.

Kamau (2004) noted that many refugees end up living in refugee camps or other insecure settings in low-income countries. The sample of the current study was chosen from one of six refugee camps in Zambia, mostly coming from poor conflicted countries. In his analysis of refugee camps and cities, Kagwanja (2000) described camps being viewed as transient settlements, reflecting the temporary nature of the refugee phenomenon. Kagwanja (2000) however notes that some camps have been in existence for years and they resemble real cities when looking at their population and density. The research setting of the current study, Mayukwayukwa refugee camp in Zambia is one of the oldest refugee camps in Africa which has become home to many of these refugees, is evidence to Kagwanja's (2000) statement. As noted in Chapter 3, this camp was established in 1966 and features a basic school, clinic, a well-equipped workshop, and two guest houses.

The majority (90.4%) of the study sample had either no education or only primary school education. This is similar to high illiteracy rate of Cambodian refugees found by Marshall *et al.* (2005). Illiteracy has been linked to mental health problems among refugees. Health care professionals, including physiotherapists, should be aware of this and take it into

consideration when dealing with refugees. Gard (2007) stated that a psychosocial approach for treatment should be considered when dealing with refugees or persons who have experienced torture. He further states that attention should be paid to various factors when planning treatment for refugees and persons who have experienced torture. These factors include knowledge about general health, torture, depression, posttraumatic stress disorder, anxiety, migration history, social support and socio-economic status.

It was noticed that in this study the majority (83 %) were male participants. Although a much higher percentage than that of Eljedi *et al.*, (2006) the latter also had more males (52.8%) than females (47.2%) in their study on refugees in the Gaza strip. The inference to this could be due to the fact that though these two study samples have different disease burdens, they both share a background of conflict in nature. This could reflect that many males are still engaged in combat activities or had managed to flee to safer places in fear of reprisals by the victors, leaving behind their spouses and children. However, women are more susceptible to harm and abuse in environments racked by violent conflicts whether or not they are engaged in the conflict. Whereas more females were prone to a lot of disease burdens (Eljedi *et al.*, 2006), this significantly differs with our present study, which found more males were prone to disabilities, more especially lower limb disabilities. A fact which could be attributed to causes of injuries in conflict affected situations.

5.3 Level of physical function of study sample

Researchers have shown that poor physical function is characteristic of physical weakness (Castaneda-Sceppa, Price, Noel, Midle, Falcon & Tucker, 2010). Researchers have also alerted to the importance of physical function as a construct in determining functional

independence as well as functional performance in carrying out both basic and intermediate ADLs (Spiriduso et al., 2005). Jette et al., (1986) further alerted to the importance of screening for disability and clinically monitoring meaningful change in function and to be aware of the full extent of a patient's functional ability as this plays a role in shaping their quality of life. The physical functioning subscales of the Functional Status Questionnaire (FSQ) (Jette et al., 1986) were used to describe the degree of physical disability in the sample.

In this study, the sample shows poor physical function indicating an inability to maintain independent living status. This was shown by the mean scores for basic ADL of 43.9 and 26.6 for intermediate ADL. Both these scores were found to be in the "warning zone" as defined by Jette et al. (1986) representing problems with physical function. The findings of the present study are much lower than that of Kalpackjian and Lequerica (2006) who reported basic ADL scores of 79.8 and intermediate ADL scores of 48.7 among a study sample of women with physical disabilities. The much lower mean scores of the present study shows that refugees with disabilities are less able to perform both basic and intermediate ADL. From a clinical point of view Kalpackjian and Lequerica (2006) suggested that functional status should be increased through evidence-based rehabilitation practices. These authors further suggest that individuals with such low functional status scores must be shown new ways of performing ADL effectively and possible use of assistive devices. These are points that should be taken into consideration when planning rehabilitation strategies at the refugee camp. However, in situations such as the refugee camp of the current study, assistive devices might be considered too expensive with the limited resources available at these camps.

Very low mean scores (26.6) for intermediate ADL was found in the present study. Two possible reasons for this could be true in this case. The low scores for intermediate ADL could possibly be attributed to the living situation in the refugee camp. On this sub-scale of the FSQ, items included refer to walking several blocks, climbing stairs and making use of public transport. All of these are questionable activities in normal day-to-day living in a refugee camp. Recognizing the environment in which initiation and progression of physical functioning limitations occur is essential in understanding these limitations. The World Health Organization (WHO) acknowledges the centrality of the environment when it defines activity limitations as “problems in activity that occur as a result of an interaction between a health condition and the context in which the person exists.

On the other hand these low scores could also be related to the severity of the physical disability of the study sample. The FSQ is a self-report measure and not a performance-based measure. Researchers have warned that self-report measures such as the FSQ measures an individuals’ perception of their ability to perform a task whereas performance-based measures observe this ability (Brach, Van Swearingen, Newman & Kriska, 2002). It is therefore questionable if this sub-scale of the FSQ is the best way to measure intermediate ADL in refugees with physical disabilities.

5.3 Health related quality of life of study sample

Preedy & Watson (2010) alerted us that quality of life has become a very important concept in the last decade. These authors further explained that the term health related quality of life refer to the physical, psychological and social domains of health of an individual. Jelsma, Mkoka and Amosun (2008) however warned that health related quality of life is very

subjective in nature and therefore making the assessment thereof very complex. There are numerous tools available that are used to evaluate health related quality of life among populations. Jelsma et al. (2008) alerted to the fact that most of the tools available were developed within a North American and European context making it difficult to use in the African context. The WHOQOL-BREF however has been used in both developed and developing countries, including Africa, in different population groups (Skevington et al., 2003). In addition the WHOQOL-BREF has also been used in assessing quality of life among refugee populations in refugee camps (Preedy & Watson, 2010) and was therefore adopted for use in the present study.

Few studies have assessed quality of life of refugees in camp conditions worse still refugees with disabilities (Preedy and Watson, 2010). Preedy and Watson (2010) further suggest that camp experiences as well as chronic diseases affect quality of life of encamped refugees. Disability remains one of the most challenging yet one of the most researched issues among the medical health problems. It is challenging due to the physical and psychological impact that it poses on the human being. The situation is worse for refugees with disabilities whose health related quality of life is compromised by functioning and health more especially in refugee camps.

This health related quality of life of the study sample was assessed in four domains, i.e. the physical, psychological, social relationships and environmental domains. The physical health domain encompasses the concept of performance status, which can be defined as the functional capacity of an individual. According to Skevington (2002) this is the domain that assesses the impact of the disease on the activities of daily living, dependence on treatment,

restricted mobility and the ability to work. In our study the mean raw score of the physical domain score was 41.1. This is similar to the mean raw score of 36.7 reported by Eljedi et al. (2006) among refugees with diabetes in the Gaza strip. In the study of Eljedi et al. (2006) the inclusion of a control group without diabetes showed strong effects of the disease on health related quality of life. In the current study however, no significant effect was found between health related quality of life and different disabilities. This could have been different if a control group of refugees without disabilities were included in the present study. Preedy and Watson (2010) however are of the opinion that the injuries or disabilities resulting from the refugee experience may have little impact on their quality of life.

In this study we found a high correlation effect between the physical domain of HRQOL and physical function (0.1114). Similarly Kalpakjain and Lequeric (2006) in their study found similar correlation between QOL and functional status. The lower the functional status, the lower QOL is expected to be. Our study sample experienced low scores in both dimensions of ADLs. However the differences in the scores could be attributed due to the environmental barriers in a camp situation following more demanding self-care activities experienced at Intermediate level of ADLs. Activities in these scales could be extremely difficulty in camp situations as compared to self care ability. The clinical implications to this are participation restrictions due to reduced physical functioning and compromised health related quality of life.

The psychological domain evaluates the individual's inner thoughts about his or her own image in terms of appearance, self esteem, personal beliefs and negative feelings (Skivengton, 2002). The mean raw score for the psychological domain for the study sample

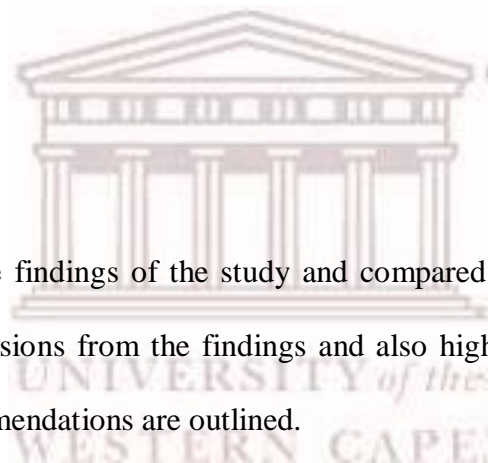
was 49.4. This was somewhat higher than the mean raw score (34.8) of that reported by Eljedi et al. (2006). In the present study a significant relationship was found between education and the psychological domain. Again this differs from the findings of Eljedi et al. (2006) who found no relationship between education and the psychological domain of HRQOL. It could thus be said that lack of education affected the participants of the present study psychologically. The difference between the present study and that of Eljedi et al. (2006) is that the study sample of this study had very low levels of education whereas 20 – 30% of those reported by Eljedi et al. (2006) had a tertiary education.

The social domain focuses on an individual's social contacts family support and ability to look after the family as well as sexual activity (Skevington, 2002). The mean raw score for the social domain of the present study sample was found to be 70.1. This was the highest score among the four domain scores. Comparatively the same situation was found to be the case in the study by Eljedi *et al.*, (2006). The only possible explanation could be that this is the result of the social networks that are created in the camp environment when staying in this environment for a long time. Preedy & Watson (2010) assert that stabilization and establishments of new social structures strengthens social relations among refugee populations in refugee camps. The other contributing factor to enhancement of social relations is the period of stay in a particular refugee camp. Some of the participants in our study sample stayed in Mayukwayukwa refugee camp since birth. Similarly this assumption was confirmed by Preedy & Watson (2010) who found that their participants stayed in refugee camps for over 50 years.

In the environmental domains issues relating to financial resources, working environment, accessibility to health and social care, freedom, security, and participation and opportunities for leisure activities on the health related quality of life are evaluated to see their impact on health related quality of life. The environmental domain score of our study sample was found to be 37.7. This was the lowest score among the four domain scores. Other studies have reported environmental domain scores among refugee populations as low as 23 (Eljedi, 2006). Refugee environments have been reported as contributing factors to the low health related quality of life among patient (Preedy & Watson, 2010). The camp environment could pose challenges to the study sample in the areas of participation restriction and activity limitations.

5.4 Summary

This chapter discussed the findings of the study and compared it with similar studies. The next chapter draws conclusions from the findings and also highlights the limitations of the study. Furthermore recommendations are outlined.



CHAPTER SIX

CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

6.1 Conclusion

In conflict situations or displacement, disability remains one of the major health consequences. In Mayukwayukwa refugee camp, the study sample consisted of refugees with various kinds of disabilities. The majority of the participants sustained disabilities as a result of gunshots, landmines and bomb explosions. This study attests to the fact that disability is an issue in conflict-affected populations, more especially among refugees. Therefore, the consequences of disabilities among this study sample depended not only upon specific dysfunctions such as lower limb amputations, but also upon the context in which these disabilities were experienced and on the meaning of the dysfunction within the individual's life. The level of physical function among these refugees influenced their health related quality of life. The factors that influence the level of disability among refugees are determined by environmental variables such as income, social support, and physical access to the home and community, social policies and services. The environmental and personal variables played a role in the determination of health related quality of life among refugees with disabilities.

6.2 Limitations of the study

The results of this study should be viewed in the light of the following limitations:

1. Data regarding physical function and health related quality of life was based on self report. Misinterpretation is thus possible. Literature however provides evidence that these measures are generally reliable and valid.
2. Data was analyzed cross-sectionally, thereby limiting the ability to make causal inferences.
3. The sample only included refugees with physical disabilities. A control group of refugees without disabilities to determine the effect of disability on HRQOL or a group of refugees with disabilities outside of camps to determine the effect of setting on physical function and HRQOL would have been useful.

6.3 Recommendations

Based on the results of the study, the following recommendations are made:

- In most conflict-affected populations disability is an outcome factor. The study showed significant prevalent rates of disabilities among refugees in Mayukwayukwa refugee camp. Therefore resources should be directed towards investing in trauma care and rehabilitation in developing countries. This is due to the fact that poverty causes disability and as such poor people such as refugees are more exposed to primary causes of injury, chronic poor health and disability and more likely to have poor access to health services, rehabilitation and social support.

- Future research should attempt to address educational issues in relation to quality of life of refugees with disabilities in camps as identification of educational issues may assist in the design of educational-specific interventions in self sustenance and improving quality of life.
- Future research could also include control groups and/or a qualitative component to further explore the variables under investigation.
- Thus, there is an urgent need for global research and consolidated action to improve the present awareness, data collection, and knowledge base pertaining to the identification and evaluation of refugees with disabilities in camp settings.



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