

**AN ANALYSIS OF HEALTH BEHAVIOUR OF CHILDREN  
FROM CHILD HEADED HOUSEHOLDS IN A SELECTED HEALTH  
DISTRICT IN KWAZULU-NATAL:  
AN ETHNOGRAPHIC STUDY**

**EMELDA ZANDILE GUMEDE**

**University of KwaZulu-Natal**

**December 2013**

**A Thesis submitted to the School of Nursing and Public Health in**

**the**

**College of Health Science: University of KwaZulu- Natal**

**In**

**Fulfillment of the Requirements for**

**The Degree: Doctor of Philosophy (Nursing)**

**By**

**EMELDA ZANDILE GUMEDE**

**Student Number: - 208529792**

**SUPERVISOR: - PROFESSOR: B.R.BHENGU**

**UNIVERSITY OF KWAZULU-NATAL**

**DECEMBER 2013**

## DECLARATION

I Emelda Zandile Gumede, declare that this thesis titled “An analysis of the health behavior of children from child-headed households in a selected health district in KwaZulu –Natal: An Ethnographic study”: is my original work and has not been submitted to any other university except the University of KwaZulu-Natal (Durban). All sources of information that I used in the study have been acknowledged in a complete reference list.

---

Student's signature

---

Date

---

Supervisor

---

Date

## **DEDICATION**

This thesis is dedicated to my late parents Enoch & Francisca Nkwanyana, late husband Harvey Theodore Ntabazwe Gumede, and my children, Nokuthula, Nkosenye, Mpumelelo and Ntuthuko, for their love and support throughout this journey

## **ACKNOWLEDGEMENTS**

I am grateful to the Lord Almighty, for giving me the inner strength, wisdom and perseverance to complete this study.

My sincere gratitude and appreciation goes to the following people and institutions:

Professor B R Bhengu, my supervisor for her guidance, patience and encouragement throughout the study. You have been my pillar of strength.

Duncan, the Director at Thandanani Children Foundation, at UMgungundlovu district, for giving me the opportunity to conduct the research in your institution, volunteers and the staff in general for your smiles, it meant a lot.

Bongani, the health care professional (nurse) at Thandanani, for assisting with the list of children who met the eligibility criteria for the study, for setting up meetings with the community developmental facilitators (cdf) and volunteers in preparation for community entry.

Children from child-headed families for opening your doors for me, I really appreciate it. It was the most enriching experience of my life, listening to your stories, sharing your life experiences was more than what I bargained for.

MEPI, thank you for funding my studies, your services were much appreciated.

The School of Nursing, University of KwaZulu Natal, management and staff, for your support, guidance and time granted to complete the study.

My friends and family for all the support, prayers and for believing in me that I will carry this to completion, thank you so much.

My late husband and children, Nokuthula, Nkosenye, Mpumelelo, and Ntuthuko, for words of wisdom, prayers, love and being there for me no matter what.

Lastly, I thank myself for pulling through, standing tall and believing that I could do it.

## LIST OF ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral treatment
ARV	Antiretroviral
CBP	Community Based Programs
DOH	Department of Health
EMRS	Emergency Medical Rescue Services
FBO	Faith Based Organization
FET	Further Education and Training
HIV	Human Immune Deficiency Virus
IMCI	Integrated Management of Childhood Illnesses
ISV	International Student Volunteer
MDG	Millennium Developmental Goals
MRC	Medical Research Council
NGO	Non- Governmental Organization
NHI	National Health Insurance
PHC	Primary Health Care
PMTC	Prevention of mother to child transmission
RDP	Reconstruction and Development Program
SAIRR	South African Institute of Race Relations
UNAIDS	United Nations Joint Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization

## **ABSTRACT**

### **Introduction**

The loss of a parent predominantly as a result of HIV and AIDS disease has a negative effect on children, which can lead to increased number of orphans. Traditionally the extended family would take in orphaned children into their extended families and make one big family where culture of “Ubuntu” still prevailed. The changes in the socio-economic systems and family structure leaves the children with very little choice but to make alternative living arrangements, where they find themselves in child headed household families. The eldest child becomes the head (caregiver) within a household.

The aim of the study was to explore the health behavior, health seeking behavior and issues of access to health and social care services to children coming from child headed household families in a selected district in KwaZulu Natal.

### **Methodology**

A qualitative approach using ethnographic method was conducted. Three households were purposefully chosen with a total of nine participants. Data collection processes included participant observation in their natural setting, individual interviews as well as focus group interviews in their own environment. Children participants were so heterogeneous that they could not be studied together in a focus group for three families, but the volunteers and professional group could be studied together in a focus group.

The data analysis followed Spradley's (1980) three levels of analysis called the domain, taxonomic and componential analysis as presented in chapter five.

## **Findings**

The children's health behavior is affected by the HIV and AIDS infection, poverty and lack of support from the extended family and communities. Their health seeking behavior is influenced by the previous history and attitudes towards the health professionals. The access to health and social care services is also surrounded with mistrust of the present health care system.

## **Conclusions and study recommendations**

The discussions in the current study focuses mainly on the logistics of awarding the child headed status by the court of law as the lengthy and tedious process, but as the best practice because it eliminates the corruption and fraud in the system by expecting the children to be physically (identified) presented before the court of law before awarding of the status. The legislative ambiguity, shortage of volunteers, unaffordable transport and the attitude of the health care professionals impact negatively on the child headed household children's health seeking behavior to an extent that children tend to avoid accessing health and social care services until they are very ill to be picked up by an ambulance which bypasses the administration section which subjects them to sad memories and embarrassing questions such as those related to HIV statuses of their late parents which could imply theirs too, within a limited space.

The study recommended a longitudinal case study to be undertaken to follow up on the children who are 18 years and above as it appears that they tend to get lost in the thick vicious world and end up in the wrong side of the law. All participants echoed that the poor coordination of services made available for such children should be urgently attended to by government, the Faith Based Organizations (FBO) meaning the structures that represent the church and responsible Non-Governmental organizations (NGO's).

The greatest limitation of the study was that it was qualitative and used only nine participants in three families, hence cannot be generalized beyond the context of the study.

**Key Concepts:**

HIV/AIDS Orphans; Child-headed families; Barriers to accessing Health Care.

## LIST OF TABLES

Table 3.1	Needs classification by Manfred Max –Neef	57
Table 4.1	Sampling procedures and participant groups within the study	71

## LIST OF FIGURES

Figure 4.1.	Map of South Africa showing KwaZulu Natal and Health Districts.	71
Figure 6.1.	Summary of discussions	128
Figure 7.1.	Model of care for CHH families	144

## **LIST OF APPENDIXES**

1. Letter requesting permission to conduct the study
2. Information sheet for health professionals
3. Information sheet for children
4. Informed consent for children
5. Information sheet for caregivers
6. Informed consent for caregivers

## TABLE OF CONTENT

Title Page.....	ii
Declaration.....	iii
Dedication.....	iv
Acknowledgements.....	v
List of Acronyms.....	vii
Abstract.....	viii
Key Concepts.....	x
List of table.....	xi
List of figures.....	xii
List of appendixes.....	xiii

## CHAPTER ONE: INTRODUCTION

1.1 Background Of The Study.....	1
1.1.1 HIV Prevalence In Sub-Saharan Africa.....	1
1.1.2 Child-Headed Households: A Global Overview Of The Problem.....	2
1.1.3 The African Context.....	3
1.1.4 The South African Context .....	4
1.1.5 Health behavior.....	6
1.1.6 Health seeking behavior.....	7
1.1.7 Child-Headed Households Within The South Africa – An Analysis Of Post 1994 Legislation.....	8
1.2 The Problem Statement .....	12
1.3 Purpose Of The Study.....	14
1.4 Objectives.....	15
1.5 Research Questions.....	15
1.6 Study Significance .....	15
1.7 Linguistic Analysis.....	16
1.8 Structural Lay Out Of Thesis.....	19
1.9 Conclusion.....	21

## **CHAPTER TWO: LITERATURE REVIEW**

2.1 Introduction.....	22
2.2 Data Search Strategy.....	24
2.3 Inclusion criteria.....	25
2.4. The Review Remit .....	26
2.5. Pre-Review Considerations.....	26
2.6. Thematic Review of literature .....	27
2.6.1. Range of factors influencing access to health care services.....	27
2.6.2. A Historical Overview of literature related Child-Headed Households.....	27
2.7. Health: A definitional overview .....	27
2.8. Health Behavior and health Seeking Behavior.....	29
2.9. Relationship between health behaviors to social demographics Socio-Economic Factors.....	31
2.10. Access to Health.....	32
2.10.1. Socio-Economic Factors.....	34
2.10.1.1 Education .....	35
2.10.1.2 Housing.....	38
2.10.1.3 Finance.....	41
2.10.1.4 Psychosocial Factors related to access to health.....	44
2.10.1.5 Health Legislation and access to health care issues.....	47
2.11. Summary of the Chapter .....	51

## **CHAPTER THREE: PHILOSOPHICAL AND THEORETICAL UNDERPINNINGS OF THE STUDY**

3.1 Introduction.....	52
3.2 Theoretical Underpinnings .....	52
3.2.1 Debate about theory in qualitative research.....	52
3.2.2 Inductive application of a theoretical framework.....	53
3.3 Deductive Application of Theoretical Framework.....	54
3.4. Theories underpinning the study.....	55
3.4.1. Health –Belief Model.....	55
3.4.2. The Social Cognitive Theory .....	56

3.4.3. Max-Neef Model of Human –Scale Development.....	56-7
3.5. Philosophical Underpinnings of the Study Methodology .....	59
3.5.1 Epistemology.....	59
3.5.1.1 Objectivism.....	60
3.5.1.2 Subjectivism.....	60
3.5.2 Theoretical Perspective.....	60
3.5.3 Research Paradigm.....	61
3.5.3.1 Constructionism.....	62
3.5.3.2 Interpretive Ethnology.....	63
3.6. Conclusions to the Chapter .....	63

## **CHAPTER FOUR: RESEARCH METHODOLOGY**

4.1 Introduction.....	65
4.2 Research Approach.....	65
4.3 Research Design.....	66
4.4 Research Setting.....	67
4.5 Participation’s Selection .....	69
4.6 Gaining Entry.....	72
4.7 Data Collection.....	73
4.7.1 Participant observation.....	73
4.7.1.1 Subsequent Participant Observations.....	73
4.7.1.2 Descriptive Observation.....	74
4.7.1.3 Focused observations.....	74
4.7.1.4 Selective Observations.....	74
4.7.2 Individual Interviews.....	74
4.7.3 Focus group discussions interviews.....	75
4.8 Document Review.....	76
4.9 Data Analysis.....	76
4.9.1 The domain analysis.....	76
4.9.2 The taxonomic analysis.....	76
4.9.3 Componential Analysis.....	77
4.9.4 Cultural themes.....	77
4.10 Academic Rigor.....	77
4.10.1 Credibility.....	78

4.10.2 Transferability.....	78
4.10.3 Dependability.....	79
4.10.4 Conformability.....	79
4.11. Ethical Considerations.....	80
4.11.1 Collaborative Partnerships.....	80
4.11.2 Social Value.....	80
4.11.3 Scientific Validity.....	80
4.11.4 Fair selection of study participants.....	81
4.11.5 Favorable risk benefit ratio.....	81
4.11.6 Independent Review.....	82
4.11.7 Informed Consent .....	82
4.11.8 Respect for Recruited Participants.....	82
4.11.9 Dissemination of findings .....	83
4.12 Conclusion.....	83

**CHAPTER FIVE: DATA PRESENTATION, DATA ANALYSIS AND INTERPRETATION**

5.1 Introduction.....	84
5.2 An Overview of Data Analysis Strategies Utilized Within the Study.....	84
5.3 Process of Data Analysis.....	85
5.3.1 The Domain Analysis .....	85
5.3.2 The taxonomic analysis.....	86
5.3.3 Componential Analysis .....	86
5.3.4 Cultural Themes.....	86
5.4 Participants Realized at the end of the study.....	87
5.4.1 Individual Interview and Focus Group Data Presentation and Analysis... ..	88
5.4.1.1 Participant- as- observer.....	88
5.4.1.2 Individual Interview Data.....	88
5.4.1.3 Focus-Group Discussion Data.....	103
5.4.1.4 Description on Experiences of Being Families.....	103
5.5 Presentation of focus group discussion.....	104
5.6 Interviews and focus group discussions for volunteers.....	107
5.7 Data Analysis for the professional group .....	110
5.8 Summary.....	114

## **CHAPTER SIX: DISCUSSIONS OF FINDINGS, CONCLUSION AND RECOMMENDATIONS**

6.1 Introduction.....	115
6.2 Overview of the data collection process .....	116
6.3 Discussions of findings.....	116
6.3.1 Logistics of awarding of child headed household status.....	116
6.3.2 Reasons for orphanhood.....	117
6.3.3 Reasons for non-absorption.....	117
6.3.4 Support.....	118
6.3.5 Stigma and discrimination.....	120
6.3.6 Health behavior.....	121
6.3.7 Health seeking behavior.....	123
6.3.8 Access to health.....	125
6.3.9 Cultural issues.....	127
6.4 Summary of discussion.....	129
6.5 MAX-NEEF Human.....	131
6.6 Recommendations.....	133
6.6.1 Research.....	133
6.6.2 Practice.....	134
6.6.3 Management.....	135
6.7 Study Limitations.....	135
6.8. Reflections of my role in the research process.....	138
6.9. Chapter Conclusion .....	139

## **CHAPTER SEVEN: MODEL DEVELOPMENT**

7.1 Introduction.....	139
7.2 Definitions.....	139

7.3 The Context.....	140
7.4 Purpose.....	141
7.5 Identification and definition of concepts.....	141
7.6 Model of care for child headed household families.....	144
7.7 Relationships within the theory.....	145
7.8 Assumption.....	148
7.9 Comparative of the proposed theoretical model in relation to Max-Needs theory of human needs.....	149
7.10 Strengths and weakness of theoretical model.....	150
7.11 Conclusion.....	151
List of References.....	152-175
Annexures/Appendices.....	176-211

## **CHAPTER ONE**

### **1.1 BACKGROUND OF THE STUDY**

In South Africa, the HIV AND AIDS pandemic has had a devastating impact, as evidenced by the exponential increases in morbidity and mortality across adults and children. South Africa has a mortality rate of 721/100 000 for people with HIV and AIDS and related infections and, 193/100 000 people for individuals with HIV and AIDS related TB (World Health Organization (WHO), 2009). South Africa, as a developing country has the largest number of people affected with and dying of HIV and AIDS related illnesses leaving behind children who are either infected or affected by the disease. Women and children are the most stricken by the pandemic, because they are the ones left behind to tend for the sick relative/parent in the terminal stages of the illness until they die. This has a devastating psychological effect (UNICEF 2011). In Africa, AIDS kills 10 000 people a day and many victims leave behind small children. AIDS has orphaned fourteen million children and twenty million African children have died from the disease and more are still expected to die within the next three years (UNAIDS 2012). The UNAIDS (2012) global report stated that almost 90% of children living with HIV are in Sub-Saharan Africa, and fewer than 10% of these children are being reached by basic support services. The infection rate of more than 10 000 new infections per day reported in 2005 will result in about 5.5 million people living with HIV, of which 240 000 are children below 15 years of age (Knight, 2006). Current infections by UNICEF (2012), confirm that 210 000 new infections among children were reported. This represents a 38% decline in the number of new infections among children as compared to 2005-2006.

#### **1.1.1 HIV Prevalence in Sub-Saharan Africa**

Sub Saharan Africa remains the most heavily affected region by the global HIV epidemic, with 92% of pregnant women living with the disease (WHO & UNAIDS 2012). A South African Department of Health study conducted in 2010, states that out of 32,225 pregnant women attending antenatal clinics across nine provinces, 30.2% of them are infected with HIV and AIDS (Department of Health 2010). Of all the provincial areas, the province of KwaZulu-Natal has the highest HIV prevalence rate at 39.5%, followed by Mpumalanga with 35.1 % (South African HIV and AIDS

Statistics 2010). WHO & UNAIDS (2012) reported a slight decline in the provincial HIV prevalence rate in South Africa, when compared to previous years. It reports a prevalence rate of 3.8% in Western Cape and 15.8% in KwaZulu-Natal. UNAIDS (2012), reported 2.5million new infections in 2011, which were made up of 2.2million adults and 330 000 children. Regional statistics indicated that Sub Saharan Africa currently has a total of 1.5 million infections in adults and 300 000 in children.

In 2011, 17.3 million children under the age of 18 years had lost both parents to AIDS. About 3.3 million children living with HIV and AIDS infection are under the age of 14 years, 330 000 children were newly infected and 230 000 children below the age of 14 years died of AIDS related infections ( UNAIDS; 2012).

Improvement in treatment and increased access to treatment has made it possible for South Africa to reduce its infection rate among children in 2012 to 14 000, this is a 63% decline in infections in children when compared to 2009-2012. At the end of 2012, 210 000 children were eligible for Anti Retro-Viral treatment.

The Actuary Society of South Africa 2008 report concurs with the report from UNAIDS & WHO (2007) and reports 282 348 deaths due to AIDS related infections in 2002, and 374 655 deaths in 2007. This signifies an increase of 92 307 cases despite the availability of free Anti retro viral treatment (ARV'S) in public/government institutions over this period. More children are becoming vulnerable and being orphaned resulting in an increase in child-headed household families. The number of orphaned children in South Africa was expected to rise from 1.5 million in 2001 to 2.3 million in 2010 (USAID , 2004). To further confirm the widespread nature of HIV and AIDS infection, the South African Child Gauge (2007) reported that the leading cause of death among children from birth to 15 years was HIV and AIDS and related infections.

### **1.1.2 Child-Headed Households: A Global Overview of the Problem**

The loss of a parent as a result of the HIV and AIDS disease has a negative effect on children, which cannot be under estimated. This can result in feelings of loss and despair, rejection and psychological trauma (McLellan, 2005). In 2006, 0, 67% of children were living in a child-headed households, this is equivalent to 122 000 children. The rapid increase of child-headed households is a very serious problem, because it highlights some weakened links of the traditional extended family

responsibilities and roles. The change in the social and family structure leaves these children with very little choice but to make alternative living arrangements. Most of the time they end up in child headed households. With the support of relatives, children may opt to remain in child-headed households to protect their property rights while arranging for permanent accommodation (Foster, Makufa, Drew, Kambeu & Saurombe: 1996). Children may still have access to one or more adult family members for advice and financial assistance. This statement is supported by Sloth-Nielsen (2004), who asserts the view that extended family members are better offering their assistance to the children in their own households. Authors like Sloth-Nielsen (2004) argue that, once these children move out of their parental home and are taken in by extended family members, there is a greater possibility of losing their parental belongings and inheritance (Foster, Makufa, Drew and Kravolec 1997). These authors further state that child-headed families typify communities with severe HIV/ AIDS pandemic.

Across the globe, some noteworthy patterns are observed, for example, Brazil like many other countries has a combination of poor and rich communities. It has a population density of 19 197 150 600, and the number of people living in the rural area are 2 768 232 912. About 113 497 394 are living in dire poverty (UNAIDS 2009). The poorest and most vulnerable group among the rural communities of Brazil is composed of women, young black females and indigenous groups (UNAIDS 2009). Households headed by women and children account for 27% of the rural communities, this is because most of the males left their homes through death, migration, divorce, wars and diseases including HIV and AIDS. By contrast, Senegal has a high infection rate of HIV and AIDS across all age groups. The reason for this is that the routes of infection are not wholly accepted and non-disclosure to partners is very prevalent.

### **1.1.3 The African Context**

Traditionally, in African culture, family members were responsible for the other members of the extended family, even if they did not have enough money or food resources for themselves. The culture of Ubuntu prevailed to such an extent that "your child was mine"; a child belonged to the anyone in the community, no orphans existed then because they were all one, representing one big family (clan). The extended families were a normal phenomenon and occurrence; children would stay

together, socialized into a unit of brotherhood and sisterhood (UNAIDS 2006 & Giddens 1994).

The change in the socio-economic status brought about by urbanization, the devaluation of the Rand and the emergence of the nuclear family structures that lead to single parenting at the death of one parent, or divorce, meant children from such households were never allowed the experience of being involved in the extended family structure. Therefore at the death of the remaining parent, most of the orphaned children became a part of the child-headed household (Foster et al 1997).

The concept of a child-headed household is relatively new in South Africa, but neighboring countries like Zimbabwe, Uganda, and Rwanda are familiar with it. It is common and perceived as a new coping mechanism in response to the HIV and AIDS pandemic (Foster et al 1997). In countries like Angola, Uganda, Rwanda and Zimbabwe, child-headed households were present because of economic migration, where parents left behind their children in order to be able to work in the cities, returning home after periods of 3 to 6 months. They also had children heading the families because of parental death due to wars and famine and even genocide, but HIV and AIDS is responsible for the largest numbers of deaths (Sloth-Nielsen 2004). In 2006, 0.67% of children were living in child-headed households; this is equivalent to 122 000 children and this figure calls for urgent intervention by all concerned.

#### **1.1.4 The South African Context**

Culturally extended families were always willing to take in children from extended family members in the event of death or any other circumstance that resulted in the adult member no longer being able to look after his/her own children. Unfortunately, this tradition and “Ubuntu” is no longer practiced. It is within a family structure that children are socialized, nurtured to become well-rounded mature and responsible citizens, therefore in the absence of such we are left wondering what will become of these children. It is a common wish of any parent, when they are dying, to leave their children in the hands of a relative. Now that the economic status, weakened social link and high unemployment rate is rife, extended family members find it difficult to accommodate another extended family member into their own family units, hence, the mushrooming of child-headed household families (Giddens 1994). The extended family ties and role functions have weakened such that they are sometimes no longer

the best option for an orphaned child. Due to issues such as financial strain and physical disability, those extended family members who are willing to take care of their grandchildren find it very difficult. Children need to grow up in an environment where he/she can be nurtured, and socialized to become a well-adjusted social being. It is assumed that children raised in child-headed households will be poorly socialized, their moral values questionable and will therefore not grow up to be mature, respected citizens that the community will be proud of (Foster et al 1997), this is in agreement with what Bandura (1997) in the social cognitive theory where he postulated that children in in child headed families lack parental guidance/models therefore may adopt unbecoming behaviour from the environmental influences or unguided physiological states or verbal persuasion from peers.

Children in such conditions are struggling for survival because they are deprived of the basic common rights that are in the Constitution of the Republic of South Africa Act (Act no 108 of 1996 section 28). It states that each child should be brought up in a safe, secure environment that is free from hazards, where all basic needs such as food, shelter, clothing, love and a sense of belonging are catered for. In these child-headed households, there is no adult to give advice and guidelines, most of the time the eldest child becomes the head of the family. These children, lack parental care, are deprived of a warm safe environment, and they also miss out on the opportunity to learn and identify with adults as their role models. This situation affects their social functioning as they grow up and this can lead to the presence of psychological problems. These children have witnessed their parents getting progressively sicker, suffering great pain and humiliation due to the stigma associated with this disease, until they die leaving behind the children to assume an adult role at a young age (South African Institute of Race Relations (SAIRR) 2009). Severe economic hardship predisposes them to alternative means of survival, like prostitution which further exposes them to HIV and AIDS, through engagement in behaviors such as substance abuse, child labor, sex worker, and forced marriages. Often the little money that was left by the deceased parents would be used for medical bills and not in feeding the remaining siblings, who are now expecting to be provided for. This is a great source of stress for the adult child (Foster 2004).

The SAIRR (2009) July Report states that in South Africa there were 148 000 households headed by children of 17 years and below. The provinces greatly

affected by this problem are Limpopo, Eastern Cape and KwaZulu Natal. About 90% of child headed household families are located in Limpopo, Eastern Cape and KwaZulu-Natal, and most of those left in charge of the families are teenagers (Meintjes, Hall, Marera & Boulle 2010).

This perpetual increase in the number of orphans because of HIV and AIDS is of much concern, such that the USAID 2002 report 11, has issued a statement that if this problem continues unabated, South Africa will have 2.3 million orphans by 2010. A Medical Research Council (MRC) (2009) briefing statement suggested that 15-17% of children would be orphaned by the age of 15 years by the year 2015. If the rate of new infections were to level off in the next few years, the long incubation period means mortality rates will not plateau until 2020, thus the proportion of orphans will remain unusually high at least through 2030 (Meintjes, Hall, Marera & Boulle 2010).

The impact of living in a child headed household has an adverse effect especially to the head of the household (care giver) as she/he has to take the sole responsibility at such tender age. Children encounter problems with finance, education, psychosocial adjustments, health behavior including health seeking behavior and issues of access to health care services.

#### **1.1.5. Health behavior**

Health behavior is defined as any activity undertaken for the purpose of preventing or detecting disease or improving health and wellness. It is common to distinguish the health enhancing behavior from health impairing one. Health enhancing behavior includes regular exercise, consumption of fruits and vegetables and use of condoms, whereas the health impairing behavior includes those activities that are detrimental to health and predispose to harmful effects and disease (Retrieved 18/9/2011:<http://www.userpage.fuberlin.de/schuez/folien/conner>).

Health behavior also includes activities towards healthy living like personal hygiene, nutrition and environment (Bouwer, Dreyer, Herselman, Lock & Zeelie; 2006). In a normal household with both parents and extended family members, children are brought up in such a way that health behavior practices are enhanced so as to promote a healthy living.

In the absence of the adult figure, as the case with orphans or children from child headed households, the health behavior is not known, unsupervised or cannot be afforded because of socio economic factors leading to onset of ill-health (SASSA 2012)

Children from child headed households are inundated by complexity of health hazards ranging from poor nutrition, absence of shelter, clothing and social security and its complications. If these problems are not attended to in time either by the extended families or care givers, may exacerbate social pathologies like crime, juvenile delinquency, prostitution ,sexual disorientation leading to high spread of HIV and AIDS and the cycle repeating itself (Foster & Williamson, 2001)

#### **1.1.6. Health seeking behavior**

Health seeking behavior is a form of health behavior assumed by an individual or group who believe that there is a form of illness in him/her or family member. This is influenced by natural (supernatural) and biomedical knowledge, attitude and practice of an individual (Hausmann-Muela, Muela, Ribera & Nyamongo 2003). Health seeking behaviors are activities undertaken for the purpose of preventing or detecting illness or diseases including improving health and wellbeing. This includes medical service usage, compliance with medical and nursing regimes and self-directed health behaviors (Ward, Mertens & Thomas 1997).

Ward, Mertens & Thomas (1997) stipulates that health seeking behavior is preceded by a conscious decision making process that is governed by an individual, household or community members and expectations as well as provider related characteristics and behavior. The nature of health seeking behavior is therefore not homogeneous across families. Each family had to decide on the best option at a given circumstance, guided by the presenting signs and symptoms, perceived nature of illness, followed by the appropriate home care and monitoring. The decision to seek medical care at a health facility, medication and compliance is the responsibility of the head of the family, and in the case of children, a huge responsibility is entrusted in the care of the adult child or a care giver. Treatment failure or non-compliance may require a return visit to the health facility or an alternate care provider, that decision too is to be made by an adult child within a family

Going back to the clinic/hospital is a very responsible decision to be made but a child at such tender age. There is often a lack of finance to go to clinic, more even so when the clinic is far and the need to be accompanied by an adult whom the child cannot afford to pay even if the volunteer is willing to assist in accordance with the legislation and the clinic charter. Children that attend school find it difficult to be accommodated by the clinic operational hours which are mainly office hours (08h00-16h00)

Health seeking behavior is thus a reflection of the prevailing conditions which interact synergistically to produce a pattern of care seeking, but remains fluid and amenable to change (Ward, et al 1997).

### **1.1.7 Child-Headed Households within South Africa - An Analysis of post 1994 Legislation.**

After the 1994 democratic elections, access to health care in South Africa became a human right for all citizens under section 27 of the Constitution of the Republic of South Africa (Act no 108 of 1996), which cemented the transformation and restructuring of health care services with emphasis on primary health care approach. Through health sector reform, the process of improving the performance of existing systems was put in place, including sustenance of efficient and equitable resources to future changes, purposefully to improve the quality and equity of health for all. The changes in health care provision were ultimately designed to enhance access to health for all. The concept of “access” is understood in varied ways and to that end, it needs to be carefully defined and clarified to better understand how instituted legislation was intended to facilitate greater access for all, including those in child-headed households as will be discussed hereunder.

Access is the opportunity and freedom to use services, and encompasses the circumstances that allows for appropriate service utilization, including a sufficiently informed individual or household, allowing them to become empowered enough to exercise choice within the health system (Van Rensburg; 2010)

Access to health care includes geographical, financial, organizational and cultural access. For the purpose of this study only the above will be discussed in detail. Financial accessibility stipulates that whatever method of payment is used, services

should be affordable by the community and the country. Access to health care was initially made free to children and pregnant women, but after 1997, it was made universally accessible to all citizens of the country in Primary Health Care Centers (PHC) (Hatting, 2003).

Geographical access includes travelling time, walking distance and means of transport. Geographic access was improved post 1994 with the development of new infrastructure, where clinics were upgraded and new ones built so as to be within a 5 km radius of most towns and rural communities. In areas where it was difficult to build a clinic, an outstation or a mobile clinic, that would visit at least once a week, was identified (Van Rensburg, 2010).

Organizational and functional access involves a well-structured, defined referral system from the primary health care service to the district hospital, depending on the condition of the client further to tertiary services. This form of access ensures continuity of care from one service to the other without interruption or duplication of services. Cultural access involves methods and approaches to health care that are acceptable and appropriate to the needs, and culture of the users determined through an analysis of the context of the users (Van Rensburg 2010)

As far as children's' access to health care is concerned, the two consecutive legislations, the Child Care Act (Act no 38 of 2005) and the recent one (Act no 41 of 2007) refer to access of children to information and health care, the definition of child-headed household and the administrative responsibilities respectively. The Child Care Act (Act no 38 of 2005), chapter 2, section 13 states that: every child has the right to have access to information on health promotion, prevention and treatment of ill health and diseases, sexuality and reproduction.

Every child must have access to information regarding his or her health status and access to information regarding the causes and treatment of his or her health status. These children also deserve observation of confidentiality regarding their health status and that of a care giver or family member, except when it is viewed as not being in the best interest of the child.

The Child Care Act (Act no 41 of 2007), Chapter 6 section 137, defines a child-headed household as that household where the parent, guardian or caregiver of a

household is terminally ill, or has abandoned the children in the household. There is no adult family member available to provide care for the children in the household such that a child over or beyond the age of 16 years has assumed the role of the caregiver in respect of the children in the household.

The act also recognizes the household if it is in the best interest of the children in the household to stay together as a family and uphold their late parents' wishes.

The act further discusses the administration of such a household by designated adults as follows: A child-headed household family must function under the general supervision of an adult designated by the court, organ of state or a nongovernmental organization, determined by the provincial head of social development. The supervising adult must perform the duties as prescribed in relation to the household and be a fit and proper person to supervise a child-headed household.

On gaining access to the research field, the researcher finds that the terminology for the eldest child who is heading the household is the caregiver. This term under normal circumstances is used for the community health care worker tasked with the specific health supervisory functions like child headed household mentor. However in the context of this study this concept will be used for a child that heads the family and the health supervisory/mentor is called a volunteer.

The child heading the household or adult contemplated in subsection (2) of the Child Care Act, may collect and administer for the child-headed household any social grant or other grant in terms of the Social Assistance Act (Act no 13 of 2004 ) or other assistance to which the household is entitled. The adult that collects and administers money for a child-headed household is accountable to the organ of state or nongovernmental organization that designated him or her to supervise the family. This adult may not make decisions concerning such household and children without prior consultation with the responsible child heading the family and given the age, maturity and stage of development of the children and also those other children.

The child heading the household may make all day-to-day decisions relating to the household and the children in the household may also report the supervising adult to the organ of state if not happy or satisfied with the manner in which the supervising adult is performing his or her duties. A child-headed household may not be excluded

from any grant, subsidy, aid, relief or other assistance or programs provided by an organ of state in the national, provincial or local sphere of government solely by reason of the fact that the household is headed by a child.

The Primary Health Care Clinic Charter (1996) stipulates that the age of access to a clinic of an unaccompanied child is 16 years, and above. As this person is regarded as mature enough to understand health information and make informed decisions. However, recent debates on issues of access for children of 12 years and above support access to reproductive health and HIV testing and treatment. This debate is not taking cognizance of the clinic charter that prevents unaccompanied access to children under 16 years of age. The above-mentioned Acts are also silent about the issue of access for children from child-headed households. Presently the government has launched a number of programs to increase access to health services by children, but there is still a grey area around the issue of children who are from child-headed households. The school health program may try to solve the problem of health information but the nurses in such programs are still not allowed to carry some drugs, which may be required by children who are from child-headed households. Children needing treatment are often referred to hospitals or other specialized services. It still remains that the orphaned child will not have an adult to take them to the hospital or specialized services as referred to by the school health nurse and primary health care practitioner.

The plight of such children is falling on deaf ears, because at the present moment there are no clear guidelines as to who is responsible for these children's health issues. There are broad guidelines, which state that the responsible caregiver is responsible for the holistic care of such children but they are not always present, since they generally only conduct intermittent visits, making it difficult for an adult child to attend to urgent health issues of the remaining siblings in the absence of a caregiver. This amounts to delays or non-attendance of a medical problem in a child, which may have a devastating or fatal effect.

Presently South Africa has 72% of children who are living with HIV, and are eligible for treatment but do not have access to it, most of these children are infected with the HIV and AIDS (UNAIDS 2012). More than 90% of children who acquired HIV in 2011 live in Sub Saharan Africa. There is no guarantee that they will ever access available

treatment, treatment that is believed to help reduce the mortality rate as promulgated in the Millennium Developmental Goal number 5.

Furthermore, various barriers to accessing health care are being identified notwithstanding the fact that denial of access to health care has life threatening implications. The common barriers to health care services are lack of finances, distance to the health facility and lack of time to seek health care, lack of knowledge among children and some caregivers, lack of appropriate services at the health facility and the negative attitude coupled with limited skills of some health care workers (National Action Plan for Orphans and other children made vulnerable by HIV and AIDS 2006-2008).

Children in child-headed households are vulnerable in terms of their age, most of whom are below 18 years old. Predominantly born of HIV infected parents and therefore also possibly infected, and have been looking after their terminally ill parents. The Child Care Act (Act no. 41 of 2007) together with the Primary Health Care Clinic Charter (1996) are contradictory, confusing, incomplete and not user friendly for a child especially those from child headed household. Therefore it would be interesting to assess their health behavior under such circumstances.

## **1.2 THE PROBLEM STATEMENT**

The HIV and AIDS pandemic is identified as the most significant reason for the exponential increase in the number of adult deaths and is primarily blamed for the escalating numbers of resulting orphans. The infection rate of more than 10 000 new infections per day globally, noted in 2008 was projected to lead to 5.5 million people living with HIV and AIDS (UNAIDS & WHO 2008). Globally, in 2011, 17.3 million children under the age of 18 years had lost both parents due to HIV and AIDS. The Actuary Society of South Africa (2008) reported 282 348 deaths due to HIV and AIDS related infections in 2002, and 374 655 in 2007. There is an increase in the number of deaths in spite of free available treatment in public health institutions.

The year 1994 set a positive starting point for addressing the needs of the vulnerable groups when children and pregnant women received the free health services in all public health institutions. They were prioritized over the other health groups, and as a result high levels of resources were targeted on meeting their basic health care

needs. However, since the changes that occurred as a result of the Constitution of the Republic of South Africa (Act no.108 of 1996), section 28, meant that resources were now equally distributed to other groups apart from pregnant women and children. The resulting consequence of this was the reduction in the attention given specifically to the needs of children, to the levels that meant that children from child-headed households were afforded lower provision of services than before (Department of Health (DOH) 1997)

Access to health care services is fraught with difficulties for children who are younger than the consenting age, not least because health care services often require that an adult guardian accompany children. There is anecdotal evidence that children below 16 years old cannot access health care services on their own without being accompanied by an adult, this further explains the impediment to health care services experienced by children when trying to access health services. The challenges of health care services providing care to child headed households have been addressed within different discipline areas within the health and social sciences, with noteworthy contributions from sociological and anthropological literature. Parahoo (2009) state this as an important point of acknowledgement that needs to be made.

The legislation and the policy ignores the fact that there are inherent problems with reproductive health which does not belong to this unit, for example; a 12 year child may suffer sexually transmitted infection (STI), which necessitate the visit to a Primary Health Care Clinic of which considers 16 years for access. This is when children encounter complications of access and management

Despite the clear benefit that may arise from sociological and anthropological contributions, author's like Parahoo (2009) including (Stannard, 2012); have indicated a need for specific contributions from the health sciences, most notably Nursing. This assertion, as argued by Tanner (2012), represents an important area of exploration that should occur to support the growth of a specialized understanding of the health care needs of child-headed families. Guided by this acknowledgment, the current study utilizes specific nursing and medical data sources as the primary evidence-sources and where necessary, sociological and anthropological perspectives will be sought.

As indicated earlier in the chapter, the health seeking behavior is a problem in relation to literacy, finance, time for attendance and accompaniment by a volunteer. Studies assert that there is a relationship between the level of education and health seeking behavior

Existing studies done in the area of child headed households covered area like psychological and emotional support within the school environment (Mkhonto 2006), social functioning of children in such households (Mkhize 2006) and the factors that hinder social integration of orphaned children into the extended families by Nziyane (2008). Another study by Mpeli (2007) was concerned with the self-control and the ability of such children in looking after their families. Whilst there are so many studies conducted in the area of child headed household, none is directed at health related issues such as access, health behavior and health seeking behavior, which the study is interested in. Hammersley (1983), asserts that research studies may be informed by the fact that the previous studies may have paid attention to certain contexts like developed countries fail to address contextual and cultural differences. Thus this study attempts to investigate child headed household practice in the context of selected district which is hard hit with HIV and AIDS.

No published study has been able to offer an exploratory overview of the reasons for poor access particularly for orphaned children in child headed families. Furthermore, no published framework for improving access for this vulnerable group exists. Given the lack of evidence based directional guidance for engaging children, the current study specifically explores the factors that influence health care access, health behavior by children from child-headed households. To conclude, the study aims to propose an evidence-based framework for improving health and social care access for child-headed household families in selected context.

### **1.3. PURPOSE OF THE STUDY**

The current study has one specific aim and as such, will explore health behaviors of children from child headed families in order to develop a framework for improving their future access to health and social care services.

#### **1.4. OBJECTIVES**

In achieving the above aim, the study has a number of objectives that includes:

- To describe the health behavior of children living in child-headed households.
- To describe the health-seeking behavior of children living in child headed households
- To explore the issues of access to health care services experienced by such children.
- To describe the activities of caregivers working with children in child-headed households.
- To explore the available health and social support services to meet health care needs of children living in child headed households.
- To develop an evidence-based health care framework to support members of child-headed households.

#### **1.5. RESEARCH QUESTION**

The study will use the following questions to achieve the pre-set objectives of the study:

- What is the health behavior of children living in child-headed households?
- What is the health seeking behavior of children living in child headed households?
- What are the factors that affect access to health care services for members of child-headed families?
- What are the activities (culture) of the caregiver's living/dealing with children from child-headed household families?
- What is the available health and social support services in place to meet these children's health care needs?
- What framework is emerging?
  - What are the gaps in the emerging framework?
  - How can these gaps be filled?

## **1.6. SIGNIFICANCE OF THE STUDY**

The study adds to the evidence about necessary interventions and actions to promote informed decisions on health behavior, health seeking behavior and better access to health and social care services for children from child-headed households. The fact that the study data will be primarily sought from the children themselves sets this study aside from all other predecessor and as a result, it will offer new perspectives about issues surrounding health behavior and access to health of children in child headed households. Hereunder the study attempts to describe the significance according to various areas of practice in health.

### **1.6.1. PRACTICE**

The study is hoped to harmonize the functioning of health care and social services in relation to packages offered to children coming from child headed families, for examples access and social sustenance packages.

### **1.6.2. EDUCATION**

The study hopes to inform the educational authorities on the needs for streamlined comprehensive support for child headed families whilst in the care for example fee benefit, meals and treatment.

### **1.6.3. POLICY**

The study may influence policy in terms of reconciling the age of access to various aspects of health and social care services

### **1.6.4. RESEARCH**

Future and prospective researchers may want to test the emerging model from this study in other context taking advantage of the detailed description of the research process (Ethnographic thick descriptions).

## **1.7. LINGUISTIC ANALYSIS – OPERATIONALISING KEY TERMS**

To facilitate meaningful exploration of the study area, some terms and specialized phrases need to be operationalized and are identified below: -

**Child**

This is a person either male or female, who is under the age of 18 years according to the Child Care Act (Act no 41 of 2007 and it is in line with the rules of the Republic of South Africa, and will be used in the study as such

**Ubuntu**

This is a " Nguni" word, which has no direct English translation, but is used to describe a particular African worldview in which people can only find fulfillment through interacting with other people. It represents the spirit of kinship across races and creed that unite mankind to a common purpose. In the study it is used in the context of extended families absorbing the orphans.

**Access**

For the purpose of the study, it shall mean the ease with which an individual can obtain much needed health and medical services. Van Rensburg ;( 2010) further define access as the opportunity and freedom to use services and, encompasses the circumstances that allows for appropriate service utilization. It may refer to geographical, financial, organizational and cultural access.

**Orphan**

This is a child who has lost one or both parents (UNAIDS 2002). Some literature further distinguishes an orphan as a paternal orphan, as the child who has lost a father and maternal orphan as the child with no mother. For the purpose of this study an orphan will mean a child who has lost both parents.

**Aids orphan**

In the context of the study the Aids orphan, is a child who has lost one or both parents to Aids, and the child is below the age of 18 years.

**Household**

This is a social unit, where continuous intensive social interactions based on loyalty and authority is taking place, (Webber 1978). In this study it shall mean any place where such children are being placed

### **Child-headed household**

This is a household where after the death of one or both parents, children are left alone and forced to assume the role of an adult and its associated responsibilities. The eldest child usually becomes the head of the family (Foster et al 1997). This is a relatively new term that came about in response to the impact of the Aids pandemic in the community. In the study the same meaning will be applied.

### **Social functioning**

This refers to a person's performance of his or her social roles as defined in terms of fulfilling a recognized, regulated position in society (Karls & Wandrei 1994). For the purpose of this study it serves to qualify that in the absence of a parent, the social functioning of the family is affected.

### **Extended family**

In the context of the study, this is a family group that consists of a father, mother, children, grandparents, aunts and uncles all living together. It may also be defined in the context of family relationships that are created through expansion and extension of the traditional nuclear family (Giddens 1994).

### **Nuclear family**

This is a family group that consists of a father, mother and children living together; there are no aunts, uncles and grandparents (Giddens 2001). These types of families are those that tend to result in the child-headed household after the death of the parents, and in this study this concept will be used as such.

### **Nurse**

Is a person who has undergone special education and training under the Nursing Act (Act no.33 of 2005), section 31, in an accredited institution to care for the sick and injured. He or she has an understanding of the concept of wellness and health of an individual. The same meaning will be applied in the study.

## **Caregiver**

Caregivers are adult persons that are entrusted with the care of orphans and vulnerable children, ensuring that the best interest of such children are promoted and upheld. For the purpose of this study, the caregiver shall mean an adult child in the household, who is responsible for the whole family. However, the focus of the study is the family and not individuals though reference is made as such in some areas of the study.

## **Volunteer**

For the purpose of this study, this shall mean all those adults who are entrusted with the supervisory functions of children from child headed household

### **1.8. STRUCTURAL LAYOUT OF THE THESIS.**

This thesis is set out as having seven chapters in order to provide an in-depth understanding of the research background, problem statement, purpose and aims, relevance to existing literature, methodology, methods of data collection and analysis, research findings, discussions, implications, recommendations and conclusions.

The first chapter provides the broad background of the HIV and AIDS pandemic, and its effect on the lives of families. The weakened family ties, where orphans were left to fend for themselves leading to the mushrooming of the so-called child-headed household. The chapter structured the context for the study and articulated the aims, objectives and expected outcomes through research questions. Linguistic analysis of operational terms was discussed for better understanding of the concepts used in the study. Significance of the study as well was incorporated.

Chapter two constitutes a detailed review of literature on the child-headed household, how they came into being. Factors responsible for the emergence of such households, and how the communities are handling such challenges. The governmental interventions and their strengths and weaknesses are also highlighted.

Chapter three presents the conceptual and theoretical framework that informs the philosophical underpinnings of the study. The conceptual framework is utilized as a

guiding framework for the development of the areas of interest within the data collection process.

Chapter four dealt with the methodology derived from the philosophical underpinnings, design, approach and the research paradigm. Sample and sampling technique, the research setting, as well as how the whole research process will be done, including ethical approaches and academic/research rigor.

Chapter five is concerned with data collection, analysis, presentation and interpretation. The issue of gaining access and gatekeepers are dealt with. Issues of varied data collection methods from observations, field note taking, interviews and focus groups. Data coding and how thematic analysis is done.

Chapter six. The chapter draws arguments (discussions) as evidenced from the analytic phase, it is here that we find a full discussions, conclusion and recommendations. Summary of the research process and findings is dealt with at this stage. Conclusions about the study are also drawn here. The strength's and limitations of the study are highlighted and better

Chapter seven presents framework /model development that is in line with the study. Within this, issues related to the potential development of a framework is proposed and highlighted, application and the comparative review of Max –Neef theory to the proposed theory. A diagrammatical structure of a model is presented, together with the definition, purpose contexts, assumptions and relational statements were discussed in relation to the children coming from the child headed household.

## **1.9. CONCLUSION**

Large numbers of orphans due to HIV and AIDS are homeless because the extended family members are not willing or unavailable to take them in due to many factors, some of which include the devalued rand and the unwillingness of some children to be separated and fostered by different families. An interpretive ethnographic study was conducted, children were observed in their natural settings, using varied data collection methods. There is no known study, which specifically focuses on the issue of access to health care services for such children. The outcome of this study may

facilitate the development of a comprehensive model/framework of health care for children coming from child-headed households.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1. INTRODUCTION**

Following on from the introductory chapter, Chapter two offers a review of literature related to child headed families and issues related to health behavior, health seeking behavior, their access to health and social care services. In addition this chapter presents an overview of the nursing, medical and health related literature, which articulates the likely barriers and facilitating factors, as related to access to health and social care services. It is noted from the onset of this chapter that very limited specific nursing, medical and health-related literature exists of this issue and in some areas, evidence relating to adult populations has been integrated into the literature review to aid in the making of inferential deductions. To this end, this literature review forms the theoretical and analytical framework that serves as the foundation for the research study.

Several definitions of what a literature review is, exist and Trafford and Leshem (2008) define it as the body of knowledge within a specific topic of interest. Literature can be accessed in the form of books, articles in journals, departmental reports, conference proceedings and other forms of collated information. In their definition, Trafford & Leshem (2008) view the literature review as the comprehensive inquiry about a specific topic, which is followed by the interpretation of such literature in order to identify the research question. Machi & Mc Evoy (2008) state that a literature review is a written document that presents a logically argued case founded on a comprehensive understanding of the current state of knowledge about a topic under study and represents an effective evaluation of selected documents on a research topic. Finally, Moule & Goodman (2009) assert that a literature review helps to provide the background information and understanding of the research topic, it also gives an overview of the existing evidence on the problem being researched, enabling the researcher to determine similarities and differences from prior studies (Moule & Goodman 2009).

Literature is an organized written presentation of what has been published on a topic by scholars with a purpose of conveying to the reader what is currently known about the topic under study (Burns & Grove 2010). In traditional positivist research, the literature review forms the basis for understanding of existing theoretical positions within a subject area. Consequently, most traditional approaches to research methodologies have argued in support of an initial review of literature to establish existing views, and to determine areas where gaps in knowledge exist. Within qualitative research traditions, the use of existing literature represents a divisive issue, which continues to spark debate, with grounded theorists, such as Bryant & Charmaz (2007) suggesting that engagement with existing literature prior to primary data collection should be carefully considered.

Bryant and Charmaz (2007) raise an argument on the use of existing literature relevant to this research topic in a qualitative research. This debate came about with the well-known scholars, like in grounded theory (Glaser and Strauss 1967)

Glaser and Strauss (1967) suggest that a researcher should enter the field without pre-conceived problem statement, interview protocols or extensive literature review.

Bryant and Charmaz (2007) believe that one needs to develop some theoretical sensitivity through familiarity oneself with existing relevant literature. The danger of not engaging in a literature review, Bryant & Charmaz (2007) believe, is the temptation to claim that one's study is a new idea or innovative breakthrough, when this is actually a reflection of ignorance to other scientist in the area. Moreover, pressure may arise from the research supervisors and examiners (professors), funding committees and Independent Research Boards (IRBs) or Ethics Committees to provide a literature review as it directs the research evaluators in determining groundbreaking work or not. Therefore this study shall present a literature review which assisted to refine the problem which was stimulated by the researcher's previous experience in her job (Hammersley and Atkinson, 1983). Specifically, the debate centers not on whether a literature review should be conducted, but rather when it should be conducted and how extensive it should be (McGhee et al., 2007). In Ethnographic research such as the current study, there is consensus within this qualitative tradition that, an in depth initial review of literature is needed (Creswell, 2009).

Many, including Parahoo (2009) have indicated that the structure and a literature review differs from study to study but whatever model the researcher opts for, there are critical aspects that are central to its development. For example, Parahoo (2009) indicates that all literature reviews must include an overview of the data search strategy that the researcher adopted and must importantly clarify their intended remit. This is a principle propagated by the Cochrane research group who disseminate literature reviews globally. To this end, a comprehensive data- search strategy is presented in the current study.

## **2.2. DATA SEARCH STRATEGY.**

For the purposes of this study, literature search has been focusing on articles reporting on child headed household, their socio-economic status, psychological trauma that they have been subjected to and issues around health behavior, health seeking behavior and access to health care services.

Different informative sources in the electronic data base such as Cumulative Index of Nursing and Allied Health (CINAHL), Google scholar, Medline and PubMed libraries were visited by the researcher in search of existing knowledge on the proposed study using the following key words:

- HIV/ AIDS pandemic
- HIV and AIDS orphan
- Child-headed families / household
- Families and vulnerable child health issues
- Socio-economic health factors related to children.
- Health behavior and health seeking behavior among children
- Child adolescent services
- Vulnerable children and health care
- Access to health care services

- Children / Education and access to health care for children.
- Government services for orphaned children in South Africa

When conducting the search, each phrase was used independently and also combined with one of the key terms to try and broaden the search parameters. To ensure local relevance, “South Africa” was used as a geographical parameter. Despite yielding a great number of studies that looked at HIV and AIDS, and its effect in the community, many of them were not adequately relevant to the subject under study, thus failed to satisfy the inclusion criteria set out below.

### **2.3. THE INCLUSION CRITERIA**

- The researcher’s literature search focused on articles reporting on HIV and AIDS pandemic, globally, sub Saharan Africa, South Africa and KwaZulu Natal province, namely, reported deaths due to the disease, effects on children, absorption of orphans by the extended family members and the emergence of the child headed household.
- Literature focusing specifically on the issue of access to health care services by such children is scant and proved to be limited during the researcher’s search process. Even so, the need for greater understanding of this area of study is very crucial, a fact that represents the reasons why this study was initiated and conducted.
- All studies, published and unpublished (grey literature), pertaining to children aged 12-18 living in child headed households were reviewed.
- Given the difficulties that exist in authenticating data from the worldwide web (internet) only literature from validated databases such as Medline, PubMed, CINAHL and the comprehensive OVID and Mendeley-2000 databases which include Ebsco Host, were considered for inclusion within the review
- Studies and other literary sources that specifically focus on child headed households and their vulnerability were also included in the literature review.
- Only studies, which were published in English, were included in the review.

## **2.4. THE REVIEW REMIT**

Preliminary searching of electronic databases and journals revealed a total of 89 studies relevant to the study area. After appraisal, only 59 studies were selected, mainly because the others failed to fulfil the inclusion criteria and had flaws, which if overlooked, would compromise the academic rigour of this review such as, unclear sampling and data analysis procedures. All the 89 studies were obtained in hard copy. Each study was read in full and assessed for relevance to the review, with reference to the inclusion criteria described above. Papers were read and assessed and for the 30 studies eventually excluded, these were re-read and re-assessed for relevance by the researcher.

## **2.5. PRE-REVIEW CONSIDERATIONS**

To ensure that a valid, coherent and relevant analysis of pertinent literature was carried out, the format and structure of the ensuing review was guided by predecessors such as Solomon and Doll (1999), Gruber (2012) and Polk-Walker et al (2003) whose work consistently highlight differing categories and structures of literature reviews. Guided by their work and more recent literature within the domain such as Rashid (2014) and Nelson (2013), this review utilises their categorisations and as such will broadly focus on thematic issues related to health behaviours amongst members of child-headed families. A thematic rather than chronological review of literature will be presented. Furthermore, the thematic sub-type focuses exclusively on exploring related themes and does not include a statistical pre-amble, as is sometimes the case in order review formats. Gruber (2012) advocates for this format and asserts the view that, the review of literature must be about literature and not statistical overviews as these are often referred to when justifying the need for a study and not as a tool for better understanding the prevailing arguments within a study area. Guided by this assertion, the current literature review focuses only on thematic debates and literature as it relates to the health behaviours of child headed families.

## **2.6. THEMATIC REVIEW OF LITERATURE**

### **2.6.1 Range of factors influencing access to health care services**

The researcher will be using a range of factors that have a direct and indirect influence on issues affecting access to health care services made freely available for all citizens, but there are perceived barriers to it. For the purposes of this study, it will be discussed under specific themes. A range of pertinent thematic focus areas including socio-economic factors, education, health, finance, housing and psychosocial factors emerged as the critical factors that are cited within literature related to access to health care services for adults. The reviewed data, although related to adult populations, has been utilized with the aim of eliciting some transferable inferences as related to children, since as noted prior, there is limited literature addressing issues of access for children in general, let alone those coming from child-headed households.

### **2.6.2 A Historical overview of literature related Child-Headed Households**

A brief analysis of related studies within the domain reveals an overall focus on the roles played by socio-economic, psychosocial and psychological factors, in determining, health behavior, health seeking behavior and access for child-headed families. As such, the current literature review will be based on a thematic review of literature under each of these pre-identified sub-headings. Polit & Beck (2008) confirm that literature reviews can either be presented chronologically or thematically. The latter is preferred primarily because it offers a meaningful way in which emerging arguments within the discourse can be collated and similarly, it offers greater prospects for identifying the knowledge gaps within the identified subject area.

Before an engagement in the review proper, it is important to briefly review some of the literature on foundational aspects that play a central role in the debates about access issues related to child headed families within health and social care services. To this end, it is important to review the notion of health as a starting point.

## **2.7. HEALTH: A DEFINITIONAL OVERVIEW.**

Health as defined by the World Health Organization (WHO) (1948) is a state of complete physical, mental and social wellbeing and not merely the absence of

disease or infirmity. Critics together with the researcher are in contrast to this definition, as it has not been challenged since 1948, on the basis that it can no longer be relevant in the 21st century when there is an emergence of burden of diseases. They argue that there is no one who can claim to be “completely healthy” especially with scourges of HIV and AIDS and social pathologies, if one is not infected but is affected, therefore physical, mental and social balance is not easy to maintain.

Bircher (2005) offers a direct critique of this definition and suggests that this definition should take into account changing health needs especially in relation to age, culture and personal responsibility and on that basis should allow for different types of “health” amongst different groups. This assertion concurs particularly with the current study’s target group, that is, children who are from child headed households. Being an orphan at such an early age represents a deviation from the original WHO definition of health but when moderated in line with Bircher (2005), it is possible for health to be achieved within this client group despite their intractable circumstance of disadvantage. It is important also to examine/review issues related to health from the added likely context of those children who are made to assume the adult role of a parent, caregiver and head of the family at a tender age, when they should be enjoying their youth or teenage life.

An ethnographic study focusing on Latino American women offers an interesting perspective by concluding that health, for this group was, at one point characterized, by a decline in the health status of affected individuals, Xu, Evans, Carrin & Aguilar (2005). This study, is in agreement with McCarthy (2004) who postulates that health and illness are connected to and interdependent to each other and differ from one population to the next so much so that, one’s health in one context may not be seen as an “acceptable state of health” for others in different groups with different expectations. With this informational backdrop, it is important to acknowledge that “access” is a particularly important health determinant for members of child-headed families given their history of exclusion from mainstream services.

Xu, et al (2005) conducted a study in West Africa in which they focused on challenges related to accessing health and social care services. The study acknowledges the continuing difficulties with access in spite of the many health reforms, and increasing government financing of health services to benefit low socio-

economic groups. Even so, Xu et al (2005) confirm that more than one billion people worldwide still have inadequate access to health care services. The other causes were political and socially based such as poor access to information, illiteracy and some cultural values, which are still upheld in place of western medicine.

Children from child-headed households are in dire need of quite a range of support from the government, community and non-governmental support groups. The study conducted by the WHO (2008) for the population of Gambia concentrates on the issues of access to health care services but only for children who are below the ages of five years, irrespective of the cause of illnesses. The findings were mainly the issue of distance (geographical), finance of health care cost. The study thus recommended a qualitative study to consider the additional barriers such as lack of social support for primary care givers, their limited autonomy in financial decision making and social exclusions at health clinics. The researcher is in agreement with this study because in South Africa all these elements of finances and geographical distances have been attended to, but still there is a problem with accessing health care services for children. The challenges related to access to health services represent one of the cited supports to the choice made by the researcher to offer an in-depth discussion of access-related issues as they relate to children from child-headed families.

## **2.8. HEALTH BEHAVIOUR AND HEALTH SEEKING BEHAVIOUR**

Health behavior as defined by Connor & Norman (1996) is an activity undertaken for the purpose of preventing, detecting diseases or for improving health and wellness. It is an action by the person to maintain, attain or regain good health and prevent illness. Health behavior reflects a person's health belief and lifestyle adopted. Gochman (1997) defines it as behavior patterns, actions and habits that relate to health maintenance, health restoration and health improvement. Behavior included here is the medical service usage ,this is done to comply with the medical regime and self-directed health behavior that promotes health like sticking to the correct diet, reducing to stopping use of alcohol and smoking, engaging constant exercise, safe sexual behavior and health screening as discussed hereunder.

## **Diet**

Getting the balanced diet in its correct proportions is ideal for healthy living, but in cases of children from child headed households, this is quite difficult to achieve. Children are living in extreme poverty, have absolutely nothing to put on the table, hence they take whatever is available to fill an empty stomach (UNAIDS, 2006). Children who attend school benefit a lot from the school feeding project, because it means that at least they afford to get one meal a day (South African School's Act, (Act no. 84 of 1996)).

## **Exercises**

Engaging in exercises is not a problem for children coming from child headed households because they are already engaged in manual labor in commercial farms trying to fend for their sibling at a tender age. It is hoped that during play, recreation and engaging in domestic chores, exercises will be covered because one is active during those processes. Therefore they would not have time to go for exercise at leisure because there is no time.

## **Health screening**

Health screening is an ideal situation for people so as to promote life. Children from child headed households are already having a problem of accessing health care services because of the legislated age limits. Even if they were aware of the importance of screening, they could not afford it (Blaxter, 1990). From experience, health assessment/screening is not honored by many African communities.

## **Sexual behavior**

All children need to be protected from diseases like sexually transmitted disease and HIV/AIDS. Children from child headed families are sometimes already infected, born with the disease or got infected while tending to their sick parents. The unemployment is very high, the extended families have failed to absorb them into their family structures, life is at a point where the eldest child needed to engage in commercial sex for a living and feed her siblings (Blaxter 1990). In an African tradition, there were strategies that were used to delay sexual activity until married

like virginity testing and sexual education by an appointed mature female person in the community.

## **Alcohol**

Alcohol consumption tempers with individual thinking and decision making. Uncontrolled high levels of alcohol is associated with accidents, crime, domestic violence, rape, murder and unprotected sexual intercourse and its complications (Conner & Norman 1996). Children from such households are at a high risk of abuse by the community members who know that they stay alone. Children themselves may indulge in all promiscuous behavior in an attempt to drown their sorrows or make money.

## **2.9. RELATIONSHIP BETWEEN HEALTH BEHAVIORS TO SOCIAL DEMOGRAPHICS**

People who are financially stable have a high tendency of attending to their health care needs and following a healthy lifestyle than those who are poor. This is further supported by the fact that they are educated, and having medical insurance, thus have ease of access to health care services. The children from child headed household are having a problem of access, and whether they are aware of their medical condition or not (usually HIV and AIDS management), they cannot access health care services as they wish (Bandura, 1997).

### **2.9.1. Health belief model (HBM)**

This model has two angles where we find people that know about the health and illness, and understand quite well all the predisposing factors to illness and wellness. This understanding then influences their health behavior. The perception of threat of illness and the evaluation of the effectiveness of the behavior counteract the threat. This evaluation guides the health behavior of an individual or group of families (Conner & Norman 1996).

Self- efficacy is defined as a means for encouraging health behavior change and is described in four main sources. Individuals develop feelings of self –efficacy firstly form personal experience, secondly, through observing other people, thirdly, through

the use of standard persuasive techniques and finally , one's physiological state may be used as a source of information ( Bandura, 1997)

A close correlation was reported between child morbidity and the quality of parenting style, where fostered children in West Africa experienced high mortality than the children from normal families, due to poor care, malnutrition and reduced access to modern medicine. Ayieko (2003) asserts that children from child-headed households are prone to household accidents, their caregivers are not as competent as maybe biological parents, and hence the mortality and morbidity rates are high with such children.

Conner & Norman (2002) advocated for health promoting behavior, since it is likely to support the development of healthy living characterized by delayed onset of chronic conditions, a high quality of life and high life expectancy. This requires people to be a role model to these children, since they were left without a parent to guide them until they reach adult age, therefore in the absence of a parent; all this cannot be learnt.

A close correlation was reported between child morbidity and the quality of parenting style, where fostered children in West Africa experienced high mortality than the children from normal families, due to poor care, malnutrition and reduced access to modern medicine. Ayieko (2003) asserts that children from child-headed households are prone to household accidents, their caregivers are not as competent as maybe biological parents, and hence the mortality and morbidity rates are high with such children.

There are many lives that are lost especially during the rainy season when children trying to cross the rivers, drown. There are no roads and often the bridge is destroyed by the rain, meaning even the mobile health services are unable to access clients. The clients on the other side of the bridge can be deprived of their basic right to health services for a period of two to three days; depending on how fast the rain subsides. The government through infrastructure upgrade and the building of solid bridges should address this form of impeded access to services.

One unpublished study commented about the issue of access to such children, citing that sometimes the fault is not with anyone from the team, but the children do not trust western medicine because they have witnessed their late parents admitted to

hospital, attending local clinics, getting sicker and sicker everyday whilst on treatment and eventually passing on. Mpeli (2007) then suggested that the issue of access to health care be approached from a psychological background, checking their confidence in the present health care delivery system, western versus traditional health so as to arrive at a more felt/perceived idea about health care, how effective, efficient and reliable are the services offered by the clinic? This may play a dual purpose of teaching the children about HIV and AIDS and the present treatment available for the public (Mpeli 2007).

## **2.10. ACCESS TO HEALTH**

Access to health care refers to the ease with which an individual can obtain needed medical/health services. The Rand National Security Research Division (2013) further examined the social, cultural, economic and geographical factors that influence health care access worldwide, the effects of changes in access, and the relationship between access and health for specific U.S. populations, including the racial and ethnic minorities.

Access to health is a basic right for all citizens of South Africa, especially children who are specifically designated as a vulnerable group. Even so, there remains some lack of clarity within existing policies and guidelines about how children from such household should be supported with regard to issues of accessing health care services. The Department of Social Welfare and Population Development (2008) engage in many strategies formulating guidelines for care, including the National Policy on Orphans and other children made vulnerable by HIV and AIDS. The policy strategies are concentrated on the provision of basic needs for affected children. Notably, the National Guidelines for Social Services for children infected and affected by HIV has a primary focus on attending to the psychosocial aspects of the child. Most of the activities within these guidelines are directed at stress reduction and social re-integration into the society

South African government policies offer specific guidance and directives about the issue of accessing social grants, housing, clothing and school uniform, feeding schemes and food hampers to satisfy wider social needs, but issues related to access to health care for this very vulnerable population remain unclear.

Sub-Saharan Africa is responsible for 68% of the global burden of HIV and AIDS infection (UNAIDS 2010). It has declined in other regions but remains high in the sub-Saharan region with 35% infection and 38% deaths due to HIV and AIDS (UNAIDS 2010). This increased statistic is of concern because children of 15 years old and above are included in the 45% new infections, and it is predicted that an estimation of 270 000 children below the age of 15 years will be infected and die of an HIV and AIDS related illness (UNAIDS 2010). With greatest concerns for issues of access for such children, where will they get their Anti retro viral treatment (ART's) now that they are freely available if this issue is not addressed as a matter of urgency? It must be kept in mind that some of these children have contracted the disease through mother and child transmission at birth whilst some contracted HIV and AIDS whilst tending to their sick parents (WHO 2008).

Most children born out of HIV positive parents are having equal chances of contracting the disease, thus in need of urgent measures to access treatment. In a district of Dindigul in India, where there are 135 infected children, with less access to health care services, high numbers of orphaned children who live alone, and the existing Home-based care network services not reaching quite all of them, poses a health challenge. Community projects aimed at assisting people with basic health care services are in place to fight the scourge of HIV and AIDS and improve health care services. The team members carry health treatments with them to give to their clients during home visits; this type of service is what communities need in the present day and age, because clinics are too full. The only problem is that the country is not financially viable to be able to afford the best treatment since children with HIV and AIDS who are living with the disease, are only given the cheapest available antibiotics, cotrimoxazole, which is responsible for opportunistic infections. They are in need of a company that could produce the Anti-retro viral drugs at a cheaper price so as to be able to provide the citizens with the right drugs to halt the progression of HIV and AIDS (Meera 2005).

Many studies in the area have been focusing on other issues that hinder the social integration of orphaned children into the extended families by Nziyane (2008), and Mkhonta (2006) conducted a study that dealt with the psychological and emotional support within a school environment, yet none attempted to focus on health behavior,

health seeking behavior and related issues of access to health care services by these children.

Xu, Evans, Carrin & Aguilar (2005) conducted a study in West Africa, because in spite of all health reforms, including government financing of health services to benefit the low socio-economical group, more than one billion people worldwide have inadequate access to health care services. Xu et al (2005) study concluded that, social exclusion in the form of disrespectful and discriminatory inappropriate cultural practices by members of the health team were the primary root factors implicated as causes of inaccessibility to health care settings.

Several factors affect health behavior, health seeking behavior and access, such as, socio economic factors, as will be discussed hereunder.

### **2.10.1. Socio-Economic Factors**

Health has increasingly become understood in terms of a range of socio-economic factors including education housing, material well-being including finance, education, psycho-social factors and legislation. The review will focus on current literary positions and what each adds to the discourse manifested within the area.

#### **2.10.1.1. Education**

The role played by education in determining issues of access to child health care services and some social services is widely debated in literature. Education as defined by WHO (2012) as that comprising consciously constructed opportunity for learning involving some forms of communication designed to improve health literacy including improving knowledge and developing life skills which are conducive to individual and community health.

Cadwell (1997) affirms that education plays a major role in the demographic transition and may also help to explain the close timing of mortality and fertility transitions. Women education in societies like Yoruba in Nigeria can produce profound changes in the family structure and relationships, which in turn influences both the mortality and fertility level, hence the saying “you teach a women you teach a nation”. Women are known for their influential roles across many ethnic groups, that is why teaching women is equated to teaching a nation because their influential power can never be over emphasized. Women are known for their child rearing

practices, and if a child is brought along the health behavior principles, that community through the socialization process will be healthier.

Many of the country's public schools face significant barriers when it comes to quality education of children. The problems may be due to various reasons including:

- Lack of significant funding,
- Small size of the school
- Limiting factors related to the communities being served, for example:
- Ineffective Teacher retention strategies.
- Inaccessible geographical location of the school.
- Lack of employment (Rahman 2000).

Evidence based studies in Sub Sahara Africa display the impact of HIV and AIDS on the education of a child as having the following repercussion's: only 29% of children continue with school after the death of their parents, whereas 45% dropped out of school despite the present government strategies of no school fees meant to promote basic education up to at least grade eight (Millennium Developmental Goals 2010). Children from child-headed households have higher illiteracy rates because their school attendance may have been affected by sick parents, making it difficult for a child to leave them behind and go to school. Hunter & Williamson (2002) support this statement by saying that some children are sick themselves, having contracted the disease whilst tending to their sick parents. UNAIDS (2009) suggested that, globally, anything up to 65% of children from child-headed families do not attend school compared to an average of 11.2% among those children in traditional family units. Some of the reasons cited for poor school attendance include the fact that, children from child-headed families tend to be more frequently tired and exhausted because of the household duties they have to perform before going to school, and sometimes because of disturbed sleep patterns due to sick parents. A tired child can never benefit from a normal school because the concentration span is low. Motihar (2006), in a study in India, concluded that children from child-headed family

households drop out of school to care for sick parents or to earn financially so that they can be breadwinners within their families. Those that manage to study further cannot go beyond grade ten (standard 8) because of financial implications (Ayieko 2003).

Another study conducted in Zimbabwe in (1999) in commercial farms, children work in the farms to earn a living and basic support services, and they had nothing at all, except what they get from the farm. The future benefits related to obtaining education are of secondary importance to affected individuals as they worry most about their present needs. There is large association between poverty in early years of childhood and poor academic outcomes at school (George & Lance 2005). This type of lifestyle is characteristic of the third world countries, which are still living below the poverty datum line. Children from child-headed households are easily exploited by potential employers, such that, a child of ten years can be found working in the farm, having not attended school at all (Motihar 2006).

Rural schools serve about 45% of the South African population (Statistics SA, 2009). Most of the time such schools are affected by political or tribal wars, and sometimes acts of nature (Tsunamie, Tidal Waves) making schooling impossible for the duration of time each and every year. Alexander (1998) states that there are many lives that are lost especially during rainy seasons when children are trying to cross the river, for example due to drowning. The government of South Africa through infrastructure upgrade, hopes to build solid bridges that should address this form of impeded access to services. The clients on the other side of the bridge are deprived of their basic right to health services for a period of two to three days; depending on how fast the flooding subsides. Rigorous implementation strategies need to be put in place to remedy the situation.

The conclusive picture is that children from child-headed families have poorer educational prospects than their counterparts from traditional adult-headed families, with both parents. The educational disadvantage has far reaching negative impacts on the lives of affected individuals. Educated children and communities, whether from a traditional or a child headed family, are aware of their health needs; they know when to use the traditional versus western approaches to cure ill health. These children also know when to consult health practitioners or indigenous healers in

cases of ill health and epidemics and seasonal flue. Children from such households have learnt a lot from their parents, it is only sad that there is not yet a formal platform for them to showcase their experiences, as to what they have learnt informally through the interaction with their parents (James & Pollard 2008) However, the adult child from the child headed household lacks adult support for reference.

Social support systems where caregivers and mothers and domestic workers share information, through peer encouragement, and knowledge sharing can play a significant role in reducing the barriers to accessing health care services for children in their care and supervision. Informal education through Community Based Programs (CBP) has an important role to play in educating the lowest category of the citizens, as it can reach quite a large number of people at the shortest time. Its advantage is that it is offered by the local community members who can be trusted, in a culturally sensitive manner in a language understood by all. This program enhances the uptake of health and wellness programs, by educating the communities' basic households tips for management of epidemics, diarrhea, cough and other chronic conditions, thus enhancing access to health care clinics now that the relationship of trust has been created by this caregiver or volunteer ( McCarthy 1999).

Education in general can increase the uptake of preventative care, which may lead to long run savings, since educated people understand health messages better and their access to health care services is driven by the need to get help and remain healthy. On the contrary, being educated does not guarantee good health or general wellbeing of an individual, as some of the educated people are stressed, with financial troubles. Social support is thus needed for a variety of health outcomes so as to improve depression and social functioning of an individual. It then transpired that education can assist in changing the ways in which the individual behaves, thinks and choices they make, this guided by the ethnicity and gender of an individual (Nelson; 2004).

Masondo (2006) maintains that education is a powerful vehicle that can transform societies and break the cycle of poverty; this is in line with Nelson (2004) who concludes that education empowers people so that they can live better prosperous lives and be in a position to make better choices for their lives. -

### **2.10.1.2. Housing**

A house is a basic need for everyone, especially children; they need to be brought up in a proper house that is going to offer protection against hazards and extreme temperature, and it should be of the correct structure so as to offer dignity to its inhabitants (Ayieko 2004). Foster & Williamson (2001) claim that the impact of HIV and AIDS on children and their families is perpetuated because of the fact that they're living in poverty, with poor infrastructure and lack of access to basic services.

The International Student Volunteer (ISV) (2013), the non-governmental organization offering services to children maintains that housing /shelter is the basic need which can never be negotiable, but children from such households are denied that fundamental right. Maslow's hierarchy of needs postulated that shelter is a basic need for every living being, the absence of it leads to an unmet need, which can be a source of ill health in many ways.

There is substantial evidence stating a correlation between housing (built environment) and both physical and mental health outcomes, adding to the burden of diseases among the ethnic minority groups (Barrett, 2010).

Health problems are common in areas of overcrowding; spread of communicable conditions, crime, incest and all forms of abuse are found in such households.

Voko', Cse'pe, Nemeth, Kosa, Kosa, Szeles and Adany (2009) in a study conducted in human settlement of Roma in Hungary indicated that population without a proper housing are equivalent to dead, because their living conditions are characterized by epidemics and high incidences of morbidity and mortality. This is affirmed by Manasta, Anderson, Ledogar, Cockcroft, Cockcroft; (2008) who indicated that such settlements had a high prevalence of diarrhea, coughing and respiratory problems due to overcrowding. Such communities are troubled by rats, no piped purified water supply, no proper disposal of waste, no electricity, still using coal and wood for energy supply, their access to health is non-existent because of the combination of the vulnerabilities. Their financial stability is limited because of unemployment and poverty.

The National AIDS Housing Coalition (NAHC) (2011) has declared the lack of housing as a threat to access to health. This is based on acceptance of evidence that

shows that, for vulnerable groups (children, people with HIV and AIDS and poverty stricken communities), one of the strongest predictors of adherence to treatment is the availability of a safe stable house.

Lack of stable housing contributes to the following:

- Low CD4 and high viral loads.
- Less adherence to anti retro viral treatments.
- High rates of child mortality rates.

These indicators are confirmed too by a study conducted on HIV positive homeless people of Chicago, whose viral load dropped to undetectable levels in 12 months of placement in a safe stable house, and this was an 80% reduction in mortality rates (Manasta et al 2008).

Kushel, Perry, Bangs, Clark and Moss (2002) states that homelessness and food security go hand in hand because they form the premise of poverty. House instability and food insecurity are associated with poor health outcomes, because the competing demands of these basic needs, may lead to the delay in seeking health care thus predisposing to acute emergencies. The study would like to highlight the strategies by present government of South Africa where the family profile of each household was conducted, and those living below the poverty line were provided with all social assistance to meet identified needs. Children in specific areas were afforded food parcels at the clinic levels, this was a way to improve access because the child has to be weighed first then immunized and all other ailments attended to before the food issue. The interesting part is that, all children with parents benefitted from such schemes, the only unfortunate group were those children coming from child-headed household, because there was no responsible adult to check all these details and keep appointments for the clinic, thus missed the program (Dept. of Social Welfare and Population Development 2007).

For some children who are living in severe poverty, having been admitted and discharged home with medication, the issue of a balanced meal before taking the medication is a problem leading to missed doses and increased morbidity and mortality in children. This is in line with the findings of a study conducted by Kushel et

al (2002) where housing instability and food security were found to have a barrier to health care access among the low income Americans.

Foster, Makufa, Drew & Kravolec (1997) together with Sloth – Nielsen (2004) are in agreement that housing is a basic necessity to such an extent that they even advocated for children not to be absorbed into an extended family structure but be assisted/supervised by an adult in their own household so as to retain those family memories and safeguard against their parental land, as it is a source of inheritance.

Gregstone, Marange, Foster, Shakespear, Chinamona, Mashumba and Jackson (1994) together with Zukow & Goldring (2002) assert that by staying together in their parental land they are honoring the last wishes of their late parents and avoiding the inevitable separation as they cannot be fostered or adopted by one family at once. The state of some houses is not good for children, as it has some cracks, the roof is leaking and windows sometimes broken, exposing them to draughts. The South African government in an attempt to address the problem is having the RDP (Reconstruction and developmental program) that is tasked with provision of houses to needy citizens, children from child headed households are legible to access such houses, but the waiting list is very long and it needed the intervention from members of the government ([www.grocotts.co.za/10/8/2014](http://www.grocotts.co.za/10/8/2014))

Chiastolite Professional Services (2008) are of the opinion that drop-in-centers could be utilized as the available safe half way houses whilst the social worker is dealing with the case of each family, citing that, children will benefit on the variety of services available such as healthy meals, after -school services, assistance with homework, clean clothing, life skills training. The greatest concern was the fact that adults and children are not aware of the available services in their local area, hence some children end up in unsatisfactory housing and accommodation.

Loening-Voysen and Wilson (2001) support the community based care programs and informal fostering of such children because it is cost effective as it does not remove the child from its ancestral land or home, but provide supportive care in their natural habitat. The challenge that faces some of them is the ability to maintain the house, payment of rates and electricity, and later the children find themselves evicted out of their parental houses because they have failed to pay for electricity or rates. This part needed urgent governmental intervention, because when a decision is made to keep

them in their late parental house, one should have anticipated this outcome, instead children lose everything in the hands of professional, whom they were looking up to for holistic care and support (Loening-Voysen & Wilson 2001)

The houses should also be built away from busy city traffic areas, because of the exposure to motor vehicle accidents, which presently account for 1.2 million deaths worldwide. McCathy (1999) predicted that by 2020, road traffic accidents would be the 3rd major cause of deaths. This is further affirmed by the present statistics that revealed that 50-60% of accidents occur in cities than in rural areas, but this does not totally exclude the rural child who might have visited the city and because of poor information got involved in an accident (WHO 2002).

### **2.10.1.3. Finance**

The role played by finance to determine access to health care services and other social care is widely debated in literature. The role played by government in addressing the financial reforms in health care delivery for the benefit of all citizens can never be over emphasized. In the year 1994, services were made free to children and pregnant women only; the resources were channeled to this vulnerable group. The scourge of HIV and AIDS and its impact indicated that if nothing were done for the rest of the population, the very same children would be without parents. Hence in 1997-8, some of the public health sector services were made free for all citizens at a primary health care level (DOH 1998).

Bequele (2007) states that a child who has lost both parents is left with nothing to sustain a living. Some children may sell off their land and inheritance to pay for hospital and medical expenses but it will never be enough because the cost of living is too high. The resources are depleted, and children need to look for employment so as to sustain a living. Tsegaye (2008) is in agreement with Bequele (2007) in saying that in such household 56% of children are engaged in unskilled labor, 35% hardly afford two meals a day, and 14% live without food a day, sometimes beg for food in the neighborhood. Some 20% live by food rationing and begging from the streets. Tsegaye (2008) found also that a girl child trades sex for food for the family, this was also confirmed by Nkomo (2006) who stipulated that the financial assistance and food parcels usually are depleted before the end of the month, so as the head of the family, she needs to provide food for the siblings, thus engage in commercial sex.

Van Rensburg (2010) defined the issue of access very well including the financial access, hence the government decided to make all services to be free, especially with the set target for 2010, which is health for all.

Clients are attended to at the clinic, and some are referred to the next level of care for specialized services, but because of high unemployment rate and poverty, fail to obtain money to travel to hospital. The next time they have to attend the clinic, will pose a problem because they will be expected to bring back the letter from hospital, thus leading to people not accessing the clinic because they fear their non-compliant actions brought about by issues of poverty. These issues need to be debated at another level of health care, because the health professional cannot call an ambulance for a person who needs to go for an eye checkup or dental carries, since this is not a medical emergency.

The issue of access for children from child-headed families is also a problem because the responsible caregiver/volunteer can accompany a child to a local clinic, but in cases of referral to the next level of care, the ambulance can take the child with the volunteer to hospital but can never take the volunteer back to the clinic or pick up point. This is documented down in the EMRS document (DOH 1996). Financing the escort of children to hospital should be dealt with thoroughly as it is viewed as another barrier to accessing health care services for children in such household.

The WHO (2007) and its affiliates entered into partnership to strengthen the health care delivery to all nations. The Millennium developmental goal, especially 4, that deals with the reduction of child mortality was adopted, but the rate of child deaths is still high.

Government revenue is responsible for 43% of health care funding, and since these services were made free to all, the issue now is that the government funding for health is not keeping pace with the inflation rate and the population growth, Van Rensburg (2010). This then resulted in poor service delivery in public health care settings manifested in many ways ranging from staff shortages, long waiting time and unavailability of drugs and immunizations in some clinics, thus leading to clients not accessing the clinic.

The gap between the poor and the rich is widening in spite of all strategies by government to increase access to all citizens by making it free. Those who can afford medical aid scheme are better off because they are not subjected to all the mentioned characteristics of public health services, and the exorbitant fees charged by private specialist make it better for them to access quality care. This is done at the expense of children who should be prioritized for quality services. The government is funding the private medical aid scheme which is benefitting only 16% of the population, the remainder is dependent on the public financing system, 17 % use private health sector on an out of pocket basis, (self-employed categories), and when there is a need for admission, they either use private or public sector depending on the business output at that particular time, whilst the remaining 67% is totally dependent on public sector for quality health care provision (Van Rensburg 2010).

The introduction of the National Health Insurance (NHI) by the government is also a strategy to bridge the gap between the elite and working/unemployed citizens, where children are the most vulnerable and their access to health care should always be promoted. The former apartheid government made it difficult for a person coming from the working class to access better health services because it was paid for. Services were not comprehensive and not user friendly for the working class. This promoted the class structure where the "haves and have-nots" were viewed as normal patterns of society yet it was embedded in the apartheid regime that was benefitting only the elite class, and not representing a democratic society (Giddens 1994).

Van Rensburg (2010) together with the Department of Health conclude that for a nation to be healthy, all services at the entry level (clinic) should be made free for all citizens to improve access to health care. This promulgation was even binding to the private sector in the sense that, if you happen to be next to a private hospital and you are involved in an accident, that private sector (hospital) has an obligation to stabilize you and then refer to a public institution if you do not have private health insurance (medical aid) (Transformation of Health Services 1997).

The high rate of unemployment and depreciation of the rand value make it impossible for an ordinary person to access quality health care at a price that can be

afforded by all, hence all services in South Africa post 1994 were made free to all (UNAIDS & UNICEF 2006).

Varied grants are available to all citizens but the value is not enough to cover all the daily living expenses, making it even difficult for a client to afford to go to hospital for specialized services having been referred to, at a clinic level. The Minister of finance in a parliamentary speech asked the cabinet on issues of finance as to "how much is enough" (Parliament today, SABC 2 channel 2007, March 8). Speeches like these are usually followed by a change in the government strategies. As early as 2008, the present government was sure of the NHI as the only strategy that could bridge the gap between the poor and the rich in accessing quality health care.

#### **2.10.1.4. Psychosocial factors related to access to health**

Psychosocial influences include those factors that affect a person's psychological or social state of being. They involve feelings, behavior, mood changes, socio economic factors and attitudes. The internal and external environment of a person is influenced by his/her psychosocial status. A well-balanced psychosocial state of a person is an indicator that a person is healthy; there is a balance between the stressors and the coping mechanism. Once that equilibrium is disturbed, the person is not healthy. Disturbance of the health continuum is evident by many cycles of illnesses that may or may not be accounted for, ranging from a general feeling of being unwell, to specific symptoms relevant to a specific condition (Phillips 2011).

The fact that a child below the age of 18 years has taken responsibilities traditionally seen as being for adults within a household is a stress on its own (Awino, 2010 and Rosa, 2004). Awino (2010) and Rosa (2004) are in agreement to the fact that, this child is ill prepared for such a huge responsibility resulting in stress related symptoms. Tsegaye (2008) further explained the terms as accompanied, meaning a household where the head of the family is responsible for both the finances and head of the family but where the adult is still alive but incapacitated by illness or old age as well as unaccompanied, meaning that there is no adult in the household, the child is responsible for both the finances and the running of the household.

Children from child-headed households have been exposed to serious traumatic events, so they are already psychologically disturbed, except that they have not been

assessed professionally. Phillips (2011) and Chizororo (2010) assert that the HIV and AIDS pandemic is responsible for child-headed households, and about 80% of such households are located in Sub-Saharan Africa

The children themselves grew out of very difficult circumstances, they have witnessed their parents getting sicker and sicker until an eventful death all by themselves. Their psychological development has been affected (South African Institute of Race Relations (SAIRR) 2009). UNAIDS & UNICEF (2006) outline that such children are confused and angry and often choose the incorrect defense mechanism.

South Africa has better strategies to assist such children because there are in place guidelines for care of such children by the government, as compared to Thailand where children whose parents died of AIDS are discriminated against by both the school and the community, making them social outcasts. These children end up doing domestic duties at a tender age to sustain their families (Pita yon, Kongsin & Jan-Jaroen 1997). Health behavior of such children is affected by financial implications, since their access is governed by availability of finances to sustain a living (Bequele 2007). In developing countries, the socio-economic impact of HIV and AIDS on children has been overshadowed by the concern for basic physical needs like food, clothing and shelter (Foster et al, 1997). In their study, Foster et al (1997) warn that the focus on maintaining basic needs that are critical for survival, may inadvertently result in affected individuals being denied access to emotional and psychological care, all of which can have long-term effects on the child and his/her behavior in later life.

Sengendo & Nambi (1997) state that stigmatization; dropping out of school, changed friends, increased workload, discrimination and social isolation of orphans all increase their stress levels due to trauma and death of a parent. Some children will display a changed behavior pattern including aggression, low self-esteem, stealing, and truancy and running away. Other children will display delinquent behaviors, crime, and prostitution.

Support groups that assist individuals or groups are ideal for children coming from such families. The group helps with personal growth, building of self-esteem and self-worth. It is in the group/team that they will be able to share their experiences, convey

information and get practical advice on different forms of treatment available. (USAID 2008) The success of the group is dependent on the facilitator, who should possess special skills to address gender, age, and cultural sensitive issues. If all these aspects are taken care of, access of children to health care will be improved.

Foster et al (1997) maintains that such children experience stigma and suffer rejection from the other members of the family and society, whilst Franklin, Drelech & Fitch (1998) claim that the grieving /mourning period is very difficult because as they mourn the passing of one family member, the other one is still critically ill, may die at any time. This leads to a situation/position called the survivor's guilt "where you blame yourself for the family member" wishing you could have done more to sustain them. Papalia, Olds & Feldman (2001) concludes therefore that children who grow up in such conditions, with no emotional attachment to the biological parents in their first four years of life become "affectionless partners" in their later life, and this has a devastating effect in the future if married, most of them end up in divorce.

The fear of rejection and discrimination by their peers, family and society is sometimes so high that the children become introverts, especially if their parents' HIV and AIDS status was not a secret. Serious discriminatory incidences have been reported across provinces in KZN in 2003, for example, a lady was murdered by her boyfriend in cold-blood for disclosing her status.

The present governmental policies are sometimes rigid, making it difficult for a child to access basic services made available to him. The issue of age, a 12 year old is not allowed to access health except if coming for reproductive services only. This could denote some form of discrimination on the part of a child by age in years. The very same child is the head of the household, but there are decisions that are presumed to be bigger than his/her capabilities to head the family, and this could be a source of stress leading to some children deserting the family and disappearing with no trace. The responsibility becomes too much, overwhelming with no strong support. Some children are at greater risk of displaying abnormal behavior, emotional and social maladjustments like disobedience, impulsiveness, and problems with the peers, poor relations and low self-esteem (Mackian 2003).

The government has many forms of support in materialistic manner, to enable a child from a child-headed household to live a happy and well-integrated life like any

normal child. However in the life span of such children, there is no one to offer/give love and affection, someone to turn to for help, guidance, advice and protection. In times of crisis children need someone to give them hope for the future, to help them develop to their full potential like other children in a normal household? Children like these, lack social energy to enable them to take up possible opportunities that arise to develop a positive approach in life.

Mackian (2003) contend that children's psychological and personal state sometimes make it difficult for them to make some informed decisions regarding their health status, irrespective of age and reaching emotional maturity. This is because other children in the house rely solely on the eldest for support, emotional and social guidance, thus creating an unbearable strain on the young but eldest child (as the head of the family), This issue may pose as a problem in cases of informed consent regarding health care for the child, access to the clinic and the realization of the seriousness of the illness at a given circumstance.

Conner & Norman (2002) argue that the health behavior of such children will be affected, and this is confirmed by Miller & Kean (2003), because this is not preceded by an involved/well-informed decision made by an individual who understands health and could identify any deviation from it.

#### **2.10.1.5. Health legislation and access to Health Care Issues**

The transformation of health services that took place after the first democratic elections in South Africa (1994) laid the foundation for universal access for all to quality health care service, offered primarily via a primary health care package. (White paper-Titled "Transformation of Health Care Services" South Africa, 1996). Many efforts have been made from the political and governmental stand point in terms of policy development over the past two decades in response to the global and country's imperatives regarding the scourge of HIV and AIDS (DOH, 2012). Children and pregnant women were the priority groups to receive such free services, lots of infra structural development and resources were put forward for this special group. Skelton (1998) states that this was a great move by the government because all children, irrespective of age and social standing, were treated free of charge in all public health sector institutions. Orphans and children from child headed household

were to benefit equally from such services irrespective of whether in possession of a clinic card or not, (UNICEF 1995).

The Department of Health had to offer in-service training to staff so as to be in line with the new modalities of comprehensive health care for children. A strategy called Integrated Management of Childhood Illnesses (IMCI) was adopted as from 1996 by South Africa to guide the management approaches to children's health. This approach makes it easier for a nurse to comprehensively assess the child with little input from the mother or child minder. This is deemed best for children coming from child-headed households because they have no one to give their health history (Dept. of Health 1997).

The Constitution of the Republic of South Africa Act (Act no 108 of 1996), section 28, provides for the basic human rights, where rights of access to health are enshrined. The Child Care Act (Act no 41 of 2007) deals specifically with matters relating to children's access to health, shelter, nutrition and basic social services. For the study the researcher will deal specifically with issues of access to health care services, because as promulgated by the government through legislation, there is a grey area as to what the law states about the child from child headed household. The health care professional who is supposed to be well vested with the care of such children are left in the dark because there is no clear guidelines on it, thus making it difficult for a child to access services.

The Primary Health Care Clinic Charter (1996) specifies, that the acceptable age for an unaccompanied individual to be seen in a clinic is 16 years and above. This was based on the fact that in the Republic of South Africa, you can apply for an identity document at this age which qualifies an individual to access some benefits in the country such as support grants (child and social). The very same person with an identity document, however, is still regarded as a child, because the age of maturity is 18 years.

Moreover, in the year 2011, the Child Care Act no 47 of 2007 made a special amendment to the age of accessing the health care services to be 12 years, but this was only for reproductive services. This poses a challenge for a 12 year old who wants to bring her sibling to the clinic as he/she needs to explain her reasons for the visit to someone else, such as the security officer, before reaching the health

professional who is the right person to make informed decisions about such children including issues of confidentiality.

Burgos, Schetzina, Dixon & Mendoza (2004) reported that the issue of access for Mexican American children had lesser /much lower levels of access and utilization of health care services when compared to Hispanic children. This calls for a greater support to the present government of South Africa for affording the citizens such a right which is not readily available in other countries, which are being viewed as living in the first world.

Shah (2013) reported that 1 billion children live in poverty, 640 million live without adequate shelter, 400 million have no access to safe water and 270 million have no access to health care services, leading to 106 reported deaths of children before reaching the age of five (5) years in 2003. This report purports that there is a relationship between poverty and health, as in areas of intense poverty there is also high morbidity and mortality rates.

Mahoney (2005) asserts that the issues affecting access to health care services for Mexican/American health care is mainly based on culture and language, ethnicity and the fact that they are immigrants, thus some services are not meant for them. This is not the same in South Africa, everyone accesses health care services, but other benefits like grants are for citizens only. There are other reported issues like physicians who are incompetent in attending to other health care issues making it better for immigrants to attend to their health needs the traditional way. Lopez (2005) is in agreement with Mendelson (2003) in stipulating that it is common cultural practice for Mexican/Americans to practice both western and traditional medicine at once, as it is confirmed by an ethnographic study which concluded that they consistently integrate both practices. Raising their children is an integrated approach to health care where in they strongly maintain family health by providing good nutrition, exercise, Mexican teas, soups, plant/leaf rubs and over counter medicine.

The government of India has been critiqued for having health policy that promotes the discrimination of the poor at the benefit of the rich. This is qualified by only 17% of the health expenditure borne by the government, leaving the remaining 83% for the better off population who can afford out of pocket payments. This gross under spending on health is responsible for the growing inequalities in health care delivery

mainly at the primary health care leading to reduced utilization by the public (WHO 2003) This is affirmed by the Indian Institute for Population Sciences (1998-99) in saying that an ordinary child from a poor family has 2.5 times more chance of dying because of poor health access, how much more to those children coming from child-headed households?

The New York City Government (2001) is also having a discriminatory health insurance that promotes segregation on the basis of economical indices. Health care system is funded on a special model that caters for specific economic classes, even the children depending on the family financial status. Statistics reflecting the health insurance coverage as in 2008, states that 7.4% children were not insured at all, meaning their health status was not in the government plans, only parental responsibility. The eligibility for any form of health funding is proof of employment, with such high unemployment rates, the gap between the rich and the poor will continue to widen with the resultant high mortality rates of children from low socio economic status like those coming from child-headed households.

The uninsured children are less likely to go for routine health checkups. Their use of medical, dental, eye and other basic health services are reduced such that the access is as good as not there because the quality of services received cannot be compared to those with health insurance. Eighty seven percent of the South African population is medically uninsured and unlikely to attend health facilities for health screening (Van Rensberg, 2010). Children from child headed households would therefore be in the worst position to access such, in addition to their own unique issues of access while the need may have been increased by the acquisition of HIV and AIDS from their late parents.

Harper & Jones (2009) advocate for revised policy development that will tackle the issue of children's right in more detail, inviting major stakeholders like UNICEF & WHO, so that it can be addressed at a world level and be binding so as to stop this fragmented service delivery to children and other vulnerable groups.

Children in child-headed households are vulnerable largely because of being aged below 18 years, they have limited rights within health services and often need adult assistance to gain access to health and social care (Bequele 2007). The increased risk of poor nutrition and housing also predispose to low immune system, thus getting

sicker is quite frequent with them, and resources are depleted long before they are left to fend for themselves. (Bequele 2007).

## **2.11. SUMMARY OF THE CHAPTER**

This chapter presented in-depth discussions on the literature around issues of access to health care services in different themes for children coming from child headed households. Challenges facing children, strengths and weaknesses of the present structures, as well as possible turn around strategies were highlighted. The next chapter presents an overview of the epistemologies and theoretical perspectives that were centrally used to provide a philosophical stance of the study and related decisions related to the research process and its logic. Finally, the chapter will focus on the theoretical framework that was utilized as a basis for guiding data collection processes within the study.

## **CHAPTER THREE**

### **PHILOSOPHICAL AND THEORETICAL UNDERPINNINGS OF THE STUDY**

#### **3.1 INTRODUCTION**

This chapter introduces the theoretical and philosophical underpinnings of the study respectively.

#### **3.2 THEORETICAL UNDERPINNINGS**

This section describes the rationale for inclusion of the theory in the study including the description of the theory that underpins this study.

##### **3.2.1. Debate about theory in qualitative research**

Whilst debates in qualitative research embrace emergent categories of data and theory without pre- conceived ideas (foreshowed problems) to avoid contamination of data especially in grounded theory, some scholars like Creswell (2009), Bryant & Charmaz (2007) and Hammersley and Atkinson (1983) advocate for the use of a 'theoretical lens'. These authors believe that the world is always perceived through 'lenses' which may be some conceptual network or theory. These networks and their language may provide an unavoidable 'tint' to what the researchers perceive, otherwise failure to use such theoretical lenses, may deprive them the ability to identify meaningful or relevant data. Bryant & Charmaz (2007) refer to this statement as 'theoretical sensitivity', that is, ability to have theoretical insight into one's area of research.

Creswell (2009) asserts that in qualitative research such as Ethnography, enquirers employ / adopt theory as a broad explanation. Furthermore, Creswell (2009) together with Bryant and Charmaz (2007) and Harmmesley and Atkinson (1983) agree that a theory can be used as a "theoretical lens" or perspective that raises the research question, problem or phenomenon. These authors further agree that a theory can be generated inductively from a qualitative data and analysis in which case the theory appears at the end of the study. Therefore this study is underpinned by theory based on aforementioned arguments by respected scholars of various qualitative approaches.

In the context of this research study, theoretical frameworks refer to the overall conceptual underpinnings of the study (Grove, and Gray 2013). Furthermore, they serve to guide and generate ideas for the research and can be utilized as the foundation for new theories (Polit & Beck, 2008). When applied inductively, a theoretical framework governs decisions made in the research process.

The meanings of the terms 'theoretical framework', 'conceptual framework' and 'grand theories' are not the same. Most of the time these concepts are used interchangeably in the research process. This is because the aim of each is not to clarify theoretical thinking but to provide information required to use concepts, relational statements and other theories to help develop studies and interpret findings (Grove and Gray, 2013).

Groves and Gray (2013) define a framework as an abstract logical structure of meaning that guides the development of the study and enables the researcher to link the findings to the body of knowledge used in nursing. Theoretical and conceptual frameworks play several interrelated roles in the progress of scientific research. Their overall function is to make research findings meaningful and able to be generalized. Theories also allow the researcher to knit together observations and facts into an orderly scheme, and are an efficient mechanism to draw together accumulated facts.

Polit & Beck (2008) further state that theories and conceptual models guide the researchers' understanding of not only the natural phenomenon under study, but also the reason why such a phenomenon occurred. Thus assisting to summarize and integrate what is known about the phenomenon more succinctly.

The inclusion of a theoretical framework within a study must be appropriately conceptualized within the context of epistemology and as such, it is important that key concepts are clarified and integrated into the discussion about the application of a theoretical framework within a study.

### **3.2.2. INDUCTIVE APPLICATION OF A THEORETICAL FRAMEWORK**

Inductive reasoning commences with the observation of a specific instance, and seeks to establish generalizations, and this is exactly what the researcher did during the data collection process, where varied methods were used. For example, the

observations of children in their natural settings. Observations of children in their natural setting were the main component that initiated the formulation of the interview guides. Qualitative research always follows the inductive process, as their primary aim is to achieve maximum understanding of a particular situation, of individuals, a group or culture [rather than predicting the future behavior of the experimental groups (Bendassolli, 2013)]. Induction is the form of reasoning based on the empirical observation in the process of developing scientific laws and theories, thus induction negotiates the relationship between empirical reality and its theorization, in addition to the production and validation of knowledge.

Bendassolli (2013) further states that the problem of induction is that knowing facts is equivalent to identifying causes and effects, however, observing facts, describing them in their manifestations does not amount to science. There must be a leap from the visible to the invisible, and that is where induction lies

### **3.3. DEDUCTIVE APPLICATION OF A THEORETICAL FRAMEWORK**

Deductive reasoning commences with generalizations and seeks to see if these generalizations apply to specific instances. Deductive thinking is one that begins with a theory or abstract principle that guides the selection of a particular method to gather data to support or refute the theory or principle in question.

In the current study, the theoretical framework will allow for the overview of the topic in respect of the current focus on children, care givers and volunteers' lives. With regards to meeting their health needs especially in relation to the issue of access to health care services. It is important to have a theory that guides you to understand human needs and the processes by which communities can identify their wealth and their poverties. The traditional concept of poverty is limited and restricted as it refers to the people's predicament as they are classified as living below a certain economic threshold. This term is highly economist, as it is used to cover for any failure in meeting the basic/fundamental human need. Poverty can be experienced in cases of insufficient income, food and shelter. Max-Neef (1983), a Chile economist writes about the human developmental model based on the fundamental needs of a human. He stated that human needs are few, finite and classifiable from the conventional economic wants, which are infinite. Human needs are constant through all cultures

and across time periods, but what changes over time between the cultures are the strategies by which these needs are satisfied. Human needs can easily be understood as systems that are interrelated and interactive. Meaning they are simultaneous, complimentary and trade-offs are features of the process of need satisfaction. This is affirmed by further work of Max –Neef (1983), where he stated that all human needs are interrelated except for the need of subsistence (to remain alive), where there are no hierarchies.

### **3.4. Applicable theories.**

#### **3.4.1. Health Belief Model**

This model has two angles, where we find people that know about health and illness, and who understand quite well all the factors that predisposes one to illnesses and wellness respectively. This understanding then influences their health behavior. The perception of threat of illness and the evaluation of the effectiveness of the behavior counteract the threat. This evaluation guides the health behavior of an individual or group of families (Conner & Norman ,1996)

The health belief model also incorporates the concept self – efficacy, which expanded in the Social Cognitive Theory of Bandura (Bandura, 1997)

Self –efficacy is defined as a means for encouraging health behavior change and is described in four main sources. Individuals develop feelings of self-efficacy firstly from personal experience, secondly, through observing other people, thirdly, through the use of standard persuasive techniques and finally, one’s physiological state may be used as a source of information (Bandura, 1997)

Children in child headed household may be immature to perceive the threat, thus their behavior will be directly exposing them to it.

#### **3.4.2.. The social cognitive theory**

The social cognitive theory has been predominantly used in psychology, education and community, but it is also applied in health. This theory states that survival of humanity is dependent upon the replication of actions of others or modelling behavior, predominantly by parents who are not available in the case of child headed household.

The social cognitive theory further postulates that there is a dire correlation between a people's perceived self –efficacy and behavioral change. Self-efficacy comes from four sources, namely performance accomplishment, verbal persuasion and physiological states.

Bandura (1997) in his social cognitive theory argues that human behavior is caused by personal and environmental influences.

Children in child headed household tend to lack parental models therefore may adopt unbecoming behaviour from the environmental influences, or unguided physiological states or verbal persuasion from peers.

### **3.4.3. Comparison of the theories**

While the health belief model and the social cognitive theory apply to this study in terms of behavior , the researcher prefer to use the Max Neef theory as the focus of the study .Health belief model and social cognitive theory focuses on behavior, and Bandura has also applied it in health behavior. While these theories are not used in the study, they will be incorporated where appropriate

### **3.5. Max-Neef Model of Human –Scale Development**

Max-Neef a Chile economist who has worked with the problems of development in the Third World developed this model as an alternative to the conventional models of development which he believed were inappropriate and worsening poverty. Max – Neef formulated a taxonomy of basic human needs and a process by which communities can identify wealth and poverty, according to how these needs are satisfied. Max-Neef's taxonomy distinguishes between needs and satisfiers, that needs are few, finite and classifiable. Further that needs are constant throughout all cultures and across historical time periods. However, Max-Neef maintains it is only the way the needs are satisfied that changes over time. Furthermore, needs must be viewed or understood as a system within which they are interrelated and interaction without a hierarchical relationship as postulated by Maslow, with the exception of the subsistence or survival needs. Hence the development of a 36 grid model of human needs. Refer to table 3.1.for the diagrammatic representation of Max –Neef's model.

**TABLE.3.1. MAX –NEEF THEORY OF HUMAN NEEDS- ORIGINAL**

<b>Need</b>	<b>Being (qualities)</b>	<b>Having (things)</b>	<b>Doing (actions)</b>	<b>Interacting (settings)</b>
<b>Subsistence</b>	physical and mental health	food, shelter, work	feed, clothe, rest, work	living environment, social setting
<b>Protection</b>	care, adaptability, autonomy	social security, health systems, work	co-operate, plan, take care of, help	social environment, dwelling
<b>Affection</b>	respect, sense of humour, generosity, sensuality	friendships, family, relationships with nature	share, take care of, make love, express emotions	privacy, intimate spaces of togetherness
<b>Understanding</b>	critical capacity, curiosity, intuition	literature, teachers, policies, educational	analyse, study, meditate, investigate,	schools, families, universities, communities,
<b>Participation</b>	receptiveness, dedication, sense of humour	responsibilities, duties, work, rights	cooperate, dissent, express opinions	associations, parties, churches, neighbourhoods
<b>Leisure</b>	imagination, tranquility, spontaneity	games, parties, peace of mind	day-dream, remember, relax, have fun	landscapes, intimate spaces, places to be alone
<b>Creation</b>	imagination, boldness, inventiveness, curiosity	abilities, skills, work, techniques	invent, build, design, work, compose, interpret	spaces for expression, workshops, audiences
<b>Identity</b>	sense of belonging, self-esteem, consistency	language, religions, work, customs, values, norms	get to know oneself, grow, commit oneself	places one belongs to, everyday settings
<b>Freedom</b>	autonomy, passion, self-esteem, open-mindedness	equal rights	dissent, choose, run risks, develop awareness	anywhere

The needs identified by Max-Neef are subsistence, protection, affection, understanding, and participation, recreation (leisure, time to reflect or idleness, creation, identity and freedom. This taxonomy or classification of needs is associated with existential categories of being, having done and interacting that is, what one becomes is one has or does not have those needs satisfied, actions or practice to satisfy the needs including the setting / contexts in which these needs are satisfied. Max-Neef, further classifies needs according to how they are met in terms of the numbers of needs met in one time, for example, whether one need is satisfied (singular satisfier) or given need while simultaneously contributing to the satisfaction of the other needs (synergistic satisfier), false claim to satisfy a need with no effect (pseudo satisfier), over satisfaction of another (inhibiting satisfier) and finally claiming to satisfy one need while making it difficult to satisfy a need.

To apply this theory in the current study, the researcher reflects on the child headed household families without parents to socialize, protect, love, and provide for. This is compounded by the fact that these children may already be infected or affected by HIV and AIDS acquired from their late parents, making them sickly and requiring close monitoring and care.

Max-Neef asserts that needs do not change throughout culture, therefore the researcher assumes that the child headed households in the context of the study will have the same needs though satisfying them may be unique to the context or the country. However the context of the study and that of Max- Neef (Chile) share the developing status making the likelihood of the needs being the same even higher though the culture and historical times may be different and Hammersley and Atkinson (1983) believed that the theories or models can be used at different stages of the study and the researcher in the current study aspires to use this study to fit the inductively collected data in a template style analysis. This would help contextualize the data and follow identified limitations of the current study.

### **3.6. PHILOSOPHICAL UNDERPINNINGS OF THE STUDY METHODOLOGY**

While several methodologies and methods are consistently chosen in the development of the research proposal, Crotty (2011) asserts that the use of methodologies must be justified with the epistemologies and theoretical perspectives to provide a philosophical stance or context that underlie the research process and its logic. This study follows the constructionist theoretical approach. Crotty (2011) states that the social enquiry, as in human sciences, needs to focus on subjective meanings and values of people or participants. Hence, reference to inter-subjectivity that occurs through social interaction, language and written text (Gephardt 1999). It is also asserted that meaning or truth comes into existence from engagement with realities in our world to derive the essential features of shared meaning and understanding. The components making the philosophical underpinning of methodologies include ontology, epistemology, paradigm, and methods (Crotty, 2011). Ontology describes nature of reality while epistemology analyses the relationship between the investigators/inquire and the phenomenon under study. The paradigm, on the other hand, guides one's approach to inquiry or research methods refer to the data collections strategies relevant for the chosen design and/or approach (Polit & Beck, 2009 and Crotty, 2011). These components will be dealt with in more detail hereunder.

#### **3.6.1 EPISTEMOLOGY**

Epistemology is the science of knowledge. It is the branch of philosophy concerned with how individuals determine what is true. Ethnography promotes the understanding of the view and behavior of humans who live and interact with each other within a common social and cultural group. The epistemological foundations of ethnography share some fundamental assumptions with the theory of constructionism or the principle that knowledge of meaning and its reality is constructed by humans within a historical social framework (Crotty, 1998). He further assesses that the reality of the world and its objects exist in partnership, and constructionism blends objective and subjective knowledge to make meaning. People therefore construct meanings in different ways from one area and culture to another, based on the socialization process and time frame.

Craig & Muller (2007) purport that language is central to the social construction of meaning. Paradoxically the “communication” process is influenced by the culture of the people in the area, verbal and nonverbal language, cultural artifacts, values, norms and assumptions. Hence construction of meaning through language is not a clear and straight forward process. Barriers to communication between the sender and the receiver exist, whereby misunderstandings take place leading to different meanings being constructed.

### **3.6.1.1 OBJECTIVISM**

The objectivist believes that meaningful reality exists out there, and that human beings simply need to discover it. Objectivism asserts that meaning is already inherent within the object being examined and the properties of that object can be measured and quantified. It subscribes to positivism and the foundational assumption that events have causes, which are distinct and analytically separate from them. These methods are mainly used in quantitative studies where they study objects, and they can be controlled since they are predictable, unlike human beings.

### **3.6.1.2 SUBJECTIVISM.**

This epistemology purports that meaning emerges from a vacuum; it does not come from the interplay between subjects and objects, but is imposed on the object by the subject. Objects are passive recipients of the meaning, and they have no say about it. Human beings (subjects) are responsible for making meaning out of the situation or phenomenon guided by social culture, perceptions or external forces, and thus meaning is very subjective as it is dependent on the dominance of the social group.

### **3.6.2. THEORETICAL PERSPECTIVE.**

A suitable theoretical perspective that builds on constructionism is the interpretivist theory, which has its foundations in the 19<sup>th</sup> century and was popular with sociologist, Max Webber. He advocated for the interpretivist as the only basis for understanding in social science, however Crotty (2011) views interpretivist as the process of empathetically, interactively and insightfully interpreting the social world. Ethnographers embrace interpretivist through the use of analytical processes that seek to understand the meaning and the value and the interpretations constructed by

and between individuals within the context of their social groups. Ethnographers share the epistemological tenets of constructionism and the theoretical assumption of interpretivist as a correct methodology for the study on the premise that when members of the human/social group interact with each other, through the use of verbal and nonverbal communication, meaning and culture is developed.

### **3.6.3 RESEARCH PARADIGM**

A research paradigm is a philosophical statement, worldview or one's belief about the real world. It provides the researcher with guidance and perspective regarding the phenomenon under study. It can also be viewed as a basic set of beliefs that guides a research or a set of philosophical assumptions, concepts or practices that constitute a way of viewing reality for the community that shares them, especially in the intellectual discipline. These assumptions guide one's approach to enquiry or research (Polit & Beck 2008). Cohen, Manion & Morrison (2000) define research paradigm as a broad framework which comprises perceptions, beliefs and understanding of several theories and practices that are used to conduct a scientific research. It is also important to note that philosophies are not isolated or cut-and-dry periods, but there tends to be a time period where one's philosophical ideology becomes dominant over others. Houser (2008) states that paradigms are an overall belief system or a view of the world that strives to make sense of the nature of reality and basis of knowledge.

Constructionists extend their concern with knowledge as produced and interpreted to an essential level. They argue that knowledge and truth are the results of perspectives, all of which result in an inter-play between subjects and objects (Berger & Luckman 1967). Constructionists also view knowledge as being actively constructed by individuals, groups and societies, and not merely as information simply transferred from generation to generation. This statement is further qualified by Crotty (2011) who states that one incident or phenomenon may occur in three to four different parts of the world/country, but the meaning constructed or the interpretation of such a phenomenon will be different to each country. Meaning creation is governed by the socialization processes of the people of that particular country, and how members define their own situation.

Crotty (2011) states that meaning is not discovered but constructed by human beings as they engage with the world they interpret. They do not create meaning but construct it. It is a view that all knowledge and therefore all meaningful reality as such is contingent upon human practices being constructed in and out of interaction between human beings and their world. Then developed and transmitted within an essentially social context (Crotty 2011).

Objectivity and subjectivity are brought together and held indissoluble for constructionists to construct meaning, and this works well with Ethnography, as we are concerned with the production of knowledge and its interpretation. The constructionist qualitative paradigm was particularly appropriate in developing in-depth understanding of the world lived by study participants and furthermore, the approaches depth of enquiry and understanding over the study's reliability. This is especially important in the current study for a number of reasons including the fact that the world experienced by children in child-headed families has not previously been studied, and little is known. Secondly, subjective viewpoints are particularly important and chosen approaches must allow for this in-depth engagement to occur.

### **3.6.3.1 CONSTRUCTIONISM – THE PARADIGM SUPPORTING THE STUDY**

Constructionism is the chosen paradigm for the study. Within this paradigm, reality is seen as socially constructed by people as they engage with the world they interpret. It is a view that all knowledge and therefore meaningful reality as such is contingent upon human practices, being constructed in and out of interaction between human beings and their world (Crotty; 2011). Subjects and objects emerge as partners in the generation of meaning. The mind is actively involved in processes like imagination, perspective, perception as well as one's own experiences. That is why different people construct different meanings from the same phenomenon. The social construction of meaning is linked to symbols, which have a social origin character and convention, and these conventional meanings provide the guidance and mechanism for human behavior (Crotty; 2011). Individuals are not passive recipients of a set of meaning, but are actively involved, resourceful and reflective participants in the construction of meaning.

For every need there is a satisfier for it, though there is no one-to-one correspondence between them. Food and shelter therefore should not be seen as needs, but satisfiers of the fundamental need for subsistence. This also applies to education whether formal or informal, studying and investigation, they are satisfiers for the need for understanding. Satisfiers may thus contribute to the satisfaction of multiple needs at a time or conversely, a need may require satisfiers in order that need to be met (fixed). A breast-feeding mother manages to satisfy the need for subsistence, affection and identity during one session, whereas a bottle-feeding mother only satisfies one need at a time, which is subsistence. The first fundamental needs are finite, few and classifiable. The second fundamental needs are the same in all cultural groups and historical periods. It is important to note that what changes over time and in the various cultural groups is the way, or means by which these needs are satisfied.

### **3.6.3.2 INTERPRETIVE ETHNOGRAPHY.**

All ethnographers share a common dedication to personal experiences, daily activities or culture of the group under study, through the use of varied data collection methods. Interpretive ethnography is characterized by the use of thick descriptions, that attempt to unravel/unearth the intricate webs of meaning within a cultural group and more accurately and empathetically interpret meaning, and tries to form an understanding of a particular culture. Thick descriptions takes the reader into a somehow otherwise closed world and by attention to detail allows the sounds, sights and scents of the setting to permeate the reader. This in turn facilitates the interpretation of meaning and significance of what is observed (Patton, 2002). Interpretive ethnography is an invaluable and unique source of interpreting meaning and understanding of particular cultures.

There are three basic epistemological constructs outlined by Crotty (2011). Objectivism, subjectivism and constructivism and each are described below.

### **3.7. CONCLUSION TO THE CHAPTER**

The current chapter has focused on providing the theoretical overview upon which the conceptualization of children's health needs has been undertaken. By reference

to Max-Neef (1983) framework, the needs of noteworthy interest have been articulated

## **CHAPTER FOUR**

### **RESEARCH METHODOLOGY**

#### **4.1. INTRODUCTION**

The preceding chapter dealt with the philosophical underpinnings and theoretical perspective of the study. This chapter describes the research process that includes the design, context/setting, gaining entry, participant selection, instrumentation, cyclic/concurrent data collection processes and data analysis. Academic rigour, ethical considerations, data management and data dissemination are also addressed.

Research methodology refers to steps, processes or procedures that are used for data gathering and analysis (Polit & Beck 2004). Myers (1997) states that a research method is a strategy of inquiry which moves from the underlying philosophical assumptions to research design and data collection. Methodology refers to the practices and techniques in research used to gather process and manipulate information that can then be used to test ideas and theories about social life. The research methodology can be viewed as a tool used by the researcher to collect information, as they define what the research activity is and how it will proceed.

The study aimed to explore the activities /culture of children in child headed households, with particular regard to health behaviour, health seeking behaviour and issues related to accessing health and social services.

#### **4.2. Research Approach**

A qualitative research approach was used in the study. Qualitative research is a systematic interactive approach used to describe daily life activities (culture) of children from child headed household. Toppings (2006) states that qualitative research methods have an interpretivist perspective, it emphasizes understanding and meaning of human actions and behavior. This qualitative approach is based on the premise that in order to make sense of the world, human behavior should be

interpreted in interaction with others. Creswell (2007) asserts that qualitative approach is an inquiry process of understanding based on distinct methodological traditions of enquiry that explore social or human problems. The researcher builds a complex holistic picture, analyzed words, detailed reports of informants' view and the study is conducted in the natural setting.

Qualitative research helps the researcher to gain ideas and insights into a phenomenon of interest from the participants' view (Burns & Grove 1997).

### **4.3. Research Design.**

An ethnographic design was found appropriate in this study as it aimed to analyze the health behavior of children from child-headed households (Brink 2000). Ethnographic design grew out of social anthropology and is best for studying culture, customs as well as activities of a group of people who share a particular norm or experience (Hammersley & Atkison, 1983) Ethnography is a strategy of enquiry in which the researcher studies an intact culture or ways of doing things (activities) in a natural setting over a period of time using different data collection processes that are very flexible. Ethnography is used in nursing not only to increase ethnic cultural awareness, but also to enhance the quality of health care for all concerned (Burns & Grove 2005). Spradley (1979) states that ethnography is the work of describing the culture. The essential core of this activity aims to understand another way of life from the native point of view. The goal of ethnography is to grasp the native point of view from his relation to life, to realize his vision of his world.

Ethnography reveals what people think and shows the cultural meaning they use daily. It is one systemic approach in the social science that leads into the separate realities which others have learned and make sense out of their world. (Spradley 1980). Every ethnographer makes use of what people say in seeking to describe their culture, because language is the primary means for transmitting culture from one generation to the next. In selecting Ethnography as the design used within the study, viable alternative designs were considered. Most notably, the case-studies were considered. Case studies are analysis of persons, events, decisions, periods, projects, policies, institutions, or other systems that are studied holistically by one or more methods (Creswell, 2009). There is growing debate about whether case studies represent a research design or whether they should be seen as a research

strategy? Proponents of this view include Creswell (2009) and Baxter & Jack (2008). The lack of wider philosophical basis on the case study limited its envisaged applicability within the current study. By contrast, Ethnography has a strong philosophical basis, and as such, its principles offer a more comprehensive guide for the research through each phase of the research process.

There are four schools of thought in Ethnography, namely the classical, systematic, interpretive and critical ethnography. Systematic ethnography is described as the one concerned with describing the structure of the culture rather than describing people and their activities. Interpretive (Hermeneutics) is aimed at discovering the meaning of observed behavior. This they do by analyzing the inferences and implications found in the behavior. The classical ethnography requires that the study include the description of the behavior and explanation as to what prompted the behavior. Critical ethnography is the one that relies on critical theory.

For the purposes of this study the researcher identified with the hermeneutic or interpretive ethnography. Hermeneutic ways of interpreting and understanding language, written text and literature assumes an affinity of some kind between text and the reader that provides the basis for understanding and interpretation that is to emerge (Crotty 2011).

#### **4.4. RESEARCH SETTING.**

The current study was carried out in the province of KwaZulu Natal, targeting UMgungundlovu district. The researcher visited child headed household families in their natural settings. Children came from different areas surrounding UMgungundlovu district, such as Willowfontein, Dambuza and Copesville. The child that is heading the household is called the caregiver, and the supervising adult is called a volunteer. These households are supervised by a Non-Governmental Organization (NGO) which is self-funded and receives a subsidy from the government, which is responsible for professional staff salaries. Volunteers are paid from the donors' fund on an adhoc basis. The volunteers are allocated into different residential areas, and they are responsible for the day to day running of the household. Volunteers do not visit every household daily because of the number of

households they are responsible for. Each volunteer has an average of 3-5 households under her/his supervision.

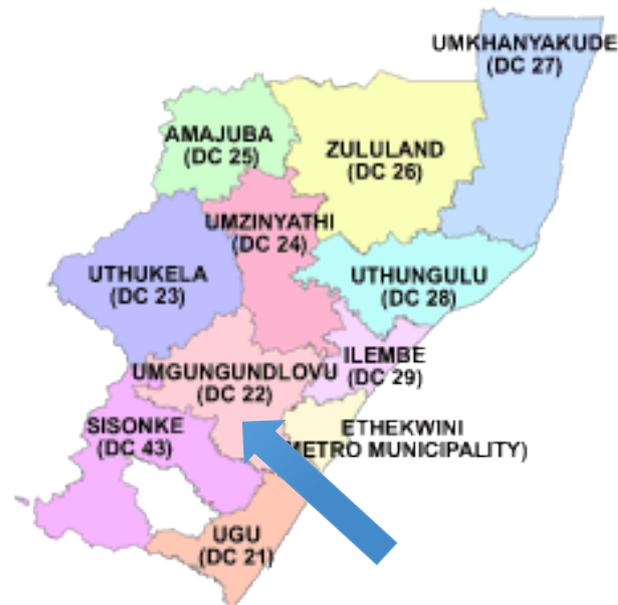
The Community Developmental Facilitator (CDF) visits the household at least two times a month, but more frequently in the initial period of the encounter with the household.

There are also Social Workers in the employ of this NGO, who are based at the center. They also conduct family visits when doing initial case analysis and document preparation for Children's court papers. The professional nurse is stationed at the center, and only visits the family in the initial stage or when necessary. They are responsible for initial health assessments of the children and referral to the next level of care. The nurse is also responsible for linking the identified family to a health care center or clinic for further management and care.

The average walking distance to clinic is 5-7 kilometer's, and there is also the service of taxis for those who can afford to pay for the transport

The area is semi-urban and populated with Zulu speaking people. The UMgungundlovu district serves them with local clinics, with referrals being made to hospitals in Northdale and Edendale for further care and management. Depending on the social upbringing in each household, the families use both the western, traditional and spiritual or divine healing at each given time. This has a bearing on their health seeking behavior. The area is still under development and has a number of reconstruction and development programs for example, housing and road construction. A number of schools are also under construction. The people travel a distance of 3-7km to get to the clinic, some enjoy the use of local taxis whereas some travel the distance on foot. There is a mixture of working class and low socio economic class (poor) families, who have limited material resources and rely heavily on government grants and food parcels donated by non-governmental organizations working in the area. The health behavior is governed by their socialization processes, as we still find some locals attending the traditional healers, spiritual and divine healers for specific types of illnesses. The westernized communities are the ones that are frequently visiting the primary health care clinics .Copesville has the service of a satellite police station ,whereas, Willowfontein and Dambuza rely mainly on the services of a well-established police stations.

The study was conducted in KwaZulu Natal, one of the nine provinces as illustrated in figure 4.1.



**Figure 4.1. Map of South Africa showing KwaZulu Natal and the health districts: UMGUNGUNDLOVU (DC 22) (DOH 2000)**

#### **4.5. PARTICIPANTS AND PARTICIPANT SELECTION.**

The research participants were divided into three participant categories namely. (i) The children living in the child-headed household families. In the interest of ensuring ethical practice, only those children aged 12 years and above were considered for interviews. (ii) Only volunteers whose relationships with the family of interest exceeded the duration of one year were considered. (iii) The member of the health professional team who attends to the health and social care issues of the children from the child-headed household was also recruited. As a basic requirement of the consent seeking process, only those individuals who could read and write were approached for study participation particularly because they were able to offer informed consent.

The population studied included all children aged 12-18 years from child-headed household families, who were placed in the care of primary care givers. The

volunteer or relative and the members of the health team responsible for the day-to-day supervision of such children were included in the target population.

Purposive sampling was used and it allowed the researcher to choose districts and centers where access to participants was ensured (Brink 2000). Strauss & Corbin (2008) further stipulate that a researcher is allowed to look for a person, site and events where he/she can purposefully gather data related to categories, their properties and dimensions. Purposive sampling represent the researcher's commitment to observing and interviewing participants who have the required experiences for the study (Speziale & Carpenter 2007). Like all researches, there is an ideal way of doing things and a more practical method. Often, because of time and financial constraints, the researcher chose the practical way of doing things.

In purposive sampling the researcher is not interested in the representation of the participants from the large population, but rather the concepts, incidents, experiences or phenomenon that will share more light on the topic being explored. This assists in obtaining appropriate and adequate information from the source within a certain time frame or until data saturation is reached (Strauss & Corbin 2008). Guided by these theoretical positions, three child-headed households were purposively selected as the natural settings for data collection. The presence of different members within each family meant that each family offered more than one unit of analysis i.e. the participants could be studied individually on their own (via individual interviews) and also as part of the family unit via focus group discussions.

Table 4. 1. Below offers a diagrammatic summary of the participants and their selection processes, the participant groups that were ultimately engaged during the data collection process.

<b>Participant group / cases under the study</b>	<b>Data collection type</b>	<b>Number of participants</b>
Individual children from child-headed families aged between 12 -18 years old	<ul style="list-style-type: none"> <li>• Individual participant interviews</li> <li>• Participant observations</li> </ul>	<p>Three families took part in the study:</p> <ul style="list-style-type: none"> <li>• Family 1: from Willofontein with 2 members, ages: 14 and 17 years</li> <li>• Family 2: from Dambuza with 4 members, ages 18, 16, 14 and 13 years</li> <li>• Family 3: from Copesville with 4 members, ages 17, 15, 14 and 7 years, but only 3 were eligible for participation (1 member was aged 7 years and was excluded on ethical grounds)</li> </ul>
Child – headed families as above	<ul style="list-style-type: none"> <li>• Focus group discussions</li> </ul>	<p>Three families (9) participants of same families</p> <ul style="list-style-type: none"> <li>• Focus group 1 = 2</li> <li>• Focus group 2 = 3</li> <li>• Focus group 3 = 3</li> </ul>
Volunteer	<ul style="list-style-type: none"> <li>• Interviews</li> <li>• Focus group discussion</li> </ul>	<p>Four volunteers=(4) one volunteer is a relief in the absence of others</p>
<ul style="list-style-type: none"> <li>• Social worker</li> <li>• Community developmental facilitator</li> <li>• Nurse</li> </ul>	<ul style="list-style-type: none"> <li>• Interviews</li> <li>• Focus group discussion</li> </ul>	<p>Multi-disciplinary health team working at the NGO=(3)</p>

Maintenance and the establishment of a good trusting relationship between the researcher and the participants was of utmost importance because they worked together cooperatively until the study was completed (Burns & Grove 2009).

#### **4.6. GAINING ENTRY**

Crabtree & Miller (1999) state that once the site for data collection has been identified, the responsibility of the researcher is to gain access to the envisaged site. This involves a tedious process of getting permission for each site, since there is no blanket permission. In dealing with the many questions from the Heads of various

departments the policy to engage in an honest, jargon-free explanation for better understanding by all was preferred.

The researcher held the first meeting with the directors of the organization, and it was made clear who was going to be responsible for my research project in the organization. The second meeting was held with the health professional, who also wanted a detailed explanation of the aims and objectives of my project, and why they were chosen. The health worker explained their organogram in the organization and how they work. It was at this meeting that I learnt that they possess Community Developmental Facilitators (CDF) who are based in the organization and are responsible for more than one community at any one time. They work with a local volunteer who then works directly with the individual family.

The third meeting was with the Community Developmental Facilitators, (CDF) who also gave me their scope of work and how we (RESEARCHER & CDF) were going to move out into the community. They had a list of all child-headed household families in their database, and it was easy to check the profiles so as to learn which families met my eligibility criteria for the study. Having done that, the researcher and the CDF made appointments with each family. It was agreed that for the first family visit, the researcher would be accompanied by the CDF responsible for the area and the local volunteer, so that the children would not be skeptical of the researcher as a new person.

#### **4.7. DATA COLLECTION**

Data collection in qualitative research is done concurrently/cyclically with data analysis according to Creswell (2009), but for the purpose of this study, these processes are explained separately. Data collection was carried out in the participants' own natural setting, multiple forms of data was gathered by the researcher and this took longer because it relied on the (processes) evolving nature of events by actors within a setting (Creswell 2009, Miles & Huberman 1994). There were times when the researcher could only arrive after 2pm, because children were attending school. The researcher used only the following methods: participants' observations, individual interviews, and focus group interviews. Audiotape was only used with the participants' permission.

#### **4.7.1 Participant Observation**

Qualitative observations are characterized by the researcher's first involvement as a passive observer, then later as an active group member. During her observation she/he collects as much data (field notes) as possible. It is at this stage where the researcher should identify the key informants so as to get the "emic " perspective. Crabtree & Miller (1999) together with Speziale & Carpenter (2007) advise that, it is at this time when the researcher should ask more explicit questions so as to gain more knowledge and understanding of the phenomenon under study.

Participant's observation was done on the first day, and each family was fine with the researcher and the study undertaken. Nothing much was done on the first visit, but the researcher managed to obtain the contact details so as to arrange the next visits to the families, and that was the start of the process.

##### **4.7.1.1. Subsequent Participant Observations**

The aim of the subsequent visits were observations starting with passive observation to active participation. However, the researcher realized that she could not be a complete participant in these families but only participated to observe the activities, people, and physical aspects of the situation without engaging in their activities (Spradley, 1980). Flick (2009) describes this type of engagement as participant-as-observer. The observations were not structured nor guided because the researcher did not know what to expect though the literature gave a vague idea to direct the observations. Hence the researcher followed the assertion by Spradley (1980) on phases of observations.

Spradley (1980) distinguishes three phases of participant observations, namely, Descriptive, focused and selective observations.

**4.7.1.2. Descriptive observations** provide the researcher with an orientation to the field under study and it is usually conducted at the beginning of the observations. This provides non-specific inductive descriptions acquire the complexity of field or setting. This phase usually assists in refining research questions for the study.

The researcher used the first two visits to observe the geographical characteristics, housing, family structure, relationships among the siblings including allocations of house chores (daily routine or activities). This gave the researcher some orientations

into general culture of children in a child headed household. During this phase of observation, the researcher also conducted informal or conversational interviews for briefing in relation to the context and culture (Spradley, 1980).

**4.7.1.3. Focused observations** narrows the perspective on those processes and problems more essentials for the research question. These may be informed by the descriptive phase of observations and 'foreshadowed problems' (Hamersley and Atkinson, 2007).

In the focused observations the researcher began to focus on specific issues related to her study informed by descriptive observations and conversational or informal interviews, for example, issues of safety while still using a dilapidated house with a new house available already.

**4.7.1.4. Selective observations** are conducted towards the end of data collection to establish further evidence and examples for the type's practices and processes found in the second phase.

During the researcher's last visit, the observations were more selective to health seeking behavior and other related issues as that had not come out clearly in the previous visits.

#### **4.7.2. Individual Interviews**

Conducting individual interviews is imperative in order to gain each and every participant's side of the story. This is done to understand what real meaning is ascribed to their lived experiences, and acts as base for realizing that no matter what position they are currently in now, (a child-headed household) matters surrounding each and everyone's circumstances differ. The researcher used the semi-structured interviews for a probing type of interview guide for children, care givers, volunteers and community developmental facilitators (Strauss & Corbin 2008). The interviews started informally during observations and eventually became formal and focused on the phenomenon of interest in the study (Spradley, 1980).

The interviews were carried out in their natural settings; the participants were willing to share their stories. The participants were interviewed individually at different times because some would be at school during the day. At some stage the researcher had to present herself during the weekend to pursue some individual family members

who came late from school because of distances. The use of digital voice recording was only used for some discussions and not for every interview because there were times when the participants would not agree to its usage.

#### **4.7.3. Focus group discussions interviews.**

With the help of the key informant (CDF), the researcher identified participants of similar background (family) and formed focus groups to have sessions with. This method is best because participants talk freely in the homogeneous environment. One can have more than one focus group meetings with the group so as to have time to reflect on the collected data, and ask more questions for clarity after listening to audio taped information (Polit & Beck 2008).

For the purpose of this study, the researcher could gather family members as a focus group for discussion but could not mix the families because there were heterogeneous in that their circumstances were very different reason for being orphaned and how their extended families were the reaching out to them. The geographical locations and time of access to the families were quite varied to the extent that the researcher had to conduct focus group discussions on a Saturday morning before 11h00.

However the researcher managed to conduct the focus group for the volunteers, the Community Developmental Facilitators and members of the health professionals composed of the nurse and social workers.

#### **4.8. DOCUMENT REVIEW.**

Qualitative researchers recommend review of documents, such as, written letters, memos, pictures, journals, minutes of previous meetings held by the participants. These assist the researcher to understand the emic perspective of participants, and the real language and words used when referring to or expressing their emotions (Creswell 2009).

In the context of the current study the researcher could only identify with photographs of past family members that were sentimental to the children. However, the researcher expected to also see identity documents and birth certificates which earn

these children benefits, such as social grants. The rest of the listed documents is not common for African population since most of them are illiterate and unemployed; the resources to keep all these memos are limited considering their socio-economic status.

#### **4.9. DATA ANALYSIS.**

The process of data analysis involves making sense out of text and image data. Data is prepared for analysis and understanding, and some researchers refer to this stage as similar to peeling back the layers of an onion (Creswell 2009). Spradley (1983) refers to three types of analyses, namely, domain, taxonomic and componential analysis arranged in sequence while Creswell (2009) describes the same phases as description, analysis and interpretation.

**4.9.1. The domain analysis** involves a semantic examination of something, in this study a culture to determine its parts, the relationship among the parts, and their relationship to the whole. The process starts with discovering patterns in the collected data in this case, cultural patterns or behavioral patterns. These are organized into domains or categories (Spradley, 1980). This type of analysis one can equate to Creswell's (2009) description phase.

**4.9.2. The taxonomic analysis** describes determining how the cultural domains or categories of data are organized on the basis of a single semantic relationship. The emphasis in this phase of analysis is relationship among the domains. Taxonomic analysis answers focused questions and are equated to Creswell's (2009) analysis phase.

**4.9.3. Componential analysis** describes attributes or components of meaning associated with cultural symbols. Such analysis focuses on contrasts which might warrant return to the field to embark on a selective interview to elicit further explanatory data asking contrast questions. This phase can also be equated to interpretation in Creswell's (2009) phases.

**4.9.4. Cultural themes** were then identified as the last step recommended by Spradley (1980). This author maintains that analysis should follow two levels of analysis conducted concurrently. These levels include smaller details of culture and

broader features of the cultural landscape or scene and statements that convey a sense of the whole. This author further recommends discovery of conceptual themes that members of the society use to connect these domains as determined in the initial analysis. By definition, cultural themes are any cognitive principle or rational beliefs/opinions, (tacit or explicit), recurrent in a number of domains and serving as a relationship among subsystems of cultural meanings. Boyatzis (1998) supports Spradley (1980) by focusing solely on thematic analysis for various reasons such as making sense out of seemingly unrelated data and to allow use of qualitative data in a manner facilitating communication with a broader audience of other scholars or researchers.

The researcher in this study started with the phases as described above, namely domain analysis (description), taxonomic analysis (analysis) and componential analysis (interpretation) although the latter was used to a limited extent. The researcher then accommodated emerging themes which she further fitted into the chosen theory in pursuit of template style analysis suggested by Crabtree and Miller (1999) to reach final interpretation in relation to the theory guiding the analysis of this study and identification of gaps to finally develop an adapted theory.

#### **4.10. ACADEMIC RIGOUR.**

The term academic rigor refers to the logic accurate scientific adequacy or trustworthiness of a research outcome with respect to openness and adherence to philosophical ideologies throughout (Burns & Grove 2005). Qualitative studies should be evaluated using the criterion that was developed to fit the concept "trustworthiness". Speziale & Carpenter (2007) states that trustworthiness in qualitative studies is when the findings of the study represent the experiences of the population being studied. Trustworthiness refers to the quality of the research findings. It exists if the findings of a qualitative study represent reality, where for the purpose of this study it represents the activities of children and care givers in child-headed household families in relation to health behavior (Speziale & Carpenter 2007). There are four strategies that are used to ensure trustworthiness of qualitative studies: credibility, transferability, dependability and conformability.

#### **4.10.1. Credibility.**

Speziale & Carpenter (2007) affirm that credibility ensures that the participants recognize the research report as their own experiences or activities, whereas Polit & Beck (2008) state that credibility is the confidence in the truth of the data and its interpretation. It is demonstrated when participants recognize the reported research findings as their own experiences. Credibility also refers to the authentic quality of data, that is, whether it reveals what one is directly looking for (Miles & Huberman 1994). It is of utmost importance for the credibility of data to ensure that the participants fully understand a question when asked, therefore the instrument for data collection and a professional translator translated the information sheet into Zulu. Interviews were conducted in Zulu, transcribed verbatim in Zulu and translated back to English in the same way. In this study the data collection phase was an ongoing process over a long period of time or until no new raw data was obtained (saturation). Thick descriptions of data were presented to allow for the assessment of rigor or credibility. Participants must be able to recognize the data as their own (emic view) which the researcher established through verification visits.

#### **4.10.2. Transferability.**

This term is used in qualitative research to demonstrate the probability that the research findings have meaning to others in a similar situation (Speziale & Carpenter 2007). This is sometimes called "fitness". This refers to the applicability of the study to one's context or different contexts. It must be appreciated that it is not the intention or goal of qualitative studies to generalize, but there are times where one can opt to generalize using the qualitative study (Miles & Huberman 1994). Thick description of the content, data base, methodology, participants and the selection processes used are made available for the reader so that they can assess the potential appropriateness to one's setting so as to make informed decisions, regarding the application to other context or not (Miles & Huberman 1994). Transferability of the study is not the responsibility of the researcher, only the potential users can make an informed decision regarding the applicability of findings in their context (Polit & Beck 2008). Hence the researcher made detailed descriptions of the research process, data, analysis and interpretation and recommendations to facilitate judgment by the interested parties on the applicability of this study in their contexts.

#### **4.10.3. Dependability**

Dependability refers to the stability of data over a longer period and over certain conditions (Polit & Beck 2008). The study must provide its audience with evidence that even if it can be repeated over a longer period of time under the same conditions/circumstances, it can still give/yield the same results. Speziale & Carpenter (2007) described this term as the criterion used to measure trustworthiness in qualitative research, where it is met through securing credibility of the findings. Dependability refers to the consistency, reasonable stability over time through triangulation, which, in this study was determined by convergence of accounts across methods and participants, for example, observation, individual and focus group interviews, context and connectedness to theory. Furthermore, data quality checks or audits and peer review of coding were undertaken to verify accuracy of research analysis.

#### **4.10.4. Conformability**

Conformability is concerned with the degree to which the findings of the study are as the result of participant's responses and conditions of the research only. It measures quality of data in terms of objectivity or neutrality (Polit & Beck 2008). This was ensured by keeping all forms of data collection tools e.g. diaries, audiotapes and interviews for an objective person to look over and check the objectivity of the results. The supervisor was given the opportunity to verify data before reporting (Brink 2000). Coding of some transcripts was done with the help of a colleague. Supervisor with academic experience also checked a few transcripts and coding consistency. Participants were given a chance to verify data before dissemination. Summary and conclusions were made available for scrutiny by the supervisor and external examiner according to university policy.

#### **4.11. ETHICAL CONSIDERATIONS**

Ethical consideration should underpin all qualitative research processes. Neumann (2006) emphasizes the issues of morality and professional behavior towards clients and participants. The main focus of qualitative research is real/live individuals who exist in the real-life situation and are sharing their activities (culture) with the researcher. Most ethical issues arise during the data collection stage, where respect of participants should be observed especially since we are dealing with children and

they are vulnerable. For the purpose of this study, the researcher would like to identify with the strategies by Emanuel, Wendler and Grady (2009).

#### **4.11.1 Collaborative Partnerships**

The study is involved with the children, their caregivers and members of the health team. The children from child-headed household families have problems with supervision of health behavior and accessing health services; therefore collaborative partnership with members from other sectors will/may enhance their health behavior and access to health care delivery system of the rest of the country. This will improve the general living conditions, as it is free for all citizens in a comprehensive health care package (Emanuel, Wendler, Killen & Grady 2004).

#### **4.11.2. Social Value**

The study developed a wider range of insights into the envisaged problem. It has assessed the depth of the health problem in question and the prospective value of the research for each beneficiary. The outcome will be discussed as recommendations for policy makers to assist in the review of the current legislation.

#### **4.11.3. Scientific Validity**

The whole research design should realize the scientific objectives whilst guaranteeing the participants safe scientific health care interventions. The data collection process ensured anonymity and confidentiality. All materials used, such as field notes, tape recorder and hard copies were kept under lock and key and will be destroyed through incineration after five years (Emanuel et al, 2004).

No names or location on any form of data can be traced back to the participant. This is a scientific study, so the researcher may like to quote information when reporting or presenting their findings. This it is allowed, but it should be done such that there is no link to the data of the participants. (Speziale & Carpenter 2007).

#### **4.11.4 Fair selection of Study Participants.**

All participants were recruited to form part of the study, for example, children and their caregivers were recruited through the NGO responsible for their day to day care and supervision through a comprehensive project. All children who were 12 years and above, who had become head of the families on /after the death of their parents,

were recruited together with the volunteers offering support to them. The researcher strictly adhered to the eligibility criteria, which stated that:

- All children should be between 12-18 years
- They should have lost both parents through death.
- Staying in the child-headed household
- Be under the supervision of a relative or a volunteer

#### **4.11.5 Favorable Risk Benefit Ratio.**

Participants were interviewed at a place that was most convenient to them, preferably in their natural setting, where complete privacy was ensured. There were instances when participants felt or wished to be interviewed in a place outside their natural environment, and the researcher respected their wishes.

Participants in qualitative studies especially when interviews are undertaken, are subjected to minimal or no harm. During interviews (individual and focus group) observations, documents and audiotape or technological means, there is no physical interference or clinical involvement with the participants; all data collection is outside the person's body. The issue of emotion and physical discomfort due to long interviews can be eliminated by having more than one session for data collection, and also by providing a counselor or social worker for debriefing sessions afterwards. A social worker working for the institution was with the researcher on the first encounter with the participants, and on standby for later use. Fortunately, there was no instance that required the services of a social worker. Children were left with the contact details of the researcher for later reference. The participants did not receive any remuneration for taking part in the study; they were made aware of the option to engage and dis engage at any time with no penalty.

#### **4.11.6. Independent Review**

The researcher obtained written and verbal permission after detailed description of the purpose, process and benefits including risks of the study to parties concerned. Ethical clearance was obtained from the Ethics Committees of the University of KwaZulu-Natal, Department of Health and relevant Director of the NGO institutions

where children were supervised. On completion of the study, the results will be made available to the collaborative partnership teams.

#### **4.11.7 Informed Consent.**

All research participants were asked to sign consent letter during/after recruitment into the study. The topic under discussion was of a sensitive nature, therefore only written consent was allowed. It was the responsibility of the researcher to provide the participants with the purpose, objectives, and risk benefit ratio of the study for the participants to make an informed decision (Polit & Beck 2008). An appointment for scheduled interviews was made and prior to any data collection process, the information sheet was read for participants' understanding and their rights explained. The information sheet was written in Zulu as the home language for many in the province. As an additional measure to guard against perceived coercion, all prospective participants had their "family heads" countersign their willingness to participate. The researcher was acutely aware of the already-vulnerable circumstances of the prospective participants and within that facilitated two additional measures: - (1) prospective participants were each given a two week consideration period, followed by a further one week to cool off and consult with other significant individuals before they could confirm consent and (2) throughout the data collection processes, participants were alerted to their right to opt out without repercussion.

#### **4.11.8. Respect for Recruited Participants**

The researcher should always treat the participants with respect and courtesy; never intrude into their private lives unless this would benefit the study. The issue of recording the conversation during data collection should be clarified before data collection and permission is sought. In the study undertaken there was none to minimal risk, since there was no clinical intervention except for discussions that might evoke emotions. The researcher had organized the social worker or counselor for a debriefing service.

#### **4.11.9. Dissemination of Findings**

The reasons for conducting research are to contribute to the new body of knowledge and practice. The researcher will therefore interpret and communicate the findings to all interested parties and individuals who can utilize the findings to improve the health

behavior and access to health care services for children coming from child-headed households.

Research findings will be presented in the form of reports, thesis, articles in academic journals and papers presented at national and international conferences. Articles focusing on the research process followed in view of the research project and its findings will be submitted for review and publication in health professional journals. Hard copies of the thesis will be presented to responsible stakeholders for future use. The researcher will give feedback to the participants and all stakeholders involved in the study only on completion of the study.

#### **4.12. CONCLUSION**

In the chapter, detailed description of the research methodology was done. The chosen approach; design, settings, participants and how they were selected are articulated with some discursive focus being afforded to considering why these choices were the most appropriate within the current study. Furthermore, data collection, analysis and dissemination strategies were presented. Academic rigor and ethical considerations that related to the study were discussed.

### **CHAPTER FIVE**

#### **DATA PRESENTATION, ANALYSIS AND INTERPRETATION**

##### **5.1. INTRODUCTION**

In the preceding section, methodological and data collection issues related to health behavior, health seeking behavior and access issues as experienced by children in child-headed families, were dealt with. The current chapter deals with management of field data. The data was generated from children in child-headed families, their volunteers and health professionals who were involved in supporting them. The focus

of the data enquiry process was to better understand the health behaviors of members of child-headed families, specifically in relation to health behavior. Health-seeking behavior and access to health care services. Secondary to this, health professionals' observations and experiences were elicited. Data reduction, organization, presentation, analysis and interpretation represents the majority of the chapter which aims to present data obtained from the field, and to draw from it, key emergent themes that offer insights related to the study questions.

## **5.2. AN OVERVIEW OF DATA ANALYSIS STRATEGIES UTILISED IN THE STUDY.**

As a result of the fact that collected data came from multiple sources, (via individual interviews or focus group discussions, observations and document review), a combination of data analysis approaches were applied to the data. As already indicated in the previous chapter domain, taxonomic, componential and cultural thematic analyses approaches/phases were employed for various purposes (Spradley 1980 and Boyatzis, 1998).

The use of multiple data-analysis approaches within a single study is further supported by a number of other theorists within the study-area including Burnard (1995), Smith (2003) and Crabtree and Miller (1999) who conclude that no single data-analysis strategy can effectively facilitate the analysis of differing types of data especially within complex qualitative studies focusing on previously unstudied areas. The use of a combination of data analysis approaches follows the advice of others such as Addison (1999) and Silverman (2004) who argue that, limiting the approach of data analysis to a single style of analysis is oversimplification and often limits the scope of interpretation for the researcher.

Within the current study, the fact that data was collected from more than one data source served as the primary driving factor which supported the decision for the use of several analysis formats.

Narrative analysis was utilized for the data in which individual participants spoke about their experiences of receiving or giving care including their views about health seeking activities and behaviors (Reissemen 2008). Similar attention was given to better understanding how members of child-headed families felt how they were

treated within health and social care services. The narratives were then utilized to support the interpretations from the data.

### **5.3. PROCESS OF DATA ANALYSIS**

The process as presented in chapter four followed Spradlery's (1980) two levels of analysis which this authors suggests must run concurrently. These levels include smaller details of culture and broader features of the cultural context. The first level included three phases of domain, taxonomic and componential analysis as presented in chapter five. The second level included the cultural themes.

#### **5.3.1. THE DOMAIN ANALYSIS**

In conducting domain analysis the researcher, as indicated in chapter three, had some ideas of what to look for based on the theoretical underpinning though she allowed some flexibility in her observations and interviews which started informally as she made descriptive observations and asked descriptive questions. The researcher, for example, initially observed the space/yard, the house, the occupants, the furniture in the house, the neighborhood, etc. These domains or categories were initially described as they appeared. In describing these domains the researcher, for example, identified, a dilapidated house, in some families a new house, and a house on construction. With objects in the house one would see old scanty furniture, and in other families, normal complete furniture. As far as occupants are concerned one would see children.

#### **5.3.2. THE TAXONOMIC ANALYSIS**

In taxonomic analysis the researcher began to observe the relationships among the observed or presented domains or categories. The house was described as in number, placement in the yard, material used, windows, doors, roof, etc. For example, the researcher further described components or object in the house (furniture), for example, an old bench, couch and old two plate stove, leaking sewerage draining into the yard .The two roomed house was extended to make a three room to cater for the number of siblings in the house. The only boy used to sleep in the Mosque together with other teens. The head of the family had joined the

house with another three backrooms, this she used to get money from the rent to cover for other basic needs. This poses a risk/threat to the safe and security of the children as the strangers can rape or kidnap the children and sell it for body parts.

### **5.3.3. COMPONENTIAL ANALYSIS**

To achieve componential analysis, the researcher began to look into contrasts, for example, old and new houses in the same yard which had to be followed with selected questions to establish why two houses were kept. Some children in the same family were attending school while others were not yet they were all at school going age. In some families the caregiver was keen to work and looking for a job while in another family the caregiver would just linger in the neighborhood without considering the siblings.

### **5.3.4. CULTURAL THEMES**

Cultural themes were then identified as the last step recommended by Spradley (1980) whereby conceptual themes used by members of the culture or society are discovered and used to connect the domains determined in the initial analysis. For example, in this study, the researcher from selected questions got to know how the new houses were acquired by some families as well as the reason for keeping the old house even if a new one was in place in one family. The dilapidated house for instance, was kept for sentimental or cultural reason where the children explained that their late mother's Kist (wooden box /chest of drawers kept for sentimental value) was kept in that house therefore could not demolish it. The new houses were acquired through donations coordinated by the NGO. Therefore the themes extracted were "strong sentiments with late parents" and in terms of acquisition of houses it would appear that the theme "support" would suffice.

In conclusion, the researcher then fitted the identified themes into the theory underpinning this study as suggested by Crabtree and Miller (1999) for example themes about sentiments with late parents was matched in the theory with 'identity' and subsistence.

#### **5.4. PARTICIPANTS REALISED AT THE END OF THE STUDY**

Data presented in this section emanates from three respondent sources that formed part of participants for the study, that is, (i) the children who acted as caregivers within child-headed families and the siblings who are members of the family, (ii) the volunteers and (iii) the different health and social care professionals who offered support to each of the child-headed families. An embedded case study sample served as the primary source of the data within the study.

Summative, the reporting of results from the data collection process reports on findings from the family units (as units of analysis) and then from the individuals within the family, as individual cases, volunteers and finally from the professionals involved with the families. As a result of these three separate but related data collection phases and indeed the differing sources of results, a combination of data analysis strategies is employed within the study. As noted in the preceding chapter, qualitative methodologies and processes often advocate for a simultaneous collection and analysis of data. In keeping with this position, the current chapter presents the data collected from participants and analyses it simultaneously, as was done within the field. The data is presented in sections, observations, and the individual interview data followed by the data from the family-unit (focus group conversations). Details of data analysis from the volunteers and the health professionals are also dealt with.

##### **5.4.1 INDIVIDUAL INTERVIEW AND FOCUS GROUP DATA PRESENTATION AND ANALYSIS.**

As indicated above, three focus groups, each made up the family members were interviewed initially as individual cases and then later as family units. The presentation of data is ordered in that sequence to acknowledge the fact that responses and emergent themes from the individual interviews were used as a basis for themes that were further explored in the focus group discussions.

###### **5.4.1.1. PARTICIPANT-AS-OBSERVER**

As indicated in chapter four unstructured observations of the families were conducted while conversational or informal interviews were done. It is during observations that the researcher orientated herself on the context like physical structure of the

households, surroundings and neighborhood, occupants or, family members, objects, for example furniture, relationships, etc. as presented earlier.

#### **5.4.1.2 INDIVIDUAL INTERVIEW DATA**

The study population comprised nine individual interviewees, all of whom were aged 12- 18 years old. The participants were from three families and as such, three of the interviewees offered perspectives into their roles as the heads of their respective families and their experiences on a range of issues related to, health behavior as well as accessing health care services.

The participants in both the individual and group (Family unit) discussions were asked to discuss issues that related to the following six generic areas:

1. Reasons they had ended up living without an adult in their households.
2. The range of factors that had preceded their current positions as members of a child headed home.
3. Insights into their daily support needs with emphasis on health and how these were being met?
4. History of their involvement with health and social care services; their experiences of these services.
5. The range of health seeking behaviors the members of child headed families engaged in with regard to accessing health and social care.
6. The range of interventions and actions they believed could be implemented to improve their care and supervision.

With regard to the above, following responses and themes emerged during the individual interviews.

#### ***QUE. 01 – PLEASE TALK ABOUT HOW YOU CAME TO LIVE IN A CHILD HEADED FAMILY***

Though the participants did not specify the exact causes of death of their parents as AIDS, it was implied in their responses. One participant, however, indicated a different response to her parents' death as having to do with assault and crime. The following excerpts illustrate their responses:

- **Reason for Orphan hood**

*They told us that our mother was sick and after sometime she died...our father died too. (Participant 3, aged 15years)*

*No one really explained what killed our parents but I presume they are afraid to tell us that they suspect it was AIDS (Participant 5, aged 16).*

*My mother was always sick, in and out of hospital, but still not sure why she died because she took all their drugs and attended the appointments (Participants 8 aged 15 years)*

*Our father was found after 7 days in the forest, his body already decomposed, and they presumed he was mugged by the criminals (Participant 6, aged 17 years)*

- **Non-Absorption**

In response to why the extended family members could not absorb them into their families, some of the reasons were financial standing, greed and fear of possible immorality related to the possible HIV positive status of their parents and city life. Embedded in this view was the idea that participants felt that their association with HIV AND AIDS had created such strong identities around being an orphan that little else about them was acknowledged. Some family members were already grabbing their parental belongings whilst they were still sick and just after the funeral. These views were expressed in the following excerpts:

*Our aunt stated that, they could not take us into our paternal extended families because our parents were not legally married belong to our maternal side (Participant 3 aged 17years)*

*I was shocked to see our only cousin grabbing our family possession on the very same day after the funeral citing that our mother was owing her some money (Participant 6, aged 15 years).*

*A day after the funeral I heard my uncle, not aware that I was listening, saying “their parents were living a modern life, no one can afford their lifestyle, they better stay alone (Participant 9 aged 15years)*

*No one wants to be connected with us because they think we are infected too (Participant 4, aged 17 years).*

*After the funeral we slept alone for three days in succession, until an old friend of my mother came to check on us (Participant 1, aged 12).*

*We decided to live on our own because they, (extended families) think we are going to be difficult to manage because we were living in the city and used to its lifestyle (Participant 5 aged 13 years).*

- **Stigmatization/ discrimination/Social isolation**

Some of the participants initiated conversation about the views of others about their “social identities” and importantly, how their communities view their situation,

*They think we are just nobody’s...I don’t even think they ask how we look after ourselves, three children alone (Participant 1, aged 12).*

*Some community members do not want us to play and mix with their children because they think we are infected too (Participant 4, aged 17 years).*

- **Social support**

One of the explanations offered was that the church was such a supportive structure that they had only survived being a child headed home because of the church to an extent that one of the participants wished to be a pastor as expressed in the narratives below:

*My parents had strong faith, and without the support and guidance from the church, we would be lost (Participant 6, aged 17years)*

*That is when the church started to understand our plight.' Without the church, we would have no one (Participant 1, aged 12).*

*People from the church and some neighbors do give us what we need, but sometimes it becomes difficult because they also have their families to care for (Participant 4, aged 15)*

*It is only in the church where I feel equal to other siblings (Participant 7 aged 14 years)*

*Singing in the church choir gives me the sense of belonging (Participant 6 aged 15 years)*

*I have thought of becoming a pastor so I can help other children in the future (Participant 2, aged 16 years).*

One participant who is the head of the family (family care giver) expressed that some community members assisted for personal gain, especially if it is voting time. However, another participant expressed the bond created between them and the volunteers to such an extent that the volunteers make time to take them to their families to meet their need for belonging. These views were expressed as follows:

*Now that it is about voting time, all children that come from child headed household will be enjoying their Christmas lunch at the community hall, hosted by the Department Of Social Development. (Participant 6 aged 14 years).*

*Some volunteers take us for weekends with their families so as to enjoy the feeling of being part of the family (Participant 5 aged 16 years)*

Some family members expressed their concerns that some members of certain religious groups assist them for unexplained reasons which may probably to access some donor funding especially because they never come back to them as contrary to the NGO which is consistent with its help. This was expressed in the following excerpt:

*Every year they take a picture of our families and houses and disappear only to see them again in the following year (Participant 3 aged 15 years).*

*It becomes difficult to trust their help sometimes especially if it's a once off thing, and they insist on taking photos with us (Participant 8, aged 16 years)*

*Without my own father and mother, I am always feeling like everyone else only supports us because they feel sorry for us and not consistently because we are not their blood (Participant 7, Aged 13 years)*

Some of the participants expressed the views of others about their “social identities” and importantly, how their communities view their situation which was tantamount to social isolation and discrimination. However, among themselves as families, they related well.

*They think we are just nobody's...I don't even think they ask how we look after ourselves, three children alone (Participant 1, aged 12 years).*

*Some community members do not want us to play and mix with their children because they think we are infected too (Participant 4, aged 17 years).*

*We understand each other well, better than any visitor who comes here (Participant 9, aged 14 years).*

## **QUE. 02 – PLEASE EXPLAIN TO ME HOW YOU MEET YOUR ACTIVITIES OF DAILY LIVING (DAY TO DAY NEEDS)**

- **Health Behavior**

On asking how they met their day to day survival needs, the participants pointed out issues of nutrition, hygiene and clothing needs, relationships or sense of belonging, housing, safety and security. For example some participants initiated conversation on the views of others about their “social identities” and importantly, how their communities view their situation though among themselves, they related well. In

addition to these needs, the participants also mentioned health support issues which were both positive and negative. These were expressed as follows:

*There are times when we go to bed on an empty stomach, not knowing who to ask for food (Participant 7 aged 17)*

*We need money to help us buy clothes and books for school, no one seem to remember that (Participant 7 aged 16 years).*

*The grant money is not sufficient for all our daily needs, sometimes I have to do piece jobs after school to be able to put food on the table for my siblings (Participant 5 aged 14 years)*

*While we do get food parcels from the center but some of the items are not included, for examples, pads (sanitary), roll-on (deodorant) and soap for laundry and bathing so that we have to use grant money to supplement though it is not enough (Participant 3 aged 17 years)*

Each family had a two roomed house built by the responsible NGO for a various number of occupants. For example, Family one had this dilapidated house that they kept even if it did not appear safe. On asking why they still kept this house, they expressed sentiments with their late parents as in the following excerpt:

*It contains my late mother's Kist. It (kist) cannot be moved out of that house without a ritual that must be performed as it was done when we moved in. We need money and an adult family member to do this. My younger sibling is also refusing not to sleep in that house. We also use the same house for cooking (Participant 1 aged 17 years).*

Family two had a single two-roomed house, the dividing wall of which was demolished to make it one big room to make more space because they were four occupants. These participants shared two beds also but one of the participants was a boy among three girls. This compelled sharing of one of the beds between a boy

and a girl. This family also designed their own ways of ensuring privacy from the boy. For example, the boy has to go out when the girls had their bath irrespective of the time of the day. When the girls were using the potty the boy had to either go out or cover himself with a blanket. When they the girls were menstruating, they would speak of a “tomato sauce” days or week as expressed in the following excerpt:

*I have used all the toilet paper ladies, it's my tomato sauce days (Participant 3, aged 14)*

One of the participants opted not to use toilet paper for her “tomato sauce days” but chose to forfeit pocket money for school to be able to buy herself preferred type of pads as she asked her caregiver whom they called “Madame” sometime when they were asking for special favors:.

*Madame, can I have “Always”. I am prepared to forfeit my carry (pocket money) this week (Participant 2 aged 16 years)*

Participants also expressed a strong need for a sense of belonging related to lack of parental, family and community support including the school sports team.

*I am lonely at times and really wish we had a grown-up who could tell what to do right, I think this is too much for my brother to oversee. (Participant 3 aged 14).*

*My sister told me that we need to respect her like our mother, but sometimes, when I want something, she just cries and not respond, (Participant 3, aged 13 years)*

*I played soccer at school, the coach sometimes does not afford to pay for my trip, and it kills me to remain behind having practiced so hard for the game (Participant 1 aged 14 years)*

*Sometimes children in our neighborhood are not available to play with us because they are on family trips with their parents, and it hurts me that I do not have any parents or family to visit with (Participants 2 aged 17)*

Participants reported feeling that they were discriminated against or excluded from possible support because of the general lack of understanding about HIV and AIDS. This could mean that the participants had grown to understand the dynamics around HIV AND AIDS well to an extent that one subjected himself to voluntary screening though was let down by the system as expressed in the following quotations;

*The disease is not spread by shaking hands, sharing utensils or bathroom, people still think they will catch it like that (Participant 4, aged 16 years)*

*I personally presented myself for HIV and AIDS screening, but my results got lost, so I guess, there is no proof whether I am also positive or not (Participant 3 aged 16 years)*

### **QUE. 3 – HOW HAVE YOU EXPERIENCED SEEKING HEALTH AND SOCIAL CARE SERVICES SINCE YOUR MOTHER AND FATHER DIED?**

- **Health Seeking Behavior**

Most notably, the concerned participants did not highlight the need for support with accessing health and social care until they were prompted by the interviewer after which they indicated that,

*I do not see the point of attending the clinic because my parents were very sick and were sent (sick) back home by the clinic staff to die at home alone (Participant 3 aged 17).*

*My sibling had a toothache, the clinic gave us the letter to see a dentist in the hospital, we had no money to go there, and the social workers could not help (Participant 3 aged 15years)*

*One nurse asked me “what happens in the absence of the volunteer,” will you be able to take treatment as told? (Participant 5 aged 15 years)*

*Are you sure about the care of medication and siblings on your own (Participant 3 aged 14 years)*

*The grant money is not sufficient for all our daily needs, especially when we need an escort to clinic, paying for two is not affordable (Participant 6 aged 14)*

Each of the identified areas of support above spoke to the fact that participants felt that their day-to-day needs with regard to financial stability, access to health care; social support were not satisfactorily met from their point of view. It would seem therefore that the participants suffer discrimination from mistrust, therefore they are isolated leading to lack of the sense of belonging. Of note is also lack of confidence by the participants in the present health care delivery system. It was also observed that the housing is not safe and conducive to adequate personal environmental hygiene and decency and dignity.

#### **QUE. 4 – HOW DO YOU GO ABOUT TRYING TO ACCESS HEALTH AND SOCIAL CARE SERVICES?**

- **Access to health**

Responses to the above question fell into three broad thematic areas, that is, those who identified (i) the stigma associated that was often attributed to their connection with someone who had died of HIV and AIDS (ii) discrimination they faced as minor orphans and (iii) legislative ambiguity (iv) general lack of inclusion they felt from their community.

- **Stigma and access to health**

In response to enquiry about their experiences about access to health and social care services, the participants and their families asserted that they felt traumatized by questions that evoked emotion like history of their parents. Another issue that came out strongly is the failure of access to health for financial inability to pay for transport and the escort by the volunteer as well as the logistical delays in accessing

the ambulance and health professionals within the health facility. This they attribute to being stigmatized for their age or possible HIV status.

*In the clinic they ask so many questions about your family health and if you don't know, you are ridiculed (Participant 1 aged 15).*

*In case they refer you to hospital for other services, it becomes difficult to travel to hospital without financial support for the transport, unless your condition needs an ambulance (Participant 5 aged 15 years)*

*We sometime even wait for the condition to become worse so that we can be transported by ambulance to hospital (Participant 3 aged 16 years)*

*Sometime, due to crime, especially at night we call the councilor to call the ambulance which speeds up access to the professionals in the hospital without having to answer traumatizing questioning's by the clerk (Participant 22)*

*I just wish there was another way of asking about your past history and your visit to health care services either than being asked about your parents (Participant 8, aged 16 years)*

*I think everyone thinks that I am HIV positive and they don't just want to help. (Participant 3 aged 16 years).*

*The way they treat us when collecting our treatment is like, they want everyone to know that we are infected or affected by the disease (Participant 1 aged 17 years)*

*It was sad to hear our uncle saying that he cannot risk the safety of his family with the infected bunch of rascals (imigulukudu) (Participant 5, aged 15 years)*

*HIV AND AIDS carries a lifelong stigma, whether you like it or not  
(Participant 9 aged 18 years)*

- **Age limitation to access to health**

The responses also spoke of key local members that each of the children would approach to help them access health and social care. This was largely due the age restrictions that some of the participants spoke about, for example:

*Whenever I need to see a doctor, I call on my aunty or that neighbor from the post-office. They listen better to adults and most times, they (the hospital) tell me to go back and get my father or mother. I don't understand why we have to do so much to just get some help (Participant 4, aged 15 years).*

*When accompanying my sibling to hospital, it takes time for the clerk to understand that I am the head of the family, they really need some updates (Participant 3 aged 14 years)*

*Sometimes we wait too long for the volunteer to accompany us to the clinic as they also have other households to look after (Participant 4 aged 16 years)*

*I don't have time to think about going to doctors when all I worry about is where and when we will eat next (Participant 7, aged 16 years)*

- **Legislative ambiguity**

One important theme that emerged in the conversations with caregivers (head of family) within the child headed households, was that, the law was somewhat discriminatory and inconsistent against young adults who were responsible for making health decisions. This view was exclusively expressed by caregivers (head of family) within the child headed families as captured by these responses;

*Being 13 years means nothing if I cannot take my sibling to the clinic for health care (Participant 9, aged 13)*

*They think we are sexually active, why only allow us to go unaccompanied for family planning and not for other health and related issues, this is insane (Participant 2, aged 16 years)*

- **Positive experiences with access to health**

However some participants had had positive experiences as indicated below:

*If you are sick enough, the ambulance will come to your house and you won't have to keep explaining why you can't bring your mother along (Participant 7, aged 16 years).*

*The nurses who visit us at home are better – they just come and do their work and don't spend a lot of time sounding surprised that we live alone with our brother (Participant 5, aged 13 years)*

*The volunteers are very good, sometimes they come to check us even over weekends, especially if one of us was not well (Participant 3, aged 13 years)*

*I see them every month when collecting my HIV treatment, and we are like old buddies now, we talk about my health and school progress (Participant 4 aged 14 years)*

*Some nurses are so helpful and one wonders as to where they come from, when one is used to being so mishandled (Participant 3, aged 17)*

All the participants did not universally express this viewpoint, for example there was one more indication that they had only failed to receive appropriate care because there were limited services in the area they lived in. This was an interesting observation particularly because it mitigated the blame of being unsatisfactorily treated from “being a member of a child-headed family” and normalized it as a result of lacking service provision and nurses even made a follow to make up for the system shortfall. The following excerpts support this statement;

*If the treatment is incomplete due to poor resources, they do request from other local clinics or give you a referral letter to go fetch treatment from there (Participant 5, Aged 15 years).*

*If all nurses could be so much understanding, there would not be such discrimination (Participant 3 aged 17 years)*

*Sometimes the nurse takes your personal details so as to send the volunteer to give you whatever was missing on the day (Participant 6 aged 16 years)*

In summary the discussion above indicates that the health behavior of the participants was not very conducive especially in terms of housing, nutrition and hygiene. However, the supporting NGO covered some of the basics for survival through fast tracking acquisition of child support grants, serving with food parcels and food vouchers.

The answers received from participants specifically highlighted concerns that they had about the lack of health service access because of the discrimination against them as minors. Even so, they each indicated personally derived approaches to seeking health and social care support, for example, eliciting the support of local people to escort them to clinics if needed or in some cases, individual participants noted that they relied on the professional care who visited them in their homes as their pathways for health and social care access.

In summary the above data from the individual participant interviews that were carried out with the nine children from the different households, one can conclude that:

1. Participants experienced a generalized lack of social inclusion.
2. Participants felt stigmatized by an assumed association between being orphan and having a positive HIV and AIDS status that seemed to exist within the minds of other community members including teachers and some health care professionals.
3. Participants view health and social care law as being biased against them in such a way that they had limited scope for real decision making about health issues including health seeking health access.
4. Health services often only focused on physical health issues but little attention was given to less obvious needs such as the need for clothing like they were given old pre-owned clothing. The lack of the sense of belonging was a great issue for example, going out with family, missing elder to socialize, etc. They

were also deprived of the need for support to take part in social activities like sport activities, such as, stick fighting and contact sports at school.

5. Children from child-headed families were often embarrassed at school by insensitive teachers who would ask personal questions about their parents discouraging them from continuing with school.

## **QUE. 5 - WHAT WOULD MAKE THE SYSTEM WORK WELL TO SUIT**

### **YOU'RE NEEDS?**

Following the initial review and assessment of individual experiences of health and social care – participants were asked to propose possible actions they believed would be good in improving the ways health and social care services related to children in child-headed families should be provided. The presented contributions from the participants were captured under thematic groupings to ensure a clearer understanding of suggestions being made by participants.

The participants purported that they would prefer that the legislation regarding the age of decision making and access to children could be just 12 years across the board for all issues. This they justify by the fact that, a 12 year old child is allowed autonomy for sexuality and reproductive health only, this equates to fragmentation of care which warrants separate visits to hospital with associated logistical problems such as escort for curative services. Otherwise the participants can cheat to gain access in the name of seeking reproductive health but find themselves in other queues. This is supported by the following quotations;

*As a head of the family, what is expected of me if my sibling is sick with something else either than reproductive health which allows access for children at 12 years? (Participant 4 aged 15 years)*

*Why are we given incomplete rights to head our families, this confuses us and our siblings too (Participant 8 aged 16 years)*

*It is like they want us to be sex workers because the reproductive rights are the only ones recognized (participant 1 aged 17 years)*

The children felt that they could better benefit from the services made available to them if they could have some way of being identified so that their current detail and status could be known. They further explained that it was emotionally draining to have to repeat their sad stories to all the strangers and health care's even when some of 'them' were not even prepared to listen and be understanding. The participants were sometime tempted to tell lies about their history to avoid uncomfortable questioning and discrimination and indeed it worked for one of the participants as seen below.

*If we could have a special card that tells it all about our situation, instead of repeating the very same story each time you need assistance  
(Participant 5 aged 16 years)*

*'I have tried giving the incorrect information about my parental history, and to my surprise the health care personnel was very understanding (Participant 2, aged 15 years)*

Secondly, children, were asked to comment on what contributions they believed could be made to promote their access and quality of access they received to health and social care services. This question was uncomfortable for many of the participants, with some feeling that many of the problems identified were a result of a failure in systems rather than their own inability to make the best of their situations. As such, the feedback elicited from participants attributed all the difficulties related to health and social care access as issues that were a result of unhelpful systems or discriminatory law or generally low levels of resources as cited by the participants;

*The availability of volunteers is not under our control, they have their own schedule of work (Participant 3 aged 17 years)*

*Volunteers have many houses to visit (Participant 2 aged 16 years)*

*Long queues and waiting periods to finalize the case by the department are not user friendly (Participant 4 aged 17 years)*

*We did not choose to be orphans (Participant 1 aged 15 years)*

#### **5.4.1.3. FOCUS-GROUP DISCUSSION DATA**

To complement and verify the initial discoveries from the individual participant interviews, three separate group discussions were facilitated with each of the different families, to elicit their views on health behavior their experiences of accessing health and social services. The discussions with each family group were in-depth and necessitated more than one session per family case unit. The determination of the number of sessions needed was determined by the achievement of data saturation, that is, a point where no further new themes were expressed by discussants during the conversations. The focus group conversations had two very specific aims – (i) To verify and complement the discoveries made from the initial individual interviews and (ii) to expand on previously identified themes, to question assertions from the first phase and identify any issues that were not adequately highlighted by participants in the first phase of data collection.

As indicated earlier in the chapter, data collection was primarily via the use of open-ended questions. As is the tradition of qualitative enquiry, the focus was primarily on understanding the participants' experiences as they were expressed.

#### **5.4.1.4. Description of participant's families.**

The first family unit consisted of two children aged 14 and 17. One was a head of the family. The father died of a chronic condition after being retrenched from work. The mother had stress related symptoms and was ill for about a week and died in hospital. The sibling was having a congenital problem of both feet but could afford to wear a normal shoe, and was still attending school. They last saw their maternal relatives at the funeral of their father.

The second family consisted of three children at 13, 15 and 18 years respectively. In this family the eldest, the 18 year old had assumed the parental role and spoke as the head of the household. In this family, the three children had been orphaned through the death of both their parents from HIV and AIDS. Only one child in the household was HIV positive and receiving treatment. The father was a foreign national from a neighboring country and as such no family members existed within

the country from the paternal side. Despite their mother being an indigenous South African, no family members had offered support following the death of their parents.

The third family was composed of four members, aged 18, 16, 15 & 13. One family member was the head of the family and the other three were still attending school. They suspected that their parents died of AIDS because, they were in and out of hospitals and clinics. They both died 3 years apart, meaning, by the time the father died, the mother was already infected hence she died soon after. No one was working, they relied on the social grant and food parcels from the local church sometime and the NGO monthly. Their maternal extended family members were known to them and were in the same municipality district, but they hardly visited to see how the children were coping. If the children wanted to visit maybe during holidays they would not be available so that the children concluded that they were avoiding them.

The three families experienced some commonalities in their experiences as follows:

- Living in a child headed households
- No support from the extended family except for the volunteers
- Some siblings were still attending school
- Social grants were not enough to cover their daily financial needs
- They were under an NGO, that was responsible for the holistic care of vulnerable children

## **5.5. PRESENTATION OF FOCUS GROUP DISCUSSION**

- **Discrimination and social isolation**

Since the death of their parents these children experienced total isolation. They are only able to refer to their own siblings for support. Some support is gained from schools and the churches they attend.

Regular clinic appointments were offered for continued care and monitoring in relation to their HIV AND AIDS status, but sometimes could not attend because of financial problems.

*When calling my cousins wanting to visit, they just make an excuse of being not available on the proposed date (Focus group no. 1)*

*When my grandmother was alive, it was better off, you would see her coming now and then to check on us (Focus group no.3)*

Most respondents felt that the community view as HIV positive and treat them negatively. The following excerpts assert this;

*None of my friends want to play stick fighting with me, they excuse themselves as if they are afraid of me? (Focus group 2))*

*Some community members are still looking down upon us as if we got HIV (Focus group 1))*

*At school during Physical Training, some teachers think we are going to infect other children through play (Focus group 3)*

In each family, the children had had more than one hospitalization lasting several days to weeks and their resultant family unit disruption. This is supported by the following quotations;

*I was hospitalized for three weeks for an operation in my foot, my sibling had no money to pay me a visit, not even once (Focus group no.2)*

*My HIV AND AIDS status has seen me hospitalized at least three times a year, with TB but at some stage they gave me blood (Focus group no.3)*

However some of the family members felt that there was a fair chance of community and family positive regard towards them.

*Our long lost aunt came looking for us after 7 years, and she was so remorseful and promised that she will never desert us (Focus group 3)*

*In winter months, some community members give us warm blankets and more soups to fight the cold (Focus group 1)*

*Some people used to come and give nice things, especially during Christmas times, like presents like toys, sweets, and some clothing (Focus group 2)*

The participants also indicated that members of the community expressed a range of alternative views about their inclusion in the family discussions. One participant indicated that she felt that the community did not fully understand the challenges that face them as indicated by this statement,

*I really don't think that they understand what we go through without our parents (Focus Group 2).*

*We did not plan to live like this (orphans) it's God's plan (Focus group 3)*

Even so, participants expressed a sense of feeling excluded from every day community activities. When asked about the possible reasons for this, one of the participants indicated that they believe this to be a result lack of understanding of their circumstances as child headed families over and above the fact that some of their fathers and mothers had died of HIV and AIDS.

Understanding the factors related to accessing health and social care services were particularly complex during this process. Firstly it was difficult for the researcher to determine exclusively whether or not access to health care services was related to being a member of a child-headed household or whether these were indications of the poor societies that the communities lived in. As a means of seeking clarity to this, participants (children) were specifically requested to indicate how they felt their status as members of child headed families contributed to their experiences. This revealed a notable pattern in which participants were all categorical in believing and perceiving that their status as members of child headed households was the primary reason for the different attitudes of the health workers.

## **5.6 .INTERVIEWS AND FOCUS GROUP DISCUSSIONS FOR VOLUNTEERS.**

There were only four volunteers who participated in the study. They were all coming from the UMgungundlovu district but working at different residential areas. Their main function is to conduct family visit, give necessary support to children and report to the responsible CDF any urgent matter pertaining to the child. The interviews were conducted during participant's visits in the local area, but the focus group was done in the institution.

This was achieved through unstructured interviews as the researcher was doing field visits, and follow up with focus group discussion.

Volunteers were asked to share their experiences of working with children from child headed households. The experiences of the volunteers were mainly from the type of family they had engaged with. The researcher was impressed with the level of ethical respect and confidentiality displayed by the volunteers. This was explicitly displayed during the probing section, where they indicated that they could not respond to some questions to protect the children. Some of the experiences were explained as follows;

*Having heard about the death of the parent and the situation of the children in your area of work, it is not easy to just go and visit as a volunteer. You need to work very discreet and identify the right person to give you relevant information (Volunteer 1)*

*Sometimes the children are still hurting and it becomes a problem if you pry just after the funeral. Yet your intention is to help (Volunteer 3)*

Volunteers were asked to share their experiences and information as to what are the really core reasons for non-absorption of such children by the extended family members. They all share the same sentiment that, the financial viability is the key factor responsible for that, though each family present with its reasons. Some of the quotations by the volunteers are as follows;

*These children were living the city life that cannot be afforded in the rural areas (Volunteer 2)*

*The extended family members fear for their children, thinking that these children will be a bad influence to theirs (Volunteer 4)*

*Some orphaned children opt to stay together in these households so as to protect their family belongings from the vultures (Volunteer 3)*

When discussing the issues of available support by government, church and the NGO, the volunteer is of the opinion that there is adequate support made available for such children, but the present legislation is the very one that make such services to be inaccessible to the very target participants. This is supported by the following statement;

*How can a child of 15 years be recognized as the head of the family, yet cannot receive a grant in on behalf of his or her sibling? (Volunteer 2)*

*The decision to acknowledge them as child headed households takes time because it comes from the government (Volunteer 1)*

*Sometimes the children have no documents like birth certificate and yet there is no specific clause to bridge that gap, Social Workers have to follow the court processes and it takes time, the child suffers in the process (Volunteer 4)*

The volunteers felt that inadequate staffing levels were mostly to blame for the inconsistent attendance to the complex health and social issues of children from child headed families. This is supported by the following quotations;

*Identifying the family that is in need of our services takes about a week for the social worker and thereafter, it could be another three weeks before they visit to conduct the situational analysis (Participant 3, aged 52 years VLC).*

On the contrary, some volunteers are happy with all the support services offered to the children and explained that, the logistics can never be avoided otherwise the fraudsters will exhaust all the budget made for this vulnerable group. This is supported by the following excerpt;

*Imagine how many children that are really deserving to get the grant but, ghost children are being paid the government money (Volunteer 3)*

*Perhaps the children are better off without the external members because some foster them for personal gain through grant money. (Volunteer1)*

*The extended family members need to be reminded of their socio-cultural responsibilities towards orphaned children (Volunteer 2)*

On interviews checking what can be done to enhance the welfare of such children by all sectors involved. The participants were very reluctant to discussion, but on further probing, they opened up to some ideas that they thought could improve services to such children, and this was expressed in quotations like these;

*if there could be one card of access for all children coming from such household, this could solve all our problems (Volunteer 1)*

*Government should commit to the working partnership with other stakeholders and supervise their donor funding policies. (Volunteer 4)*

*If there could be some form of subsidized transport services for such children so as to enable access to health and other social services not in the neighborhood (Volunteer 3)*

Volunteers were also asked to share their experiences with regard to the health behavior of such children with particular regard to issues of accessing health care services. There was quite a stimulating debate about what should and should not be done. Most of the discussion was around the issues of accessing the clinic and what the nurse should do instead of chasing the child away; this was explained in the following statement;

*The children are living in poor conditions, such that sometimes they are go to bed on an empty stomach. (Volunteer 2)*

*One card with their particulars could ease the load of being frequently asked about the children's' late parents, because we sometimes relieve each other (Volunteer 4)*

*The clinic charter should be specific about the care of children from child headed household, such that the health professionals will clearly understand their expectations when dealing with such children (Volunteer 1)*

On the contrary, there are volunteers who happened to share their negative experiences with regard to health service and its access, as detailed in the following statement;

*There is no special service for children from such household, they join the queue like everyone, and this had a negative effect on the side of the volunteer because as an accompaniment of the child, her whole day is wasted on one family having planned to visit at least three families (Volunteer 1)*

*Some nurses in the clinic are not cooperative even if we try to request special attention for children in our company, (Volunteer 2)*

*What is the use of being allocated to a household if sometimes you are not supported and respected by the members of the same team you playing for (Volunteer 4)*

## **5.7. DATA ANALYSIS FOR THE PROFESSIONAL GROUP**

The professionals that are involved in the social and health care of child headed household range from social workers, nurses, psychologists, developmental facilitators and sometimes specialist doctors. For the purpose of this study, only the social workers, nurses and community developmental facilitators are referred to. This group echoed their views on the plight of these children at different levels of care according to their special areas of focus in the team.

One participant echoed her unhappiness with the legal process that needed to be followed before the final awarding of the status of the child by the court including the declaration of the head of the household. The children at such tender age sometimes had to be taken to court to make sworn statements under oath, doing things that they do not understand, relying on the second person. The court proceedings are also not fast enough to remedy the situation, thanks to the relief fund that is accessed whilst awaiting the court decision. The health professionals' and social workers' were in agreement that, legal processes and specific policies by the department of Social Welfare were in fact, working contrary to expected aspirations. For example, while

the head of the household is also declared by the court, they still cannot access all the rights like receiving a social grant on behalf of their siblings as demonstrated in the following excerpt:

*The child heading the family is not allowed to receive a grant in respect of his or her siblings, yet we are required to record and acknowledge them as the head of the family (SWC).*

*Sometimes it becomes so painful and emotionally draining to see a child in need, with no shelter, clothing and having gone for days without food to eat, such that I really wonder if I chose the right profession? (SWC)*

*Whilst awaiting finalization of the child headed household status by the court, as social workers, we tap into the social relief fund but this fund is limited (SWC)*

*Our reports are sometimes second guessed by the responsible social worker, thus delaying services to the children (CDFC)*

*As nurse, one can only assess, treat and refer to the next level. How the child reaches the other level is not falling within my scope unless it's an emergency where we are allowed to call an ambulance (PNC)*

On the issues of enhancing the services of such children by all sectors involved, the participants are in agreement in stating the unconditional support of the non – governmental organizations, because there is no red tape, as long as you are a child and in need of care, you are catered for.

The non-governmental organization also should be applauded for their unconditional support to children in need of care, because they can go an extra mile, build shelter, provide for all the basic support in quicker and faster ways than the government red taping. Their directors are on site, have their budget at their disposal and are allowed to treat each case on its own merit, whereas with the government, it really takes time because of the bureaucratic systems.

The community developmental facilitator's are the ones that really do the ground work for all the children in the organization. They do the family assessments, classify the type of needs, and assist with the application for birth certificates. In the process, they have to make plans to keep the children in a livable household. Luckily, they have their own building contractors who can identify the need and build a two to four roomed house within a week. The child headed household is thus entered into their database and allocated a volunteer to do daily checkups and report to them matters of urgency. One participant noted that,

*It is within my scope to report a child headed household to the local councilor and the clinic in cases where they needed support with anything so as to understand their situation' 'but it is not like all are willing to cooperate with us (CDFC)*

*The entry to a safe house is not as easy as they claim in adverts, one end up keeping the destitute child with you for a period of 24 hrs. or so (CDFC)*

*I have received complaints that when the children go for services they are ill - treated by the very same people (nurses, councilors, etc.) that are meant to protect them (CDFC)"*

On the issue of working relationship between members of the teams, they all echoed that the governmental policies are good and straight forward, but the only missing part is the coordinating link of services for them so that everything runs smooth.

The nurse is responsible for the holistic assessment of all health and related aspects of children, and this she/he does independently and only refers cases beyond her/his competencies to relevant hospitals and specialist agencies like the Psychologist and counselors. It is encouraged that children who are still not well are managed closely so as to have the medical record for it. If the child is admitted or needs a special operation, the institutional social worker together with the nurse make the presentation and sign consent for the child, but in cases of emergency the medical superintendent of the hospital signs it. Health care services are free at a primary health care level, therefore children are encouraged to use their local clinics.

The nurse reported that one child was abused by the local member and was psychologically disturbed such that when she saw a male passing by she would freeze and scream like she is re-living the scene. The nurse further explained that

*Children from such families are really struggling, once admitted, they have no visitors, they envy other children who get visited by their family members and bringing them nice goodies (PNC)*

*It is so pathetic at work, the way we are busy, we cannot afford to go and visit the child, knowing pretty well that he/she has no one, the other siblings at home cannot afford transport money to visit the hospital (PNC).*

The issues of barriers in accessing health care services was very complex primarily because of the fact that the age of access is 16 years, but with the help of volunteers, children from such household should not be struggling to get health services. It is also appreciated that the lowering of age of access to 12 years only for reproductive health is an issue that needs to be discussed further because once that 12 year old is inside the clinic, having done her family planning and the rest, you cannot afford to deny her services if she requests to be treated for sexually transmitted infections, because it is part and parcel of reproductive health utilization. The participant echoed her frustrations in that:

*I wish there was no legislation governing access for anyone, because this poses an ethical dilemma for us all, because it has been found that children are faking their reasons for access to the clinic claiming they are coming for reproductive health, once inside report tummy ache, headache, sexual abuse or dental pain. What is a nurse supposed to do, because they (children) are really in need of care? (PNC).*

*If a 12 year child is already in the clinic, is it ethically and professionally acceptable to send her back if she decides to join the queue for other health services either than reproductive health? (PNC).*

*Given the high volume of work, one is not affording to visit a child in hospital, the only one that are visited are those that we should prepare for discharge planning arrangements (CDF)*

The impediment to accessing health care services is the age factor, attitudes, ignorance, distance and poverty. Some children do not trust the health care delivery system because they have witnessed their parents using medical treatment but still passed on, hence they are orphans.

The professional nurses' experience with the problems encountered by the children from the child headed households has discouraged her to an extent that she would not recommend nursing as a career for his children as illustrated in the statement below:

*Nursing was a noble profession, I chose it because of that, but not sure of it now, sometimes you feel like the essence of it was lost with democracy. I will not encourage my children to take it as their profession, so much has changed and we are no more proud of our profession. (PNC).*

## **5.8. SUMMARY**

The current chapter dealt with management of field data. The data were generated from members of child-headed families and care providers (volunteers) and professionals who provided support to the identified family members. During the management of data, quality was retained and managed through an integrative in, which data from the different sources was compared and corroborated to elicit areas of agreement and disagreement between those issues highlighted by participants. The section discusses participant's observations and also presented a description of qualitative data to complement personal accounts.

## **CHAPTER SIX**

### **6. DISCUSSIONS OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS**

#### **6.1. INTRODUCTION**

This chapter will present the discussions of the findings of the study, drawing conclusions, making recommendations and describing the limitations of the study.

The discourse relating to the inclusion of child headed household families in health and social care services, and issues related to health behavior and access have both received increasing attention in the past years particularly in the South African context as this group has grown with the escalation of child orphans. Studies in the area have been broadly quantitative and qualitative, as such have only had limited ability to critically review in depth factors associated with health and social care usage among this group.

The current enquiry explores the study area from both orphans' and clinicians' perspective using different but arguably complimentary data collection methods. The study utilizes the Max- Neef (1983) Human developmental model as a framework for considering participants accounts of factors related to their access to health and social care.

In advance of the study, a thorough review of related literature was conducted, and this assisted in highlighting the current and prevailing thinking within the study area. It also emphasized prominent themes from relevant literature, especially knowledge gaps with respect to the area of interest were identified. It was the area of limited clarity within the study area which served as the background for the research purpose for the current study. This study utilizes the findings elicited from members of the child headed families and health professionals that work with them to develop

theoretical perspectives to guide future work with this vulnerable and often marginalized population.

## **6.2. OVERVIEW OF THE DATA COLLECTION PROCESS**

The study was carried out in three separate but related data collection steps, i.e. observations, individual participant interview and individual family focus group interview. Steps like participants observations and the individual interviews, involved a research led set of interviews with child headed household members for three families, volunteers and the health professionals who worked with the families. This was followed by three family focus group discussions as families could not be combined for such because their circumstances were very different.

In all these steps the focus was on understanding the range of health behavior, health seeking behavior and issues of access of children coming from child headed household for primarily understanding the participant experiences as they were expressed without any attempt to ensure fidelity to any preexisting model.

## **6.3. DISCUSSIONS OF FINDINGS**

### **6.3.1. Logistics of awarding of child headed household status.**

Both the volunteers and the professional group agreed that the process of awarding the child headed household status by the court is a lengthy one, in the meantime the child may have no shelter nor food to survive, sometimes the volunteers and professional participants end up taking these children into their own homes. Thereafter another process is followed to confirm the physical existence of each child as specified in the report by the social worker in the Children's court. Compounding the delay is the involvement of several levels of staff (volunteer, cdf and the social worker). However this lengthy process is necessary because of corruption and fraud where ghost children have been found in the system. This issue of system abuse was observed in the UNISA Multiprofessional Study (2008).

The volunteer conducts the initial visit, followed by the Community Developmental Facilitator, who then conducts a comprehensive situational analysis for each family and refers the case to the social worker, who then finalizes the case as per identified need.

Furthermore, is the distance among the servicing offices (health services, social services and housing, etc.) which are far apart warranting several visits to separate offices and related cost and time wasted?

The National Guidelines for Statutory Services to Child Headed Household (DSD 2010), has given more clarity on the processes to be followed to expedite the services made to alleviate suffering of children from such household by all structures involved. Nevertheless, none of these issues was mentioned by the children, they probably were still confused or didn't know what to expect. The issue of system abuse was also observed in the UNISA Multiprofessional Study (2008).

### **6.3.2. Reasons for orphanhood**

The Global Aids Report (2012) indicates the rate of orphanhood related to AIDS at 95%, and is in agreement with Statistics SA (2013). This is reflected in the current study in that two of the three families had lost their parents to AIDS, with only one family whose one parent died from assault related to crime and his wife followed from stress and related illnesses. This highlights the severity of the problem of AIDS in the society. One can only expect worsening of the problem because there are still new infections and high prevalence (UNAIDS 2012).

It is noted with great concern that some participants still do not understand why their parents had to die because they were on treatment and compliant to treatment

### **6.3.3. Reasons for non-absorption**

The children and the volunteers expressed one and the same reasons for non-absorption by the extended families. One reason was stigma associated with possible HIV and AIDS infection in fear of infection of their families. The socio economic status and generalized poverty among these communities were also highlighted as the major contributing factor, as they hardly had enough for their immediate families. The most cited constraint is the economic changes brought about by the spreading out of the already limited resource of the family and the expected social adjustment by family members in an attempt to accommodate the orphans (Reid 1993)

Cultural and social responsibilities were also found to be having a very serious

impact on the decision made by the extended family on the basis that children born outside the wedlock belong to their maternal side. Nziyane (2008) concurs with Foster, et al (1997) in stating that children born under these circumstances are always growing under the shade of not knowing which culture or tradition to follow and they end up in the middle with no family support. This has a far reaching implication for a male child who needed to carry on the legacy of the paternal side. This situation is further exacerbated if the single parent was leaving a modern or city life and the children had no previous relations with others from the extended family. In one family the father was a foreigner and when both parents died the children were deserted because their extended family would not absorb them for possible Xenophobia. It seems that this is a symptom of a bigger problem identified in the UNISA Multiprofessional Study (2008) where it is asserted that increasing numbers of non-South Africans die in South Africa making necessary for the government to look after the remaining children. However this current study found this problem not prevalent in KwaZulu-Natal.

The participant (professional) view the non-absorption as a better option for such children, eliciting the benefits of preserving their family unity and its assets as observed in one participating family where the uncles took the assets with the reason that their mother was owing them money. The UNISA Multiprofessional Study (2008) maintained that even if children were not from poor background, they fell victims of some extended family members or relatives who grab their inheritance.

The exercise has been described in the current study by the professionals as psychological healthy and reduces the risk of children from one family being adopted /fostered by different families and the risk of never seeing each other for the rest of their lives and the complications thereof. Separation of siblings under such circumstances may end up with them marrying each other and discovering this blood relationship later as described by Barton (2008).

#### **6.3.4. Support**

The volunteer and the children are of the same opinion in stating that the support provided by the Church, Non-Governmental (NGO) and the communities played a great role in sustaining the lives of children from child headed household. This they attributed to the fact that, the church offers its unconditional support to all children in

need of care irrespective of the social standing. Both these organizations serve as the haven for children whilst waiting for the government logistics, following court processes in preparation to award them the full status of being Child headed household and entered in the departmental data base, national, provincial and regional (DSD, 2009)

It is noted with much appreciation that, these organizations can remedy the situation faster than the government because their decision making powers and budget allocation are controlled internally as compared to the departmental processes that take time, following specific bureaucratic structures,(red tape). The support provided by NGO, church and communities usually covers the basic needs of subsistence, and the only challenge is that their services are not well organized. They are poorly coordinated and not guaranteed as they depend on the donor funding (MacLellan 2005), yet the government cannot dictate to them how to run their program.

The government funding through the social assistance grants like, child support grant, foster care grant and social relief grant are always delayed because of the logistics mentioned above, but once captured on the data base, one is guaranteed of the support as per the specification of the Child Care Act (Act no 41 of 2007). However, some participants were also suspicious of some seasonal organizations who only assist them during specific times of the year and insist on taking photos of them, disappear and pitch up again the following year almost at the same time. According to Multiprofessional Study by the University of South Africa (2008), NGO's are the most actively engaged in support of child headed families as is the case in the current study.

Professionals and volunteers in this study are of the opinion that more support is still needed, especially in financial aid to assist in improving issues of access to health and social care services. For example children needed money for transport to the clinic for the first encounter, for transportation of an escort to hospital in cases of referrals, visiting other children when admitted in hospital so that the children do not envy other children when visited in hospital by their parents and siblings. UNAIDS (2012) has come to the rescue of these children through provision of funding, but it would seem that coordination of these remain a problem.

The professional participants specified that the only chance where they are mandated to visit the sick child in hospital is only when the child is for discharge and is going to be cared for by the staff in the NGO so as to learn and acquaint themselves with the discharge plan for the child to ensure continuity of care. This improves the support and emotional growth for discharge and new coping mechanism. All the participant were categorical in declaring that such support no matter how little it may be plays a major role in the psychological well-being of children. This support should be individualized focusing on specific needs of the child as determined in the collaborative discharge plan (Interview with the S/W)

It is of significance to note that the volunteers and professional are in agreement in stating that, they wish there could be a common ground for all sectors involved in the care of children coming from child headed households. This they base on the premise that some organizations offer one and the same services (duplication), yet there are areas of great importance that are not covered. The fact that they are voluntary organizations puts a strain on the responsible NGO, because they cannot prescribe to the other what needs to be donated and what time. The unpublished UNISA Study (2008) identified the same issue of poor coordination of services to the child headed families and supports the professionals in expressing their concerns about the services of subsidized transport that has not yet reached the children as one of the vulnerable groups like the aged and the disabled.

### **6.3.5. Stigma and discrimination**

Some participants echoed their experiences of having been stigmatized and discriminated by all involved in their care and management, but at different levels, ranging from school environment, family, communities, health and social care services. The professional participants expressed concern about this because all the above mentioned structures are supposed to be protecting the children. Children also assumed that they were stigmatized and discriminated on the basis of age as the legislation, the Child Care Act (Act no 41 of 2008) stipulates that the acceptable age of access to health care and other social care services should be 16 years and above, because the children at this stage are in a possession of a South African identity document. The stigma and discrimination were also perpetrated by their

AIDS status and being linked to parents who possibly died of AIDS, hence they were not absorbed by their own extended families

The psychological trauma to children can never be estimated because each family dealt with the loss and the grieving process in their own unique ways. The behavior elicited by anger is insurmountable for example, some may be involved in crime, juvenile delinquent and prostitution, and hence they need unconditional understanding and support, as claimed by Mackian (2003). This author asserts that the psychological trauma and personal circumstances in the child headed household makes it difficult for them to make informed decision in terms of delinquent behavior depending on emotional maturity.

#### **6.3.6. Health behavior**

All the participants are in agreement that such children are characterized by extreme poverty and HIV and AIDS prevalence, hence their health behavior will be influenced by many needs for subsistence that are not well met.

The professional participants were very vocal about the process (logistics) of finding a suitable place or shelter for such children which it is not as easy as it is specified in the government policy documents. The tedious process is seeing some children staying with either the professional from the NGO for a period of not less than 24 hours or more. These places usually called SAFE HAVENS OR DROP IN CENTERS are full and the destitute children are piling up in numbers because of parental death and issues of non-absorption by the extended family members. However Meintjies, Hall, Marera and Boule (2006) in their quantitative study found that only a small percentage (8%) of double orphans living in a child headed family are living with an adult, these authors suggest that kinship networks continue to provide care for these children this assertion is contrary to the findings in the current study from both the children, the volunteers and the professionals who even maintained that extended families were irresponsible for not absorbing the orphaned children

The houses that the children lived in were either old, dilapidated and not offering safety and security or they were the two roomed houses built by the government or donor organizations, that were sometimes overcrowded by so many children predisposing them to poor living conditions such as spread of communicable

conditions, lack of privacy, poor hygiene, incest and early sexual orientation as described by Hatting, Dreyer and Roos (2006). One female participant echoed her problem of having to share a bed with a male sibling as the only solution because there was no extra room for the opposite gender and this could lead to possible incest. Gwandure (2010), in a study on psychological impact of children growing up in a limited space and privacy found that there is high levels of anxiety, depression, conduct disorder and risky behaviors were associated with limited living space and privacy.

Food insecurity was a general problem for the children in the current study as they came from poor families. It is not uncommon for a child to go to bed on an empty stomach as was found in the study and supported by the report on challenges of AIDS across the globe (UNAIDS 2012).

The governmental, the church and non-governmental organizations provided some food hampers to attend to the nutrition needs of the children. The rules surrounding the distribution of these food hampers was on a ratio of 1:1, meaning that one household was to get one food hamper. This rule did not take into account the number of siblings within the household and the gender, as it has been equally reported that boys eat more than girl, making the household with boys to finish their hamper earlier than the one with girls only (Yanovski 2010)

All families affirmed that the food hamper irrespective of the gender of participants did not last till the end of the month, meaning that they had to make means to get some food supplements until the next supply. Ayieko (1998) maintains that child headed household cannot afford to buy the basic food because of poverty, drought and moreover, they cannot even plough their land/farms to get other types of food and sustain the living because they are sick themselves or busy looking after their sick parents or siblings. This author further claims that even the former rich families' resources get depleted by medical bills, hospitalization and end up poor like the rest of them all. Hence the professional participants in this study were categorical in stating that children from child headed families are at the bottom of the list and heavily stricken by poverty, thus proposing that, supporting companies or agencies should dwell on skills upgrading through small project implementation like agriculture and small scale farming. However the challenge would be the present laws of the

country that prevent child labor and this ends up bringing back the cycle (wheels) of poverty. Some children flee from homes and engage in commercial sex to feed their siblings. The UNISA Multiprofessional Study (2008) in addition suggests skills in management of available wealth which they observed to be lacking.

The volunteer and the children participant in the study identified that the grant money was not enough to cover up for the basic needs of children like clothing as some children grow faster than the others. From experience, if a child was wearing too small or too big clothing, it becomes uncomfortable and predisposes to ridicule by peers and its complications, like self-pity, withdrawal, feeling inferior to others and social isolation. It is however noted with some appreciation by all participants that some organizations donated some pre-owned clothing for needy children, but the distribution of such was at the hands of the responsible organizations. The children only received what was allocated to them.

The supporting NGO's, were known to only conduct the size check for school uniforms and shoes. Each child got what was really meant for him/her. This exercise was reported as the most uplifting one, where the children felt equal to their peers, and this is supported by Skelton (1998) when he proclaimed that it is only at school level where children are developing their personality, life skills, financial intelligence and emotional maturity. At school level, the children's self-esteem is boosted, moral is high especially if the child participated in sports and recreation. Everything is done in a team, emphasis is on 'we' than them, and this has been found to be the only time where such children get the fulfillment and the sense of belonging and social identity, but after school, all that is gone, children recoil back to their shell (cocoon). This is probably why German (2005) and Desmond et al (2004) advocated for the involvement of the children in self-assertion including extra mural activities like sport and leisure.

### **6.3.7. Health seeking behavior**

Participants acknowledged the fact that children from child headed household were living in severe poverty and stricken by HIV and AIDS and its complications. The eldest child usually becomes the head of the family, he/she is still very young but the situation is throwing him or her at the deeper end. The head of the family is already expected to make informed decision about health issues affecting her/his siblings,

and this may pose a challenge because he/she is a minor too. Connor and Norman (2002) contend the fact that other siblings rely on him or her creates an unbearable strain to the head of the family who is also a child. In the event of medical emergency in the absence of a volunteer, issues of access to health may pose a challenge because the age of a reported access to health and social care services for an accompanied children who is 16 years, therefore such children would have a problem if younger than 16 years (The Primary Health Care Clinic Charter, 1996). This assertion was confirmed by all participants because they believed that the legislation ambiguity was the one responsible for such limited access to services specially meant for orphans and vulnerable groups, yet they could not access it freely.

The very departments of social development in the Multiprofessional Study by UNISA (2008) agree that the policy framework for orphans and vulnerable group by HIV and AIDS though it is good, it lack guidelines for implementation and enforcement, and failed to address some issues for example family inheritance. However this issue did not affect the participants in the current study.

Shah (2013) reported that the decrease in access to health and social care services is responsible for increased morbidity and mortality among children across the globe.

The logistics involved where the child needed medical care, the issue of an escort by an adult or volunteer to access health services, is acting contrary to the guidelines by the government that were designed to promote access of such children to such amenities. It has been observed by the researcher that the amendment from 16 years to 12 years for reproductive services has made the situation even worse now, that the children have identified the loophole in the present system, where they claim that they attended for reproductive services and once inside the clinic queue join the curative side. The professional nurses in the clinic, under such circumstances were faced with an ethical and professional dilemma and decided to give children medicine irrespective of their age hoping that the volunteer will guide them at home. The professional does this against ethical and professional guidelines to secure therapeutic relationships with the clients (The Primary Health Care Clinic Charter 1996). Kemp (2013) supports this relationship when stating that the unique intimate relationship that exists between the medical team and his/her patient is possibly one of the most important relationships that can come into being. This relationship is not

only the cornerstone of the culture of medical care, but is vital to the quality nature of the ethic of care and influences the outcome and relative success of the medical care.

Another most pressing issue was the debate on the grant money. All participants were in agreement that the financial implication of attending the clinic and transfer to hospital were a serious threat to them because they lived in dire poverty. The money to pay for the escort was further compounding the already existing problem. This situation had seen the children waiting for the condition to get worse so that they could get the service of an ambulance and be escorted to the hospital and bypass the normal system where one was subjected to an intense interview by the clerk in places with less or no privacy at all. Professional participants emphasized that these children were really struggling for survival, and thanks to the social relief fund that was accessed on behalf of the children until their application for relevant grant was processed and completed. Cheatham, Barksdale and Rodgers (2008) concur with the participants in a study that investigated the health behavior of an American Black men, where the findings were the same, in relation to not seeking health services in time, only waiting for the condition to get worse so that they can skip the health promotion phase.

The children participants also expressed mistrust of the local health care delivery services from the experiences with their parents, who were in and out of hospital without help until they passed on.

#### **6.3.8. Access to health**

All participants were in agreement that access to health and social care services was influenced by the availability of an escort. In the absence of an adult or volunteer, the access to clinic was delayed or completely missed. Stigma and discrimination based on the premise that the children could be HIV and AIDS infected had a strong impact which further reduced access to health and social care services (CSV, 2008). Negative staff attitude also added to the issue of access to health as expressed by the all categories of participants who were concerned about being questioned about their family history in public in each visit, making them to repeat their sad stories.

Age limitation of 16 years together with the legislative flaws, which reduced the age of access to 12 years only for reproductive services, has further confused the children and their volunteers. This has promoted increased access of unaccompanied children to the curative side of the health center under the banner of seeking reproductive services leaving the professional nurse with an dilemma of chasing them away or taking the risk of attending them unlawfully and exposing them to possible drug adverse events which may attract litigations and professional misconduct discipline (Child Care Act No 41 of 2007)

All participants in this study mentioned that the shortage of volunteers to assist children every time they needed to visit the clinic or social services was of very importance because their unavailability influenced access and its implications to children lives. The issue of shortage of volunteers was also identified in the UNISA Multiprofessional Study (2008), which affected the capacity to respond effectively and efficiently to the needs of child headed household families. In addition, these authors also pointed out the issues of varying stipend from the NGOs' and the government

The staff attitude that was reported to be somehow unprofessional and responsible for reducing access to services. An orphaned child has already suffered a lot by the mere fact that he/she is an orphan, maybe infected, was not absorbed by the extended family members, and when the government is trying to uplift their socio-economic position by providing them with such services, the staff is mistreating them as if they are non-entities, these children's ego is easily bruised, one need to tread carefully around them (Kravolec 1998). The children in this study viewed the treatment by staff as very unstable, more like their basic prerogative right had become a privilege which could be given and withheld by anyone in the employ by the government, and hence this had lowered their willingness to access these services.

Professional participants from the NGO, in this study pleaded for the smooth coordination of all sectors involved in caring for children coming from child headed household. The emphasis was on a well-coordinated team approach so that the package offered to children could meet all their basic needs for subsistence, reduce inequity and imbalances. The UNISA Multiprofessional Study (2008) supports the

assertion by the current study participants in recommending collaboration of sectors to provide effective services. Professionals participants also commented about the legislative ambiguity exposing them to ethical and professional dilemmas as mentioned above.

On a positive note, children were still having positive regard for some volunteers and professional nurses from the clinic and were very happy with their services. This they ascribed to the fact that some of these professionals went an extra mile to ensure that their needs were well taken care of. Some nurses in liaison with the volunteers would even visit them at home to bring outstanding treatment items which they could not access because of drug shortage at a clinic during their visit.

### **6.3.9. Cultural issues**

Both the volunteers and the children affirmed that the absence of an adult member in each family is a great draw back for such children. The socialization process is lacking especially the boy child would need to know and understand his roots to carry the legacy of the clan forward. A boy child who grew out of these households, would have no history of his family, or clan, nor understand his culture and tradition exclusive to his family.

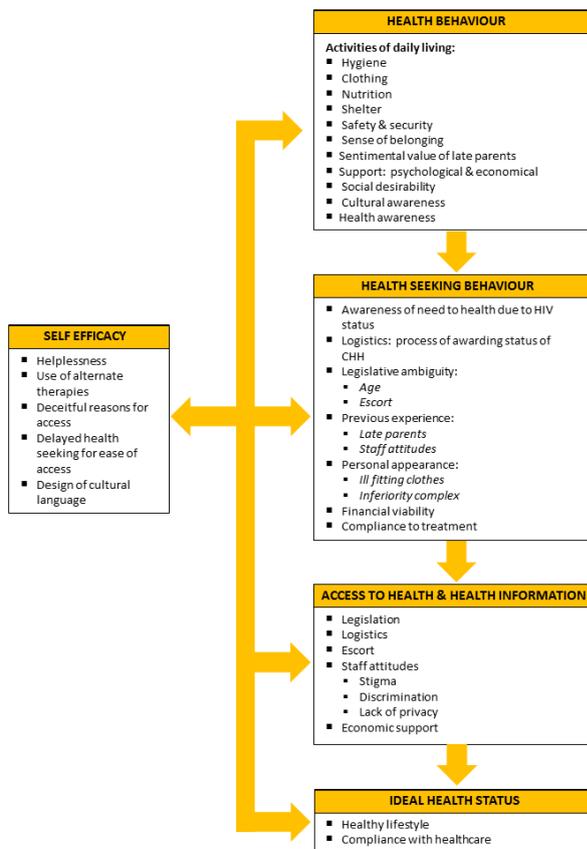
One family was still keeping their mothers' Kist in an old dilapidated house because they had no adult to perform the ritual to remove the Kist, no money to afford the expenses incurred from the ritual and lastly, they did not know how to do it because they grew up without parents, no socialization regarding such issues was conducted.

Nel (2007) in his thesis asserts that in Zulu culture, both the traditionalist and Christians honor their parents whether they are alive or dead. This author further describes the family as an emotional unit including the nuclear, extended and multigenerational families which includes the ancestors. It would therefore seem that the children in this child headed family observed this assertion by keeping their old family house and mother's Kist.

The other participants who shared a two roomed house with a boy child, had opted to develop their own language to promote confidentiality during menstruation for the exclusive communication among girls. During menstruation the girls would speak of 'tomato sauce 'days, disguising the information for the boy child. This really needed

to be discussed because it meant a change in the sleeping arrangement within a household.

In African culture and tradition, a man (boy) is not supposed to share a bed with a woman (even the wedded wife) when she is menstruating, as it is believed that it casts some negative spells on a male. In this family too, since there was limited space, they needed to come up with a plan to protect their brother from such and not affect him psychologically. Roberts, Goldenberg, Power and Pyszczynski (2002) asserts that there is still evidence of people viewing menstruating women as polluting and unhygienic to their embarrassment, therefore women go an extra mile to hide the evidence of their menstruation periods to an extent that they even use disguised packaging to using euphemism to disguise discussions about menstruation. The UNISA multiprofessional study (2008) in support of the assertion about cultural issues in this study, acknowledges the uniqueness and cultural sensitivity in dealing with child headed household families, thereby advising on not imposing but listening to them.



**Figure 6.1. Summary of Data.**

#### 6.4. STUDY CONCLUSIONS

- The process of awarding the child headed household status is a lengthy one while the children are living in complete poverty and struggle to survive, thanks to the NGO staff who go extra miles to ensure the survival of these children through securing the social relief fund and vouchers depending on the identified need, sometimes they even take them along to their families.
- Child headed families predominantly result from HIV and AIDS, and children are more absorbed into the extended families as was the tradition in the Zulu culture. This could be attributed to the socio-economic dynamics prevailing in recent times, such as fear of contracting HIV, nuclear family prevalence, poverty and greed for inheritance.
- Supporting agencies like NGO, church, and the government play a pivotal role in support of children including facilitation of acquisition of support services from the relevant departments, like awarding of the child headed household status and food vouchers during the processing and finalization of the process. Other services include social assistance grants, feeding schemes, uniform allowances, and fee remission.
- HIV and AIDS status of the late parents, the children and the vulnerable age group of the children result in the children being subjected to stigma and discrimination, suspecting that the children may be infected themselves. This is likely to be the fear of the extended family and neighbors for their own children to be infected. Nursing professionals who are supposed to be protecting these children unfortunately they themselves, subject the children to lack of privacy by asking about their late parents and their pathetic circumstances each time they visit the clinic.
- The child headed families were faced with poverty and cannot meet their subsistence needs, thanks to the NGO and the church which provide housing, clothing, and food vouchers. However, the food vouchers are not adequate especially during weekends and school holidays when the feeding schemes provided at school are not accessible. While housing is provided by the NGO, some cultural issues and unavailability of elders leave them hanging /clinging

on to the old dilapidated houses as their expected ritual cannot be performed. At times overcrowding with even sharing of beds between boys and girls is seen with possibilities of complications like deviant behavior such as incest. Pre-owned clothing that is sometimes given to children embarrasses them when it is ill fitting and make them feel inferior.

- The ambiguity of the legislation, shortage of volunteers, unaffordable transport and the attitude of the health care workers impact on the child headed household children's health seeking behavior to an extent that children avoid accessing health services until they are very ill to be picked up by an ambulance which bypasses the administration section which subjects them to sad memories and embarrassing questions ,such as those related to the HIV status of their parents which could imply theirs too, without providing privacy.
- Even in their tender age, children in the child headed household still observe their cultural heritage. For example, children still aspire to perform rituals that would honor their late parents, as they would need to move their late mothers Kist from an old house to a new one

Boys are also respected by girls when they are menstruating. The children that were sharing the bed with a boy would observe the cultural practice of hiding the menstrual periods and their associated materials using euphemism.

Children born out of the wedlock abandoned by their paternal family and rejected by their maternal family, still tried to visit their paternal family to identify with them and honor their culture, especially the boy child who is expected to carry the legacy of the clan forward.

## **6.5. MAX-NEEF HUMAN –SCALE DEVELOPMENTAL MODEL PLACING THE DATA INTO THEORY**

As indicated in the earlier chapter the researcher attempted to classify the needs of the child headed household children as presented in Max-Neff's Human –Scale Developmental Model.

### **Subsistence**

The child headed household children sometimes hardly had food to eat to an extent that they thought they could not worry about anything else if such basic need could not be satisfied. Their houses were dilapidated to an extent that their safety and security was threatened. At the same time they were too young to work in an environment that prohibited child labour by law. However, once their status as child headed household was awarded things got better as houses were built for them, food vouchers and clothing were provided even though that was not enough due to increasing numbers of orphans from various reasons predominantly HIV and AIDS. Therefore the health of these children both physically and mentally is most likely not to strike a balance. Compounding this factor would their possible HIV and AIDS status. This assertion is in line with Bircher (2005) who contends that the definition of health must take into consideration the changing health needs especially in relation to age, culture and personal responsibility to meet the needs. However, Max-Neff claim that needs remain the same through culture and time.

### **Protection**

The health status of some of the child headed household children warranted close monitoring from the volunteers and health care workers due to their HIV and AIDS and psycho social and emotional states from the loss of parents. The NGO and the health care centers like clinic needed to cooperate with the NGO staff to protect and take care of the children when the need arose.

The legislation while it provides for the children, things like social assistance grants and the whole comprehensive packages for the vulnerable groups such as free education and free health care services, had failed the child headed

families in some aspect, for example, the issue of the age and the need for accompaniment /escort has hampered their access to health.

### **Affection**

The children from the child headed families need for affection is grossly deprived because of the late parents and non-absorption by the extended family members. They were left on their own to intimate as siblings. However an abnormality exist when they share even beds between boys and girls in their small donated houses to the risk of incest (violating satisfiers)

### **Understanding**

To facilitate education, the department of Education is providing free education to children coming from child headed households, including the feeding schemes. However satisfying access to education without moral development acquired through socialization in a family unit, education may not succeed.

### **Participation**

NGO and the church play an essential role in support of the children in collaboration with the government department. However, children could participate in meeting their needs, for example, joining community projects to acquire skills for survival. However the labour law prohibits the child labour, making the children to be dependent on the available system.

### **Leisure**

The child headed household children participated in sports at school and sometimes in the community after school, on weekends and during holidays.

However there were times when they could not get company because the other children would be out with their parents. Sometimes parents in the neighborhood would keep their children away for fear of being infected with HIV and AIDS which they were linked to because of the status of their late parents.

## **Identity**

The child headed household children in the study demonstrated their concern for their identities which they thought was dented by orphanhood, age and non-absorption. For example one family was rejected by the paternal family, yet they needed this family for identity so that they could carry the legacy of their father on. Failure to carry out the specific rituals related to their family or clan depressed the children. The sense of belonging was lost and one boy child in one of the families slept in an old dilapidated house even when the new donated one was completed because he had this sentiment with his late parents. This need for identity and sense of belonging was not satisfied.

## **Freedom**

While the children from child headed households had freedom to access most of the amenities like school, health services, etc., there were instances when they had no choice but take the circumstances as they presented themselves, for example unavailability of the escort to access health care, pre-owned clothing sometimes ill-fitting when, as adolescents they were so conscious of their appearance, making them feel inferior or helpless, further tainting their self-image and identity.

## **6.6. RECOMMENDATIONS**

The findings of the study showed that children from child headed households needed quite a variety of support. The main area of concern and that forms the basis for recommendation was the coordination of all sectors and agencies that work with children, both the government and the NGO and the churches.

The specific recommendations form the highlight of the study;

### **6.6.1. Research**

It is recommended that a longitudinal case study be undertaken to follow these children after 18 years and beyond as it appears that they tend to get lost in the thick vicious world and end up in the wrong side of the law.

A model that was developed need to be tested since this was a small scale study that was qualitative in approach, so the findings cannot be generalized beyond the context of this study. There is a great need to do a scale quantitate study with some qualitative aspects. Further research could explore the lived experiences of the care givers (the eldest child in each household and volunteers involved in the care of such children)

### **6.6.2. Practice**

The health and social care services should be well coordinated such that all structures involved with care of children from child headed families could speak in one voice so as to influence health behavior and access to health care services.

The NGO and the government should increase the number of volunteers working with such children because there is a great shortage of them in the community and that has a negative influence on the health behavior and access of children to services made specifically for them.

There is a great need for subsidized transport to clinic or social care services. This is because the children are living in dire poverty and it has been found that they do not benefit from some services because they have no money to visit these offices and to pay for the escort to the clinic or social care services, and again do not benefit from the services made for orphans and vulnerable groups.

It would seem that the only time and place where such children's social identity and morale are high is at school with the acquisition of school uniform and team work through sport and class activity, therefore these activities are strongly recommended in this study.

### **6.6.3. Management**

All the participants recommended that the age of 12 years should be open for all types of visits to the clinic as it has been found that this has caused too much confusion for both the clients and the health professionals, and its implications to access to health and social care services.

They recommended the utilization of one card that will carry all their information regarding their status, as they find it embarrassing and emotionally draining to keep repeating their sad story of their life to all strangers that happen to be in the offices. They propose the card like the one used by SASSA for accessing grants.

One would have wished that the government departments like department of health, education, social development, non-governmental organization and faith based organization could form a strong coalition with all structures working together in meeting the needs of these children, with specific terms of reference and well-coordinated linkages

## **6.7. STUDY LIMITATIONS**

The researcher's study was limited by the following:

- The greatest limitation of the study was that it was qualitative and used only nine participants in three families hence cannot be generalized to other contexts.
- Study period, though it was done at a doctoral level, the timelines to completion hindered the researcher from doing a large scale study that was going to give detailed data.
- The researcher wanted to include as many families (participants) as possible, but the number of families who were already awarded the status of child headed household by the court were very limited, some cases were still pending, thus not meeting the eligibility criteria for the study.
- The study covered the children that were already receiving services from the NGO while the majority of the children may be worse- off and some may still be awaiting the award of the status by the government.

- Some families were still in the data base for the responsible organization but above 18 years of age, thus could not be included as they were already outside the scope of the study.
- Financial constraint's also influenced the scope of the study as the researcher had only one sponsor with limited funding.
- The study participants were all children coming from child headed households at UMgungundlovu district, but the issues of gatekeeping were a problem with other Non-Governmental organizations and the researcher ended doing one organization.
- Some children were still attending school, so the researcher had to collect data very late, after three in the afternoon to accommodate them.
- The researcher had to conduct the focus group interviews only on weekends because it was difficult to get all the children at home at one time during the week as they studied in different school and travelled long distances on foot back home.

#### **6.8. REFLECTIONS OF MY ROLE IN THE RESEARCH PROCESS.**

It was critically important throughout the research process for me, as the researcher, to evaluate my influence on aspects of the research process. My evaluation specifically focused on the impact I had on participants of the study and on the research process, especially in light of the fact that I personally collected all the data for the study, designed and implemented the interview procedures with clinician and child-headed family participants. Frankel & Devers (2000), in their analysis of research roles, point out the critical importance of self-awareness for the researcher,

especially within a qualitative framework, where the researcher acts as the main research tool. Critically evaluating my role within the study is best considered in relation to each of the two data collection phases of the study (i.e. the individual participant interviews and the group discussions) and additionally in relation to complications arising from my dual role as the researcher and a clinician.

I entered into this project as a clinician with nearly two decades of post qualification experience in various service areas within family practice work, and also with some previous research experience in the study area. In many regards, my experience both as a researcher and clinician with specific insights into service-usage issues appropriately placed me to appreciate and grasp knowledge gaps within the domain. Despite these apparent advantages, I was particularly aware of the associated pitfalls that relate to having previous experience and knowledge of the study area, especially with regard to the increased risk of having preconceived ideas about what the study would uncover, such as pre-conceptions in relation to the association with HIV and AIDS. To guard against this negatively impacting on my role as the researcher, I took time to note all pre-conceptions ensuring that the design(s) of my data collection tools were not biased towards 'discovering what I believed'. Presenting my data collection tools for pre-implementation evaluation, via a transparent peer review process was primarily intended to highlight any such obvious issues, which may have compromised the objectivity of the study.

The literature review was an important process in the development of the study and in many ways, provided both the scientific basis and personal justification for pursuing the objectives of the current project. The review of literature occurred in all stages of the study, and informed most of the decisions taken in the design of the methods utilised within the study. The commitment to thoroughly understanding the area under study was carefully balanced with ensuring that I did not get so immersed in the literature that it clouded my judgement about unanswered questions in the practice area.

## **6.9. CHAPTER CONCLUSIONS.**

Discussions were presented including conclusions and recommendations. Limitation of the study were also presented. The study was compared to the chosen theory by Manfred Max- Neef (1983) including the identification of gaps which informed the model that is presented in chapter seven.

## **CHAPTER SEVEN**

### **7. MODEL DEVELOPMENT**

#### **7.1. INTRODUCTION**

The preceding chapter presented discussions of findings, summary and recommendations. The results of the study offered insight into the support needs of child headed families, most specifically their health behavior, health seeking behavior and issues of access to health care. The exploration of these factors is particularly difficult by virtue of the complexity of needs and huge variety of factors influencing them. This recognition serves as the impetus for the researcher of this study to engage in both intrapersonal discussion on constructing organizing structures for enhancing understanding of the needs and wants of children as well as their interconnectedness.

Achieving this will provide guidance that will facilitate health care professionals to promote access to health care as well as effectively meet the needs of child headed families. Hale & George (1980) support this view by asserting that organizing structures that are well developed do not only organize extant knowledge, but they also facilitate the making of new and relevant innovations to improve practice. This chapter will therefore focus on the process of model development.

#### **7.2. DEFINITIONS**

A model is a symbolic representation of an empiric /practical, observed or perceived phenomenon in the form of words/ concepts, pictorial or graphic diagrams. Model replicates the real phenomenon or object in short represents reality or experiences (Chinn & Kramer 2011).

Frequently used models are conceptual models which evolve into and assist in testing theory. Conceptual models are frequently used interchangeable with theoretical models, conceptual framework and theoretical framework (Chinn & Jacobs, 1983).

Conceptual model is a set of relatively abstract and general concepts that addresses the phenomenon of central interest to a discipline, in the case of this study, the propositions that broadly describe those concepts and the propositions that state

relatively abstract and general relations between two or more of the concepts (Fawcett, 2005).

Chinn & Kramer (2011) recommended the use of the following components to describe a model:

- What is the purpose of the theory
- What are the concepts of this theory
- How are the concepts defined
- What is the nature of the relationship within this theory
- What is the structure of the theory
- On what assumptions does the theory build

For the purpose of this study, all the components are defined in their respective sections.

### **7.3. THE CONTEXT/ ENVIRONMENT**

This conceptual model is described within the formal child headed household families which are supervised by an NGO in collaboration with the church and the government. Only one district was involved in the study. This conceptual model / framework is derived from three core concepts namely; health behavior health seeking behavior and access to health and social care services. Data that informs this model is derived from children in child headed households, volunteers and members of the multi-disciplinary health care team (nurse, social worker and community developmental facilitator).

Environment is the geographical, the physical or the community where the children live. The supportive structures are the government, the church, and the non-governmental organizations that assist the children in need, hence the need for their collaboration is greatly needed to provide a comprehensive package to the vulnerable children.

#### **7.4. PURPOSE**

The purpose of this model is to enlighten health care workers working with children from child headed households with the factors influencing their health behavior, health seeking behavior including challenges encountered in accessing health care and social care services. In addition, the model explores any demonstration of self-efficacy by the children in child headed households for self-sustenance. .

#### **7.5. IDENTIFICATION AND DEFINITION OF CONCEPTS**

A concept is a word or phrase that summarizes ideas, observations and experiences. Concepts are tools that provide mental images that can facilitate communication about and understanding of phenomena. Concepts in this theory include health behavior, health seeking behavior and access to health. Each of these concepts will be defined and associated with sub concepts (Chinn & Jacobs, 1983).

- **Health behavior**

Health behavior is defined by Ward et al (1997) as any activity undertaken for the purpose of preventing or detecting or improving health and wellness. Health behavior includes health enhancing behavior like personal hygiene, environmental safety, regular exercise, consumption of a well-balanced diet, etc. Health impairing behavior which encompasses activities that are detrimental to health, in addition to the above, the study has put emphasis on the activities of daily living, safety and security, clothing, shelter, sense of belonging, sentimental value of the late parents, social desirability, psychological and socio-economical support, health awareness and cultural awareness.

This model therefore encourages structured health promotion initiatives by volunteers and health care professionals with more emphasis on health information.

- **Health seeking behavior**

Health seeking behavior is a form of health behavior assumed by an individual or group who believes that there is a form of illness in him/her or family members (Susanna –Hausemann-Muella, et al, 2003). This is also influenced by natural (supernatural), biomedical knowledge, attitude and practice of an individual.

Health seeking behavior are activities undertaken for the purpose of preventing or detecting illness or diseases, including improving health and wellbeing. This includes health service usage, compliance with medical and nursing regimes and self-directed health behavior. Health seeking behavior is influenced by lengthy process of awarding the child headed household status as influenced by the legislation. Previous experience with the sick parents who eventually died and staff attitude in the health services also have influence on health seeking behavior among children in child headed families.

This model suggests health information on health seeking behavior to enable informed decision on such issues. Health professionals need to be cognizant of the needs of children from child headed households. This could be facilitated through in-service training and a special identification card for such children with comprehensive data.

### **Access to health**

Access to health implies the continuing and organized supply of care that is geographically, financially and functionally within easy reach of the whole community which in the context of this model includes children from child headed household families irrespective of age and purpose (Van Rensburg, 2004). Access to health is a basic right for all citizens in South Africa, especially children who are specifically designated as a vulnerable group (Constitution of RSA, Act no. 108, 1996) hence free health services for this group were phased in since 1994. Associated concepts in this particular model are legislation, logistics of accessing health services, availability of an escort, staff attitude, distance and economic support.

This model proposes use of concession cards for transport of children from child headed household families as used for the aged and disabled in public transport. Due to the need for such children to be escorted to a health facility warranting the availability of adequate numbers of escorts/volunteers and financial support for this service, the model proposes that the escort be given allowances to travelling with these children or carry special identification cards for use in public transport.

- **Self-efficacy**

Self-efficacy is defined as a means for encouraging health behavior change and is described in four main sources. Firstly is that individuals develop feelings of self –efficacy from personal experience, secondly, through observing other people, thirdly, through use of standard persuasive technique and finally, one’s physiological state may be used as a source of information (Bandura, 1997).

Self – efficacy is an indicator of the likelihood of taking recommended health actions which may be influenced by perceived benefits of taking action minus perceived barriers to action as extracted from the Health Belief Model (HBM) (Conner & Norman 1996). This aspect may be demonstrated by helplessness, use of alternative therapies to western health service, deceitful reasons to access health care services or delayed seeking medical care until the condition gets worse for ease of access with an ambulance though this is risky behavior.

This model recommends that health professionals empower these children specifically on health behavior, health seeking behavior and access to health through health information and supervision.

- **Ideal health status**

The definition of health by WHO (1948) states that health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity. Critics like Bircher (2005) are not in affirmation with this definition since it has never been challenged since 1948, on the basis that it is no longer relevant in the 21<sup>st</sup> century in the advent of the high burden of diseases like HIV and AIDS and much social pathology. All this was based on the premise that if you are not personally infected with HIV and AIDS, you are somehow affected through family members who are suffering with the disease.

This model suggests strengthening the inter-sectoral collaboration of all structures involved in the support and care of children from child headed household families with one of the government departments leading these initiatives. This recommendation is based on the fact that complete health cannot be provided by one department but is a combined effort, for example, health, housing, education, social welfare, etc.

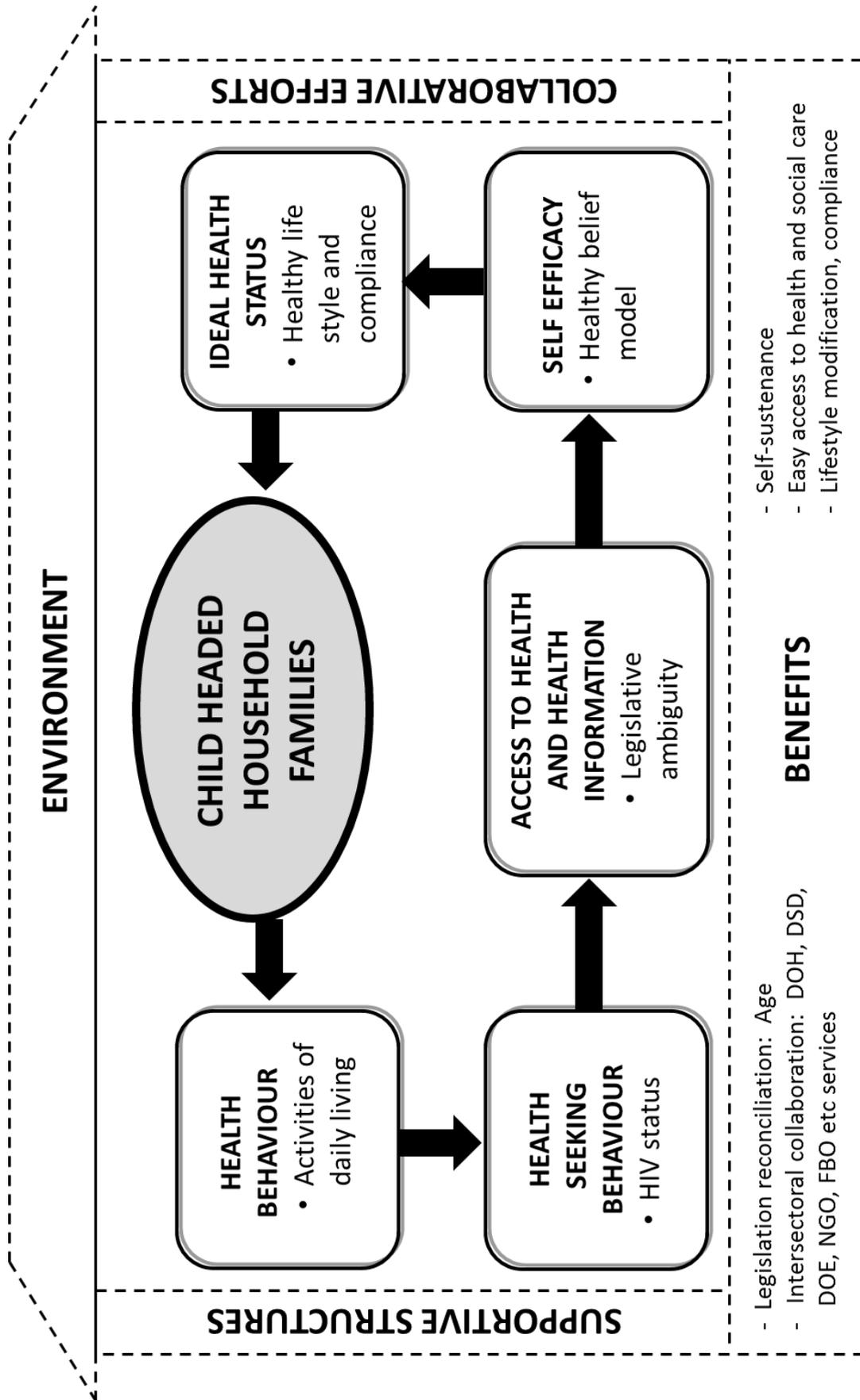


Figure 7.1: Model of Care for Child Headed Household Families

## **7.7. Relationships within the Model**

Chinn & Kramer (2011) suggest that a theory/model further describes the nature of the relationship among and between concepts. Concepts may be interrelated in several ways and others are related in only one or two ways. There are also concepts that may stand alone or unrelated to others. The model used core concepts borrowed from the health systems, namely health behavior, health seeking behavior and access to health care. However, in the current study associated concepts were identified as influencing these core concepts within and among them.

- **Health behavior**

Health behavior is influenced by awareness of healthy lifestyle which would otherwise be provided by either parents or extended family members and health workers if accepted in the case of children from the child headed household. This service is not available therefore their health behavior may be unhealthy, physically, mentally, socially and financially. Children from such families end up in deviant behavior such as juvenile delinquency, substance abuse, prostitution, crime etc. Health maintenance is specifically undermined to these children because of the possible HIV and AIDS status which most of them may have already acquired from their parents or from unhealthy health behavior.

It is anticipated in this model that self-directed healthy behavior will lead to an ideal health status for children in child headed household families. This the children can acquire through health information and socio-economic support.

- **Health seeking behavior**

Literature defines health seeking behavior as an aspect of health behavior. Health seeking at a health facility, medication and compliance is a huge responsibility of the head of the family, in the case of child headed family it is an adult child. This is a huge responsibility entrusted to a child whose decision making powers are not mature and mishaps are more likely to happen than in normal family. The adult child may not be able to handle or identify such mishaps and this may have detrimental effects like guilt feeling and psychological ill-health.

Children in child headed households are often HIV infected and particularly need to comply with treatment or visit the health service frequently for opportunistic infections, and maintenance of healthy lifestyle. Legislative ambiguity in terms of age to access for curative services versus reproductive services has led to discrimination of such children by age. The need for an escort for curative services results in delay in seeking health services. Previous experience of the child headed household children with their sick parents in and out of hospital ending up dying leads to mistrust of health care services therefore affecting their health seeking behavior negatively. Moreover, staff attitudes, questioning them of the late parents and their HIV status with limited privacy, influences their health seeking behavior negatively. Personal appearances bestowed upon them by ill-fitting pre-owned clothing leads to low self-esteem thus health seeking behavior suffers. Health facilities are sometimes more than 5 km of walking distance, therefore children who are often not financially viable to pay for the transport may miss the opportunity to seek available health especially when they have to also sponsor the escort.

Health seeking behavior is a component of health behavior as described in literature and this model endorses this assertion. If a person's behavior is not healthy, this person will not seek health even when the need exists and therefore will not have demonstrate ideal health status.

- **Access to health and health information**

Access to health can either be a facilitator or a barrier to health. Legislative ambiguity in allowing differential access to curative and reproductive services has become a barrier because children in child headed household delay accessing health because of the unavailability of the escort who has many households to supervise.

The processing through the various sections of the health facility before reaching the professional nurse is cumbersome with embarrassing questions with other clients in close proximity. The long process is worse for the escort whose daily scheduled visits are interrupted.

The staff tend to attach stigma to child headed household children due to their late parent's HIV status. Furthermore, asking these children embarrassing questions

revive the memories of their late parents and discourage children from accessing health care services.

It is therefore obvious that access to health affects health seeking behavior to a very great extent. The model therefore suggests removal of the above mentioned barriers to access in order to promote health seeking behavior.

- **Self-efficacy**

Children in child headed household tend to be helpless, without an adult, the volunteer from the NGO, and the health and social care services, especially in the waiting period while the awarding of the child headed status is being processed. However there are a few self-efficacy strategies that these children have developed to overcome issues of health seeking behavior and access to health. For example, these children have developed alternative therapies such as faith / divine healing seeing that the church is so supportive to their needs. To access health, children use deceitful reasons, for example, claim to be going for reproductive health and switch to curative services once they are inside the health facility. However, in this event, nurses face the dilemma of whether to still attend to the child without an escort especially dispensing medication in the absence of an adult supervisor. Children in child headed households purposefully delay health seeking until the illness is advanced so that they are fetched with an ambulance to bypass the long process and queues, however this is not an ideal situation because mishaps or anything can happen.

Children from child headed household families may appear healthy but have reasons to be unhealthy, namely physical health is affected by HIV status, opportunistic infections and low immune status due to possible HIV infection, nutritional imbalance, lack of hygiene, safety and security, etc. The psycho social health is affected by stigma and discrimination, social isolation, embarrassment of being asked same questions related to their late parents HIV status as it revives sad memories. Furthermore, health is tarnished by mistrust of health services while access is blocked by several issues as described including legislative ambiguity.

Self-efficacy promoted by adequate health information can lead to healthy behaviour and timeous and appropriate health seeking behaviour.

- **Ideal Health Status**

The ideal health status for the children denotes understanding of expectations on their health behavior and behaving likewise. Furthermore, ideal health includes timeous and appropriate health seeking behavior, positive attitude towards health services and utilization of such when needed. This will ensure compliance with treatment and self- sustenance. The foundation for all this is appropriate health information.

### **7.8. Assumptions**

Assumptions are acceptable, untested truths that are fundamental to theoretical reasoning. Assumptions may take the form of factual statements or value positions. Factual statements dente truth derived from perceived experience while value statements state what is right, good or ought to be (Chinn & Kramer 2011), in this model, the following assumptions were derived:

- The **health behavior** of children in child headed household is not conducive to healthy lifestyle because of the lack of supervision, poverty and limited health awareness.
- Health behavior is influenced by health information acquired and supervision,
- Orphaned children are at risk of being rejected by the extended family members and the community
- HIV and AIDS is the predominant reason for the discrimination of the child headed household families by their extended families and local communities
- **Health seeking behavior** in child headed household families is negatively influenced by the ;
  - (a). legislative ambiguity in relation to age and the need for an escort
  - (b). mistrust of health system from previous experience
  - (c).personal experience in ill-fitting pre –owned clothing as adolescent

- Health seeking behaviour depends on the previous experience with the health services
- **Access** to health is negatively influenced by previous experiences with attitudes of health care workers, the process of registration, the availability of the escort, and the legislative ambiguity of age differences for curative versus reproductive health.
- The child headed household families survive predominantly through the socio-economic support of the responsible NGO, and the church.
- Inter-sectoral collaboration can improve access to health and social care services
- **Self-efficacy** depends on acquisition of health information. The more health information one has, the more self-efficient one can be.
- Child headed household families are less likely to take actions in ensuring healthy lifestyle especially in the period awaiting awarding of the child headed household status relative to predominant poverty and lack of health information
- The head of the family is less likely (helpless) to take action in decision making with regard to their siblings due to their age, complexity of the situation, medical emergencies among siblings and accessing social grants.
- Child headed household families are likely to take alternative actions to access health, for example, faith/divine healing due to their availability.
- **Ideal health status** depends on health behaviour, health seeking behaviour and access to health.

### **7.9. Comparative review of the proposed theoretical model in relation to Max-Neefs' theory of human needs.**

Within this study, Max-Neef's model (1983) served as an important foundational theoretical perspective in that it articulated the range of human needs that exist for populations to meet their fundamental human requirements. This model has been subjected to significant review within literature and there is consensus that it offers

exceptional direction in defining the scopes and areas in which human needs exists. To this end, Max-Neef (1983) identifies a number of fundamental human needs which include: subsistence; protection; affection; understanding; participation; leisure; creation; identity and freedom. The model accepts that these are the range of needs that exist across human beings and remain relatively constant from individual to individual and from group to group. What is clear is that Max-Neef's Model does not offer insights and/or guidance about how these needs are expressed uniquely by different groups and indeed how these human needs are satisfied.

The proposed theoretical model focuses on health behavior, health seeking behavior and access to health and social care services and in so doing, offers an advance from Max-Neef's work in three very specific regards. The currently proposed framework is based on participants within a Zulu culture and bears more cultural relevance than the Eurocentric focus typified by Max-Neef. This cultural relatedness of the model singles out the very reason why it is a more culturally aligned model than others including Max-Neef (1983) especially as a means of understanding issues of health behavior, health seeking behavior and access to health and social care. This is a material advance on Max-Neef's work which, as identified above, only specifies the range of human needs but doesn't speak to how each of the resulting needs can be attained, including the range of barriers that may exist in this regards. Finally, the model by Max-Neef is very specific and places boundaries on what range of needs should be engaged with – and in that respect, represents a limiting perspective which is addressed much more specifically within the proposed framework. It is important to consider the strengths and weaknesses of the proposed framework and as such, the ensuing work looks closely at the utility of the proposed framework.

#### **7.10. STRENGTHS AND WEAKNESSES OF THEORETICAL MODEL**

Although the model developed serves as an informed identification of factors that may influence health care provision and access, the identified factors are not weighted by importance, and the impact of each may vary from individual to individual. From a quantitative researcher viewpoint, this lack of weighting of

influential factors can be seen as weakness of this model. However, it is consistently reiterated in the literature of qualitative research that human experiences are not quantifiable, and any attempt to quantify them can be seen as a direct contradiction of a key tenet of the current study.

This framework serves an educative support for care professionals in enhancing their understanding of health behaviour, health seeking behaviour and health care access needs of child headed families and how these can be met in practice. Even though the framework has practical utility, there is scope for future researchers to test it quantitatively with the view to enhance its predictability.

The theoretical framework is grounded in data elicited from a defined population in South Africa. So the identified influential factors may have limited application in describing issues of access to care of other care professionals and child headed family populations.

#### **7.11. CONCLUSION**

This chapter has offered clear discussions of the term theory, model, theory development and application. The identification and definition of terms in relation to the study was conducted .The theoretical model, developed from data of this study and extant literature is critically discussed here, including its strengths, weaknesses and contribution to the body of knowledge.

## **Bibliography**

Actuary Society of South Africa 2008: The state of African Children: Child Survival, vol 34 (50-56) [www.books.goggle.co.za](http://www.books.goggle.co.za)

Addison, G 1991. Helping Hands for Cooperate Sexual Responsibility Campaign. 2002/09/11. <http://wikipedia.org>

AL defer, C: 1972; Existence, relatedness and growth; New York, Free Press

Alexandra R L 1998: The art of Mergers and Acquisitions Integration: A guide to merging resources

Anderson, J. B. 1980: Quantum Chemistry by Random Walk: vol 10 (528-561)

<http://www.books.goggle.co.za>

Arvidon. M: 1996: Caring for children orphans in the Aids Affected Zimbabwe Programme on Population and Development: Report no 3.Sweden University: Lund.

A guide for school governing bodies and management teams, 2003, Develop an HIV/AIDS plan for your school-Department of Education 2003.

Ayieko M A; 1998: From Single Parents to Child Headed Household; The case of children orphaned by Aids in Kisumu and Siaya District; Paper no 7; New York

Ayieko M.A, 2003.Household; the case of children orphaned by Aids in Kimusu and Siaya district: Unpublished study report no (7) HIV and development program

Ayieko; M.A. 2004: From single parents to child headed household: The case of children orphaned by AIDS in Kimusu district of Kenya: Unpublished thesis

Awino, D. 2010. Life in a child/adolescent headed household "a qualitative study on everyday life experiences of children living in Child headed household in Western Kenya

Bandura, A; 1997; Self-efficacy: The exercise of control, New York: W.H.Freeman

Barton, F.2008: Shocking realization of adopted children.

Barrett, LF, Russel, JA. 2010 The psychological construction of emotions. New York. Guilford

Barrett, CB. 2010: Measuring food security Science, vol 327, No5967, 21 February 2010- p825-828

Basaza R & Kaija D 2002, Impact of HIV/AIDS on children, Lights ad Shadows in the successful case of Uganda. Public Policy and wellbeing-UNICEF-IRC Publishers

Baxter,K & Jack,S:1995; Women fights of possible robbery and sexual assault: [http://www.channel 3000.com/HDM](http://www.channel3000.com/HDM)

Bazeley, P; 2013; Qualitative Data Analysis; 1<sup>ST</sup> edition; Sage Publication; London

Bendassolli, P.F :2013. Theory Building in Qualitative Research: Reconsidering the Problem of Induction. Forum Qualitative Social Research 14(1). Article 25.

Bequele, A .2007: The emerging challenge of children heading household: Some reflections. The African Child Policy Forum Speech delivered at the Opening Session of the 5<sup>th</sup> African Conference on Child Abuse and neglect on HIV/AIDS and children: The challenges of care and protection of children in Africa organized by the ANPPCAN Uganda Kampala, Uganda (27-29 March 2007)

Berge, P & Luckman, T.J; 1967; The Social Construction of Reality; New York: Doubleday and Company, Inc.

Bircher, J 2005. Towards a dynamic definition of health and disease, Med health care Philos. Vol, 8 (335-341)

Blaxter, M: 1990; Health and Lifestyles. London: Routledge

Bloom, B.S; 1956: The Christian Educators Handbook on Adult Education: Baker Books Copyright

Boyatzis, R.E: 1998; Transforming Qualitative Information; Thematic analysis and development; Sage Publication: London.

Bouwer, M; Dreyer, M, Herselman, S, Lock & Zeelie, S: 2006: Contemporary trends in Community Health Nursing: Oxford University Press

Bray, R. & Brandt, R. (2007); Child care and poverty in South Africa: An Ethnographic challenge for conventional interpretation; Journal of children and poverty, vol 13 (1-19)

Bryant, A & Charmaz, K: 2007: Grounded Theory; Sage Publications: London

Brink, H: 1996: Fundamentals of Nursing Research 1<sup>st</sup> edition, Juta & Co.

Brink, H: 2000: Fundamentals of Nursing Research for health professionals, 3<sup>rd</sup> edition, Juta & Co.

Brown, T & Sihitrai W 1996. The impact of HIV on children in Thailand: Thailand-British Embassy

Brown. L, 2003, The challenges of rural America in the 21<sup>st</sup> century: University Park; P A; Pennsylvania. State University Press

Burgos, M. Schetzia, N. Dixon, D; Mendoz, 2004: Preventing Obesity in Mexican: American Children and Adolescents – The national Academics Press- p81 -127  
<http://www.nap.edu/openbook.php>.

Burns, N & Grove, S.K; 1997: The practice of nursing research: Philadelphia, Saunders

Burns, N & Grove S.K; 2005: The Practice of Nursing Research: Conduct, Critique &Utilization, 5th edition.Philadephia: W B Saunders Company.

Burns, N & Groove SK, 2007: The practice of nursing research: Appraisal, synthesis and generation of evidence, 6th edition, Texas, Saunders

Burns, N & Groove S K 2012: The practice of Nursing Research: Appraisal, Synthesis and Generation of Evidence, St Louis Missouri, Saunders Elsevier

Cadwell, L.B. 1997: Bringing Reggio Emilia Home; An Innovative Approach to Early Childhood (Early Childhood Educational Series) 1<sup>st</sup> edition, Teachers College Press

Carr, L.T 1994; The strengths and weakness of quantitative and qualitative research: what method for nursing? Journal of Advanced Nursing, vol 20, October 2012, pp 716-721

Center for the Study of Violence and Reconciliation, 1998; Urban Crime and Violence in South Africa: Justice for Children: London: Save the Children

Center for the Study of Violence and Reconciliation 2006 "Child Headed Household and Human Rights" A capacity building guide, Publisher (CSVR), Braamfontein.

Cheathan, C; Barksdale D, & Rodgers,S: 2008: Barriers to health care and health seeking behavior faced by Black men: Vol 11, 20 November 2008

Chiastolite professional Services, 2008; Department of Social Development, Gauteng province: Child Headed Household Projects

Child Care Act no.74 of 1986.Pretoria. Government Publishers

Child Care Act no 38 of 2005. Pretoria. Government Publishers

Child Care Act no 41 of 2007.Pretoria. Government Publishers

Chinn, P.L & Kramer, M.K: 2005: Middle range Theories: Application to Nursing Research, Exclusive Books, Kalahari.com.Lippincort &Williamson Copyright

Chinn, P.L & Kramer, M, K 2011: Integrated Theory & Knowledge Development in Nursing, 3251 River port Lane, St Louise Mosby.Inc

Chinn, P.L & Jacobs, M.K: 1983: Theory and Nursing; A systems approach, C V, Mosby Company

Chizororo, M.F. 2010: Growing up without parents: Socialization and Gender Relations in Orphaned- Child- Headed Households in Rural Zimbabwe, Journal of Southern African Studies, Volume 36, Number 3, September 2010.

Cockcroft, A. 2008 : Minority health and small numbers epidemiology, A case study of living conditions and health of children in 5 foreign Roma camps in Italy, American journal of public health ( 2035-2041)

Cohen, L, Manion, & Morris, K; 2000: Research Methods in Education, 5th edition; Routledge Falmer; London

Conner M and Norman P: 1996: Predicting Health Behavior. Buckingham, U K: Open University Press

Constitution of the Republic of South Africa Act no 108 of 1996: Pretoria. Government Publishers.

Corbin & Strauss, A 2008: Basics of Qualitative Research, 3rd edition, Sage Publication: Thousand Oaks

Cornia, G .A & Zagonari, F: 2002; The Impact of HIV/AIDS on child mortalities, an economic

Crabtree F & Miller, W. L; 1999: Doing Qualitative Research, 2nd edition, Sage Publication. Thousand Oaks.

Craig, R.T. & Muller, H.L; 2007: Theorizing Communication; Readings across Traditions; Sage Publications

Creswell J.W, 2007: Qualitative inquiry and research design: choosing among five traditions. 2<sup>nd</sup> edition. London: Sage

Creswell J.W.2009: Research Design, Qualitative, Quantitative and Mixed Methods Approaches: 3<sup>rd</sup> edition, University of Nebraska-London: Sage Publication

Crotty, M. 1998; Foundations of Nursing Research; Meaning and Perspective in the Research Process; Sage Publications; London

Crotty, M; 2011; Research in Education; Thousand Oaks; Sage

Department of Education, 2003; A guide for schools governing bodies and management teams, Develop an HIV/AIDS plan for your school; Pretoria

Department of Education: 2007; Conference on HIV and AIDS, and education sector together with educator's conflict against HIV and AIDS policy: Pretoria.

Department of Health, 1996; White Paper for the Transformation of Health Services in South Africa; Introduction of the Clinic Charter: Pretoria

Department of Health, 1997; White Paper for the Transformation of Health Services in South Africa; Pretoria

Department of Health, 2000; White Paper for the Transformation of Health Services in South Africa; Pretoria

Department of Health 2003; White Paper for Integrated Management of Childhood Illnesses

Department of Health, 2010 National antenatal sentinel HIV and syphilis prevalence survey in South Africa, 2012 retrieved January 2013, <http://www.unaids.org>

Department of Health, 2010 (b) National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa 2009, Pretoria

Department of Health and Children (2003) A Research for Nursing and Midwifery in Ireland: Final Report, Dublin. Department of Health and Children, Ireland. Stationary Office.

Department of Social Development; 2002; National guidelines for social services to children infected and affected by HIV and AIDS: Pretoria

Department of Social Development; 2006; Policy framework on orphans and other children made vulnerable by HIV and AIDS in South Africa; Pretoria.

Department of Social Development, 2008: Global Report on social services offered to orphans and vulnerable children. Pretoria.

Department of Social Welfare and Population Development; 2008; Draft Policy on handling the Vulnerable Children in South Africa

Desmond G & Gow; J. E; 2001: The cost effectiveness of Six Models of Care for orphans and other Vulnerable children, Health Economic, HIV/AIDS-HEARD: University of Natal & UNICEF

De Vos, A.S. 1998; Research at grass root, a primer for caring professionals, Van Schaik; Pretoria

De Vos A.S. 2005. Research at the grass root; for social science and human science professionals, 5<sup>th</sup> edition, Van Schaik, Pretoria.

De Young .A.J. 1991. Rural Education: Issue and Practice; New York: Garland Publishing Inc.

Drew; R. S. 1997; Estimating coverage of Community Based home care programme-Tropical Doctor; vol; 27

Earp, J.A. & Ennett, S.T. 1991; Conceptual models for health education research and practice: Health education research, vol 6, June, pp163-171

Emanuel, E.J., Wandler, D., Killen, J. & Grady, and C.2004: What makes clinical research in developing countries ethical? The benchmarks of ethical research

Emanuel, E.J, Wendler, D; & Grady, C; 2009; What makes clinical research ethical? JAMA, vol.283, May, pp 2701-2711

Environmental Health Perspective, 2005; March 18, vol 113.

(<http://www.ncbi.nlm.nih.gov/za>.)

Eskom 2007; Electro wise pamphlet

Fawcett, J .2005; Contemporary nursing knowledge, analysis and evaluation of the nursing models and theories; F. A.Davies; Philadelphia

Fleck, Uwe; 2009; An introduction to Qualitative Research, 4th edition: Sage Publication: London

Flick, U. 2009: An Introduction to Qualitative Research.4<sup>th</sup> edition. London: Sage Publications.

Franklin,B :2013 : Annual Report and Growing Global water and fueling system

<http://www.franklin-electricity.com/corporate>.

Frankel, R.M & Devers, and K.J:2000: Study design in qualitative research – Sampling and data collection strategies. Vol .13 (263-271)  
<http://www.ncbi.nlm.nih.gov/pubmed>

Foster G, Makufa C, Drew R, Kambeu S & Saurombe K;1996 “Supporting children in need through community based orphans visiting programme:Aids Care-( 8)

Foster G; Makufa C; Drew R; & Kravolec E, 1997;”Factors leading to the establishment of Child Headed Household; The case of Zimbabwe. Health Transition Review, Supplement 2-7

Foster .G .2000: The capacity of the extended family for orphans in Africa: Psychological Health and Medicine. Vol 6

Foster. G. & Williamson, J; 2001. Understanding community responses to the situation of a child affected by Aids. Lessons for external agencies (draft)

Foster, G.; 2004; Study of the response by Faith Based Organization to orphans and vulnerable children, World conference of Religion for Peace: UNICEF/ESARO/NAIROBI.

Foster; G; .2004; Safety net for children affected by HIV/AIDS in Southern Africa, Monograph; 109

Franklin B; 2013: Annual Report and Growing Global Water and Fueling System <http://www.franklin-electricity.com/corporate>

Frankel R M & Devers K J; 2000: Study Design in Qualitative research- Sampling and Data Collection Strategies. Vol 13 (263-271) <http://www.ncbi.nlm.nih.gov/pubmed>

Friedman & Reed: 2007: A history of women in Russia: From Earliest times to the present: Bloomington: Indiana University Press

Gephardt, R; 1999: Paradigms and Research Methods; Research Methods Forum: 2 vol (4) July 2011. Pp319-331

Germann; S. E; 2005; An exploratory study of quality of life and coping strategies of orphans living in child headed household in a high HIV/AIDS prevalent city of Bulawayo; Zimbabwe; Unpublished doctoral thesis , UNISA; Pretoria

George, R & Lance, D: 2005: Wrox's SQL server, Express Edition Starter Kit, Wiley Publishing, Inc. Indianapolis

Giddens .A 1994; Sociology, 4th edition. Cambridge, Polity Press

Giddens. A 2004; Sociology, 7th edition. Polity Press

Giovanni A C 2002: Aids Public Policy and Child Wellbeing-Preliminary version; Innocenti Research Center-Florence-UNICEF

Glaser B.G Strauss. A.L. 1967: The discovery of Grounded theory, strategies, qualitative research Chicago, Aldine

Gochman, D.S: 1997: Health Behaviour Research. Personal and Social Determinants: University of Louseville, Kentucky Press, New York

Gow, J.E; & Desmond G;2001; The long term socio-economic impact of HIV/AIDS on children and the policy responses in South Africa; University of Natal ;Durban

Gow, J.E & Desmond G; 2002: The impact and intervention. The HIV/AIDS epidemics and the children of South Africa.

Gregston,S; Marange,C; Foster,G; Shakespear,R,;Chinamona,F ;Mashumba,S & Jackson ,H; 1994: The Family and HIV Today; Recent Research and Practice; Redwood Books: Trowbridge.Witshire

Grove S, Burns M, & Grey J, 2013: The practice of nursing research. 7<sup>th</sup> edition: Elsevier Press

Gruber; 2012:"It was just a mistake" An Obama architect explains a 2012 quote that fuel. 18 Jan 2012.<http://www.newrepublic.com/article>

Guba, E.G & Lincoln Y.S 1994; Competing Paradigms in Qualitative Research; Newbury Park; C A

Guba, E .G. & Lincoly ,Y.S.2001. Competing Paradigms in Qualitative Research, 2<sup>nd</sup> edition, Bostom; Pearson's custom Publishing.

Guba .E.G. & Lincoln .Y.S. 2005; Paradigms " controversies, contradictions and emerging influences". 3<sup>rd</sup> edition; Sage. Thousand Oaks

Gwandure, C; 2010: Life with limited privacy due to housing challenges: Impact on children psychological function

Hall, C '2009; A need to refine "orphan"; Cape Town, South Africa.

Hale, F.G & George, R.T:1986: Dynamical Systems and Nonlinear Partial Differential Equations. <http://www.mtholyoke.edu/course/schwart>

Hammersely, M & Atkinson, P; 1983: Ethnography: Principles in Practice; Tavistock Publication Limited.

Hammersely, M.1992: What's wrong with Ethnography? Methodological Exploration: London: Tavistock

Hamersley, M. & Atkinson, P: 2007; .Ethnography: Principles in practice: London: Routledge

Hansmann- Muela, S, Muella, R, Ribera, J, Nyamongo, I. 2003.Health seeking behavior and health system response- DCP. Working Paper no. 14

Hatting, A.S: 2003; Sustainable agricultural development; Recent approach in water research commissioning: Pretoria

Hatting, A.S: 2008: Foreign policy aspect of Lisbon Treaty: 3<sup>rd</sup> report session 2007-2008. Great Britain Parliament, House of Commons: Exclusive Books.Kalahari.com

Hatting; Dreyer & Roos: 2006; Aspects of Community Health, 3rd edition, Oxford University Press

Harper, T & Jones, L; 2009: Designing effective assessment: Principles and profiles of good practice; San Francisco. Jossey –Ban

Hillman, A.L; 2001: Innovative Teaching Strategies in Nursing and Related Health Professionals, 5th edition; Jones & Bartlett Publishers

HIV and AIDS Statistics 2008: Sub-Saharan Africa, HIV/AIDS Statistics, retrieved December 2010 – <http://www.avert.org/subadult.htm>

HIV and AIDS 2006- 2008: National Action Plan for orphans and other children made vulnerable by

Houser, J; 2008: Nursing Research: Reading, Using and Creating Evidence; Jones and Bartlett Publishers: London

Hulley; C; 2006: Child headed household and human rights: Center for the study of violence and reconciliation

Hunter G & Williamson J 2000;"A review of current literature on the impact of HIV and AIDS on children in the Sub-Saharan Africa; Aids (14)

Indian Institute for Population Science 1998- 1999. Biomass looking Fuels and Prevalence of Blindness in India – Journal of Environmental Medicine1-pp 189-199

James; M & Poland: 2009; International Student Volunteer 2013

Karls, J.M. and Wandrei, K.E. (1994) PIE Manual: Person-in-environment System: The PIE classification system for social functioning problems, Washington DC: NASW Press

Kemp, C.J; 2013: Children in need: Vol 3, 3/7/2013

<http://www.goodreads.com/author/show>

Knight, R 2006. South Africa 2006: Population and HIV-AIDS. Retrieved April 17, 2010 <http://richardknight.homestead.com/files/SouthAfrica2006-PopulationandHIV-AIDS.pdf>.

Kravolec, C; 1998; What Parents, Researchers and Popular Press have to say about homework-No.7. (10-31) <http://opus.pfw.edu/cgi/viewcontent>

Krippendorff, K. 2004: Content analysis: An introduction to its Methodology; London; Sage

Kosa Z; Szeles; G; Kardos ;L; Kosa ;K; Nemeth; R; Orszagh ;S; Fesus ;G; Mc Koe; M; Adany ;R & Voko; Z : 2007: A comparative health survey of inhabitants of Roma settlements in Hungary " American Journal of Public Health no 97 (5)

Kushel; M.B, Perry; S, Bangserg, D; Clark, A; Moss; A.S: 2002: Emergency department use among the homeless and marginally housed: results from a community based study: Am J Public Health. Vol 92 (778-784) Pub Med

Kvales, S; 1983; The qualitative research interview; A phenomenological and hermeneutical mode of understanding: Journal of Phenomenological, Psychology. Vol 14 (2) pp 171-196

Lieblich, A; Tuval-Mashiach, R & Ziber, T; 1998: Narrative Research; Reading, analyzing and interpretation (applied Social Research Methods), London: SAGE Publications

Leininger, M.M 1985: Qualitative Research Methods in Nursing; New York: Grune & Straton, Inc.

Levine, C; 1995: Today's Challenges, Tomorrows Dilemma; Forgotten Children of the Aids Epidemic; New Haven-Yale University Press

Lincoln .Y.S & Guba. E.G: 2000: Paradigm, the controversies, contradictions and emerging confluences

Loening-Voysey H & Wilson T 2001; Approaches to caring for children orphaned by Aids and other vulnerable children; Essentials to quality services. Pretoria, UNICEF, & Institute for urban primary health care; South Africa

Lopez, A.D:2005: Global burden of disease and risk factors. Comparative Quantification of health risks. Hyderabed; India

Machi .L, A & Mc Evoy, B.T: 2009: The literature review, Christopher Hart

Mackian, S; 2003: Health seeking behavior studies. Health systems development program. University of Manchester

Mahoney; J; 2005: Research in the social scientific study of religion, Vol 19 pp 27-36

Mahoney; J; 2007: The new methodology of qualitative research, Vol 38; 8 .Journal on comparative political studies, retrieved 7/6/2013

Manasta.L, Anderson. N, Ledogar, R.J, Cockcroft, A & Cockcroft, T. 2008; Minority health and small numbers epidemiology: "A case study of living conditions and health of children in 5 foreign Roma camps in Italy.

Maslow. A .H:1943; A theory of human motivation 1<sup>st</sup> edition; New York; Press

Maslow, A.H:1970: Motivation and personality, 3rd edition, New York, Harper Collins

.Masondo, T: 2006: Unpublished study of Social Functioning of children in a child headed household.

Masondo .G: 2006; The lived experiences of orphans in a child headed household in Bronkhorstspuit area: a Psycho-educational approach, (unpublished study)

Max –Neef, M 1983; Human Scale Development, New York, The Apex Press

Max-Neef, M .A; Elizalde, A & Hopenhayn, M; 1991: Human Scale Development: Conception, Application and further Reflections. New York; Apex Press

McLellan M 2005; Child headed household; Dilemma of definition and Livelihood Rights; African Studies Center-Coventry University

McCarthy, M; 1999; Transport and Health in Social Determinant's of Health, Oxford University Press; Oxford

McEnry, P. C & Price, S. J: 1994: Families and change; Thousand Oaks; Sage

McGhee, G; Maryland, G. D.; Atkinson, J: 2007: Grounded theory research literature reviewing and reflexivity, Journal of advanced nursing 60, 334- 342

McKerrow; N: 1996; Implementation Strategies for the development of models of care for

orphaned children; Lusaka; UNICEF

Medical Research Council: 2001: The impact of HIV/AIDS on adult mortality in South Africa; Technical Report (9)

Medical Research Council Report: 2009: The impact of child headed households in the economy of South Africa.

Medical Research Council: 2009: Preventing rape and violence in South Africa; Call for leadership in a new agenda for action; A policy brief (November 2009)

Meera; B; 2005: How migration shaped our world and will define our future. Journal of studies in International Education, vol 9 (3) pp196-228, retrieved, 13/9/2012

Meintjes; H, Hall K, Marera D.H and Boulle. A: 2010. Orphans of the AIDS epidemic? The extent, nature and circumstances of child-headed households in South Africa. AIDS Care. 2010 January 22(1) 40-49.

Mentjies; H, Buolender; D, Giese; S & Johnson, L: 2003; Children in need of care or cash? Questioning the social security provisions for orphans in the context of the South African Aids pandemic; Children Institute; University of Cape Town.

Mendelson; T: 2003: Center for adolescent health, PhD, Duke University

[www.jhsph.edu/research/center/](http://www.jhsph.edu/research/center/)

Millennium Development Goal : 2005: A critical analysis of the third goal of the the millennium development goal "gender equity".Vol 13, 1/march/2005 (14-15)

Miller & Kean, S: 2003: Encyclopedia and Dictionary of Medicine, Nursing and Allied Health, 7<sup>th</sup> edition. <http://www.amazon.com/miller-kean>

Miles MB & Huberman AM 1994: Qualitative Data Analysis, An Expanded Source Book; 2nd edition, Thousand Oaks: Sage Publication.

Mineh P 1994; Child Care and Development; London; Murray

Mkhize.Z.M: 2006; Unpublished study on the role of Social Worker in handling of child headed household.

Mkhonto, E.M: 2012; Unpublished study on assessment of the use of psychological support for children in child headed household

Morse, J.M; 1994: Critical Issues in Qualitative Research Methods; London: Sage Publication: International Educational and Professional Publishers

Motihar, A: 2006. India Condensed: 5000 years of history and culture: <http://books.google.co.za/books>

Moule, P; & Goodman, M; 2009; Nursing Research Introduction, California; Sage Publishers

Mouton. J; 2002: How to succeed in your Masters and Doctoral Studies. A South African Guide and Resource Book. Pretoria, Van Schaick publishers.

Mpeli, L; 2007: Needs of children affected by HIV/AIDS, vol 30, (3) 28/9/2007

Muecke; M.A:1994: On Evaluation of Ethnographies, in Morse (1994).Critical Issues in Qualitative Research Methods, Thousand Oaks; Sage Publication

Myers, M.D: 1997; Qualitative research information system: Retrieved July 25, 2013 from [http; // www.qual.auckland/org](http://www.qual.auckland.org)

National AIDS Housing Coalition 2011: Listening session national conference on ending homelessness. Washington DC. 22 July 2011.

National Action Plan for orphans and other children made vulnerable by HIV and AIDS 2006- 2008.

National Department of Health, (2001). A Policy on Quality in Health Care for South Africa. Pretoria.DOH Publishers

National Department of Health, (2007). A Policy in Quality in Health Care for South Africa. Pretoria.DOH Publishers

National HIV prevalence, HIV incidence; 2008: Behavior and community survey: Nelson Mandela Foundation Cape Town: HSRC Press

National Policy on HIV and AIDS 1999; Government Gazette no .20372, Pretoria, Govt Printers

Nelson, C.G. 2004; The diversity challenges in Rural Education, English Journal; no 93, Vol 6 (22-23)

Nelson, P. 2013 South Island Masters games – Pub Charity- DONATIONS supporting charity organization- Financial Statement Section 4/December 2013: <http://www.pubcharity.org.nz>

Nel, J.A. 2007: Crime and violence prevention /trauma intervention, UNISA; Pretoria

Neuman, W.L. 2000: Social Research Methods; Allyn & Bacon Publishers

Neumann W L 2006: Social Research Methods; Qualitative and Quantitative Approaches; 6th edition, Sage, Allyn & Bacon

Nkomo,N. 2006; The experiences of children varying responsibility for child headed households as a result of parental death due to HIV/AIDS; University of Pretoria

Ntozi J P M 1993 "Effects of aids on children: The problem of orphans in Uganda; Health Transitions Review; Vol 7

Nziyane; L.F. 2008; Practice guidelines for the integration of child headed households into extended families, unpublished study

Parliament Today, 2007: Speech by minister of Finance on 8 March 2007 on SABC 2 Channel

Parahoo, K. Walker, P.R; Fleming; P: 2010: The role and place of knowledge in grounded theory. Nurse Researcher 17, 8-17

Papalia; D. E, Olds; S. W & Feldman; R. D: 2001; Human Development, 8th edition, United States of America; Mc Graw-Hill Co.

Patel; 2005; Social Welfare and Population Development in South Africa, Cape Town; Oxford University Press

Patton, M.Q; 2002: Qualitative Research and Evaluation Methods; 3<sup>rd</sup> edition; Sage Publication Inc.

Patton, M.Q; 1990: Qualitative Research and Evaluation Methods, Newbury Park, California. Sage

Phillips, C.2011; Child Headed Household; A feasible way forward or an infringement of children's right to alternate care

Phiri, G; Foster; G & Nzima, M: 2001; Expanding and strengthening community action; A study of ways to scale up community mobilization intervention to mitigate effects of HIV and AIDS on children and families; Washington D. C. Displaced children and orphans fund.

Pita-Yon, Kongsin & Jon- Jaroen: 1997: Children affected by HIV AND aids in the aftermath of the successful control of HIV epidemic: The case of Thailand–  
[www.unicef-ire.org/publications/pdf](http://www.unicef-ire.org/publications/pdf) .

Polit, P & Hungler, B.P; 1999: Nursing Research; Principles and Methods; Lippincott Williams & Wilkins

Polit, P & Hungler, B.P.2001; Essentials of Nursing Research Methods; Appraisals and Utilization, 5th edition; Lippincott Williams & Wilkins

Polit, P & Beck, C.K, 2004; Nursing Research Methods; Critical Appraisals and Utilizations; Mosby Company

Polit, D F & Beck C T 2008: Nursing Research: Generating and Assessing Evidence for Nursing Practice, 8th edition; Lippincott Company

Polk-Walker, J; 2003: Find your obituaries and birth notes;  
<http://www.archiver.rootsweb.ancestry.com>

Powell;G :1999; S O S in Africa ,the need for a fresh approach; Unpublished paper ; University of Zimbabwe; Medical School; Harare

Primary Health Care Clinic Charter: 1996: Patients Right Document, Department of Health, Govt Press; Pretoria

Rand National Security Research Division; 2013: Pretoria. <http://www.rand.org.co.za>

Rahman .S.A:2000; Utilization of Primary Health Care Services in Rural Bangladesh- Unpublished thesis; University of London

Rashid; A; 2013; "Locked in Syndrome" War Crime and Criminals, Vol .4, October 2013, India, <http://en.wikipedia.org>

Reid, E: 1993: Children in families affected by HIV epidemic: A strategic approach [online] [http://www.umd.org/hiv/publication/issues/english/13\\_c.htm](http://www.umd.org/hiv/publication/issues/english/13_c.htm) accessed 21/10/12

Reissman, C.K: 2008: Narrative Methods for Human Science. USA, Sage Publication

Renuka .M; 2006: Children and young people affected by HIV/AIDS in India, unpublished study

Richter, M; 2004: Legal development in South African Law, HIV/AIDS; Policy Review, vol 9 (1) April 2004

Roalkvam, S: 2005: The children left to stand alone; African journal of Aids Research; 4: 211-218

Roberts, T.A; Goldenberg, J.L; Power, C & Pyszczynski, T: 2002; Famines Protection: "Effects of menstruation on attitudes towards women", Vol 26; pages 131-139

Ropar, J.M. & Shapira, J; 2006: Ethnography in Nursing Research: Thousand Oaks. CA, Sage

Rosa.S; 2004; Counting on children: Realizing the right to social assistance for child headed households in South Africa: A Children Institute Working Paper Number .3; University of Cape Town

Schultz, A: 1973; The Problems of Social Reality; The Hague: Martinus Nijhoff

Scholz .R.W & Tietjie .O; 2002: Embedded case study methods; Integrating Qualitative and Quantitative Knowledge: London: Sage Publication, Inc.

Sengendo, J & Nambi, J: 1997; The psychological effects of orphan hood: "A study of orphans in Rakai District – Health Trans –Review; Number 7 (suppl) 105-124

Shah N. 2013, Retail customers and setting trends in age of E- commerce- Globe correspondence Report. <http://www.bostonglobe.com/business>.

Silverman, D; 1993: Beginning Research: Interpreting Qualitative Data, Methods for Analyzing talk, text and interaction: London: Sage Publication

Silverman, D; 2004: Qualitative Research: Theory, method and procedure, 2<sup>nd</sup> edition. Sage Publications

Simpson, G; 1998: Urban crime and violence in South Africa, London: Save the children

Skelton; A: 1998: Children and the Law; Pietermaritzburg: Mills Litho

Skelton, D, 1998: Children with Disability and the law: [www.uct.ac.za/dept/chi/mch/12:rtf](http://www.uct.ac.za/dept/chi/mch/12:rtf)

Sloth-Nielsen; J: 2004; Realizing the rights of children growing up in child headed house hold; A guide to law, policies and social advocacy; Cape Town

Smith, B.L.:2003: Learning communities and liberal education, Academia 89-(1) 14-18

Smith, J.A; Flowers & Larkin, M; 2007: Interpretative phenomenological analysis; theory, method and research, UK: SAGE Publication

Social Assistance Act no.13 of 2004; Policy, Pretoria; Government Printers

Socio-economic status fully mediates the effects of ethnicity on the health of Roma people in Hungary: Journal of Epidemiology and Community Health, No.63 (455-460)

Solomon, I & Doll, C: 1999: The Development and preliminary validation of a new measure of adult attachment projective. Vol 3; 3 April 2001

South Africa Catholic Bishops Conference 2004;” To live a decent life”-Bridging the gaps. A study of SACBC programs in support of orphans and vulnerable children in South Africa & Swaziland

South African Catholic Bishops Conference 2005: “Guidelines for Catholic Church’s support of orphans and vulnerable group in South Africa

South African Child Gauge, 2007. Children’s right to sexual services: University of Cape Town.

South African Institute of Race Relations 2009; South African Education is a Mess, the families in crisis; 8 April 2008. [www.timeslive.co.za](http://www.timeslive.co.za)

South African Schools Act no 84 of 1996; Policy: Pretoria; Government Printers

South African Educators Act no 37 of 1996: Policy: Pretoria; Government Printers

South African Social Services Agency: 2010: Strategic and annual Planning – Pretoria, Government Printers

South African Nursing Council: 2005: Nursing Act 2005 – Act No 33 of 2005

Speziale, H. J & Carpenter, D. R: 2003: Qualitative Research in Nursing, Advancing the Humanistic Imperative. Lippincott Williams, Publishers

Speziale, H. J & Carpenter; D. R: 2007: Qualitative Research in Nursing, 4th edition, Lippincott Williams, Publishers

Spradley, J. S: 1979: Ethnographic Interview: New York; Holt Rinehart & Wilson

Spradley, J S: 1980; Participatory observation: New York: Holt Rinehart & Winston.

Statistics South Africa: 2009: Mid-year, population estimates. Pretoria Government Press

Statistics South Africa: 2013: Mid-year, population estimates. Pretoria Government Press

Strauss, A. & Corbin, J; 2008; Basis of Qualitative Research; Sage Publication; California, USA

Streubert, S.H.J & Carpenter; D.R 2007: Qualitative Research in Nursing, Advancing the Humanistic Imperative, 4<sup>th</sup> edition: Lippincott; Wilkins; Philadelphia

Stannard, R: 2012: Innovation in learning technologies for English teaching, <http://russelstannard.com/articles-online>

Tanner; J; 2012: Children, Women and War. St Martin's Press: New York

Tapp, P; Taylor; & Henaghan, M; 2003: Agents or Dependent children and the family law system in John Dewar and Stephen Parker (eds) Family Law: Processes Practices, Pressures; Oxford: HART; 303-310

Topping, S. A, 2006, Qualitative- Quantitative continuum- The Research Process in Nursing, student edition, Blackwell Publication.

Trafford, G & Leshem, S: 2008: Thinking like a researcher; A target for candidates and a challenge for the supervisor. [vntrafford@aol.com](mailto:vntrafford@aol.com)//[www.vernontrafford.com](http://www.vernontrafford.com)

Trivedi, P. & Wykes, T. 2002: From passive subjects to equal partners: qualitative review of user involvement in research: British Journal of Psychiatry, vol.181.March pp468-472

Tsegaye S.2000; Reversed Roles and Stressed Souls: Child Headed Households in Ethiopia, report under African Child Policy Forum (ACPF)

UNAIDS 2003- National HIV and Aids Policy, A call for a renewed action on Aids.

UNAIDS 2004- July-Report on global Aids epidemic, Geneva.

UNAIDS 2004-Improving Protection for children without parental care, p.12. New York and Geneva

UNAIDS 2006; December -A faith based response to HIV/AIDS in Southern Africa: The choice to care initiative.

UNAIDS 2006- Global facts and figures, Retrieved June 12 2006, from <http://www.unaids.org>

UNAIDS 2007-Report on global AIDS epidemic in South Africa

<http://www.unaids.org/en/resources>

UNAIDS 2007; National HIV and Syphilis sero-survey and National HIV prevalence and AIDS estimates reports.

UNAIDS& WHO 2008 –Worldwide HIV/AIDS Statistics, global estimates, end of 2007, retrieved November 2008.<http://www.avert.org/worldstat.htm>.

UNAIDS 2009- Global HIV/AIDS statistics of women and children morbidity in Sub Saharan Africa

UNAIDS 2010: Report on the global AIDS epidemic, Geneva, Joint United Nations Program on HIV/AIDS

UNAIDS 2012 – Global Health Program- Call by President Obama to end extreme poverty among children

UNICEF 2001; Child workers in the shadow of Aids, listening to children. NAIROBI/UNICEF/ESARO

UNICEF/UNAIDS 2004: A framework for the protection care and support of orphans and vulnerable children living in a world with HIV/AIDS; New York; UNICEF

UNICEF 2010-Highlights of progress made in improving sanitation and drinking water. WHO. Press

UNICEF 2010. South Africa statistics, Retrieved October 16, 2010; from <http://www.unicef.org/infobycountry/southafrica-statistics.html?=&printme>

UNICEF 2012-The state of world children; <http://www.unicef.org/sow> 2012

University of Pretoria 2002: Policies: Cancer treatment policies, referral policies

<http://www.vc.up.ac/online/super> courses/lecturer/lec

University of South Africa, 2008: Multiprofessional Study, unpublished thesis

USAID; 2002; Land development in Latin America- Openings for Policy Research.  
USA/ CANADA/ ECUADOR

USAID; 2003: Family and Community Interventions for Children affected by  
AIDS.WK Kellogg Foundation, HRSC, Cape Town

USAID; 2004- Children on the brink –joint report of new orphans estimates and  
framework for action. Washington .D C

USAID: 2005; Committee for Evaluation of President Emergency Plans for AIDS  
Relief

(PEPFAR) <http://www.nap.edu/catalog/11905.htm>

USAID; 2006: Igniting the power of community; The role of CBO's and NGO's in  
Global Public Health. John Hopkins; US.

USAID; 2007: The feeding of Nations: Redefining food security for the 21<sup>st</sup> century,  
CRC Press, US.

USAID: 2008: Educating children in conflicting zones; Research, Policy and Practice  
for system change: Teachers College Press; New York

USAID; 2009; Preparing for the future on HIV and AIDS in Africa: A shared  
Responsibility. The National Academic Press; Washington.D.C.

USAID; 2010; Whose aid is it anyway? Politicizing aid in conflict and crisis. Oxfam  
briefing paper no.145, 10 Fe.2011.<http://www.oxfam.org>

Van Rensburg .H.C.J. 2004; Health and Health Care in South Africa, 1<sup>st</sup> edition,  
Van Schaik Publishers

Van Rensburg H.C.J. 2010.Health and Health Care in South Africa,  
Van Schaik Publishers

Voko',Z ; Cse'pe.P ; Nemeth.R ; Koza.K; Koza.Z; Szele.G & Adany. R; 2009: Does socio-economic status, fully mediate the effect of ethnicity on health of Roma people in Hungary? Journal of epidemiology Community Health; Vol,63 (455-460)

Walker, L.O. & Avant, K.C; 2005: Essential Concepts of Nursing: Building Blocks for Practice; 1<sup>st</sup> edition, Elsevier Limited

Walsh, F: 1993-Normal Family Process, 2nd edition, New York; The Guildford Press

Ward H, Mertens T & Thomas C 1997, Health Seeking Behavior and the control of sexually transmitted diseases in Health Policy and Planning

Webb, D. 2001; Best practice in HIV/AIDS program me development; SAFA/DS News .Vol 9

Webb, D. 2004; Legitimate Actors? The future role on NGO's against HIV/AIDS in Sub- Saharan Africa in the political economy of Aids in Africa: University of Natal; Durban.

Webber, M 1978. Economy and Society, Berkley, University of California Press

Williamson .D; 2000; Health Behavior and Health: Evidence that the relationship is not conditional on income adequacy social science and medicine; volume 51

White Paper Transformation of Health Services in South Africa 1995; Pretoria. Govt Printers

White Paper for the Transformation of Health Care Services in South Africa: 1997: Pretoria. Govt Printers

White Paper for Social Welfare Population and Development 1997; Pretoria. Govt Printers

World Health Organization; 1948: The world definition of health: Geneva: World Health Organization.

World Health Organization; 2000: The World Health Report. Health Systems: Improving Performance. Geneva: World Health Organisation.

World Health Organization; 2002: The World Health Report. Reducing risk, promoting healthy lifestyle: WHO Library Catalogue in Publications: Geneva

World Health Organization; 2003: The World Health Report: Statistical Annex, Geneva WHO

World Health Organization; 2004: The Global Burden of Diseases Update: Geneva WHO

World Health Organization; 2006: The World Health Report: Working together for Health. Geneva. WHO

World Health Organization; 2007: World Report on Implementation of International Health Regulations; Geneva: WHO

World Health Organization; 2008: World Health on Universal Access to Health, Geneva: WHO

World Health Organization; 2009: The World Health International Conference on Primary Health Care, Geneva: WHO

Xu, K; Evans, D; Carrin, G; & Aguilar-Rivera, A.N:2005: Department of Health Systems Financing; World Health Organization, Designing the Health Financing System to Reduce Catastrophic Health Expenditure: Technical Briefs for Policy Makers, Number 2: Geneva

Yanovski, J. A. 2010: Study explores teenage boy's huge appetite, New York

Yardley, J; 1997: Maternal Discourses of Health & Illnesses: 1<sup>st</sup> edition, Routledge, New Fetter Lane, London

Yin, R.K.; 1994; Case study research, design and method: Thousand Oaks. CA; Sage

Yin, R.K.; 2003: Case study research design and methods, 3<sup>rd</sup> edition, Newbury Park; Sage Publications

Zukow, P & Golring C; 2002: Center for study of women; Retrieved May 3 2012, <http://cbd.uclg.edu/a...>

## **ANNEXES/APPENDIXES**

### **APPENDIX 1**

University of KwaZulu-Natal  
School of Nursing & Public  
Health

Desmond Clarence Building 5<sup>th</sup>  
Floor Durban

4041

10/08/2012

TO: Lisa Strydom

Thandanani Children's Foundation

Private Bag X 9005

Pietermaritzburg

3201

Dear Sir/Madam

#### **Request to conduct a research study**

I Emelda Zandile Gumede, a PhD student in Nursing at the above mentioned university request permission to conduct a study on the topic "Ethnographic study of the health behavior of children from child headed household with the aim of developing a framework of health care".

I would like to conduct the study between September and January 2013, if my application received your favorable consideration.

Please find my attached short proposal detailing the intended process and the contact numbers for more information.

Hoping my request will be favorable considered.

Yours sincerely

Mrs E Z Gumede (gumedez@ukzn.ac.za) 0722605376 (c) 0312602901 (o)



27 November 2012

Mrs Emelda Zandile Gumede 208529792  
School of Nursing and Public Health  
Howard College Campus

Dear Mrs Gumede

Protocol reference number: H55/0984/012D

Project title: An analysis of the health behavior of children from child headed households in a selected Health District, in KwaZulu-Natal: An Ethnographic study

**Full approval notification – Full committee reviewed protocol**

This letter serves to notify you that your application in connection with the above has now been granted full approval following your response to queries raised by the Humanities and Social Sciences Research Ethics Committee.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number. Please note: Research data should be securely stored in the school/department for a period of 5 years

Best wishes for the successful completion of your research protocol

Yours faithfully

Professor Steven Collings (Chair)  
Humanities & Social Sciences Research Ethics Committee

px.

cc Supervisor Professor BR Bhengu  
cc Academic leader Professor M Mars  
cc School Mrs Caroline Dhanraj

Professor S Collings (Chair)  
Humanities & Social Sc Research Ethics Committee  
Westville Campus, Govan Mbeki Building  
Postal Address: Private Bag X54001, Durban, 4000, South Africa  
Telephone: +27 (0)31 260 3587/8350 Facsimile: +27 (0)31 260 4609 Email: ximbap@ukzn.ac.za / snymanm@ukzn.ac.za  
Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

INSPIRING GREATNESS





Section 21  
No. 2002005186/08  
006-136 NPO

05 September 2012

To whom it may concern

**Permission to conduct PhD research with beneficiaries of Thandanani Children's Foundation**

This letter serves to confirm that we have had discussions with Mrs Zandile Gumede around the possibility of her conducting her PhD research with some of our beneficiary families. Based on the information she has provided, we are willing, in principle, to give her permission to do this. The practical details will need to be discussed in more depth once she is ready to commence with the fieldwork.

Yours faithfully

**Duncan Andrew**  
Director

## APPENDIX 2

### INFORMATION SHEET FOR HEALTH PROFESSIONAL

**Title:** An analysis of the health behavior of children from child headed household in a selected health district, KwaZulu-Natal: An Ethnographic study.

My name is Emelda Zandile Gumede, student no: 208529792, I am a student at the University of KwaZulu-Natal and currently registered for my PhD degree, and this research project is part of the requirement.

#### **Purpose of the Study:**

The purpose of the study is to analyze the health behavior of children from child headed families with the aim of developing the health care framework for dealing with such children.

#### **Inclusion**

#### **criteria:**

You have been approached to participate in the study because you meet the eligibility criteria which are:

- You are responsible for the medical/ health care needs of children coming from child headed household

#### **Description of the Procedure:**

Your participation is requested as you are representative of the target population under study. As part of the research process, you will be required to avail yourself for data collection processes which may be in the form of participant's observation in their natural settings, focus group and interviews. The interviews will take about 20- 30 minutes to complete, but there might be more than one sessions, this process is guided by saturation. All the data collection will be conducted in the participant's environment at a time convenient to them. For the focus group and interviews, the researcher will also request the permission for digital recording of the conversation. The recordings will be transcribed into text and given to participants for corrections and feedback.

All the collected will be treated with utmost respect, no names or places will appear in the document. Participant's anonymity and confidentiality will be maintained throughout the process. Participation in the study is purely voluntary and they are free to participate and disengage at any time with no penalty or prejudice in the future. There are no financial/monetary rewards for engaging with the study

There will be no physical harm/risk to participants, but due to the sensitive nature of the topic under discussion and the detailed data collection process, it may evoke some emotions, the debriefing session with the Social Worker will be arranged who may also refer to a Psychologist where necessary.

**Ethical considerations:**

Please be advised that your identity and information will be treated with the utmost confidentiality. Please feel free to ask any questions you may have so that you are clear with what is expected of you. Please note that

- You are free not to participate
- You are *free* to withdraw at any stage without any compulsion
- Your name will not be used nor will you be identified with any comment made when the data is published.
- There will be no risk attached to your participation

**Advantages to you as a respondent:**

The findings of the study will be made available to you on completion. The study may benefit you in informing the leaders about your experiences so that they may effect changes to your advantage.

Thank you

---

If you need further information, please DON'T hesitate to contact us:

Supervisor : Prof B R Bhengu

Contact No : 0836615563

E mail : [bhengub2@ukzn.ac.za](mailto:bhengub2@ukzn.ac.za)

Researcher : E Z Gumede

Contact No. : 0722605376

E mail address : [gumedez@ukzn.ac.za](mailto:gumedez@ukzn.ac.za)

Research Officer : P Ximba

Contact No : 0312603587

E mail : [ximbap@ukzn.ac.za](mailto:ximbap@ukzn.ac.za)

**INFORMED CONSENT FORM FOR HEALTH PROFESSIONAL**

**Title:** An Analysis of the health behavior of children from child headed households In a selected Health District, KwaZulu -Natal: An Ethnographic study.

**Researcher:** E Z Gumede

**Name of Supervisor:** B R Bhengu

Student Number: 208529792

Contact No: 0836615563

E –mail: [gumedez@ukzn.ac.za](mailto:gumedez@ukzn.ac.za)

E –mail: [bhengub2@ukzn.ac.za](mailto:bhengub2@ukzn.ac.za)

Contact: 0722605376

**Research Officer:** P Ximba

Contact: 0312603587

E- mail: [xlmbap@ukzn.ac.za](mailto:xlmbap@ukzn.ac.za)

**DECLARATION**

\_\_\_\_\_ (Full Names of participant) hereby to confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project.

I understand that I am at liberty to withdraw from the project at any time, should I so desire.

Name of a participant: .....

Signature of participant: .....

Date: .....

Name of a witness: .....

Signature of witness: .....

Date: .....

Name of a researcher: .....

Signature of researcher: .....

Date: .....

## **Interview guide for health care team**

### **A: Demographic data:**

- Choose a pseudo name to be used for data collection:
- Age:
- Work experience:
- Sector:

### **B: Open ended questions:**

1. as a member of the health professional team responsible for children in need of health care , share your experiences in dealing with children from such families (probe)
2. what do you think could be done to improve their living conditions so as to attain complete health
3. What do you think can be done to facilitate the provision of health care to these children?

## **APPENDIX 3**

### **INFORMATION SHEET FOR CHILDREN**

**Title:** An analysis of the health behavior of children from child headed household in a selected health district, KwaZulu-Natal: An Ethnographic study.

My name is Emelda Zandile Gumede, student no: 208529792, I am a student at the University of KwaZulu-Natal and currently registered for my PhD degree, and this research project is part of the requirement.

#### **Purpose of the Study:**

**The purpose of the study is to analyze the health behavior of children from child headed families with the aim of developing the health care framework for dealing with such children.**

#### **Inclusion criteria:**

**You have been approached to participate in the study because you meet the eligibility criteria which are:**

- **You must be a child from the child headed household**
- **You must be 12 years of age and above-you can be able to make your own decision**
- **You must be staying under the care/supervision of the caregiver**
- **You may be staying in the institution, foster care hostels, or in your parental home**

#### **Description of the Procedure:**

Your participation is requested as you are representative of the target population under study. As part of the research process, you will be required to avail yourself for *data* collection processes which may be in the form of participant's observation in their natural settings, focus group and interviews. The interviews will take about 20- 30 minutes to complete, but there might be more than one sessions, this process is guided by saturation. All the *data* collection will be conducted in the participant's environment at a time convenient to them. For the focus group and interviews, the researcher will also request the permission for digital recording of the conversation. The recordings will be transcribed into text and given to participants for corrections and feedback.

All the collected will be treated with utmost respect, no names or places will appear in the document.

Participant's anonymity and confidentiality will be maintained throughout the process. Participation in the study is purely voluntary and they are free to participate and disengage at any time with no penalty or prejudice in the future. There are no financial /monetary rewards for engaging with the study.

There will be no physical harm/risk to participants, but due to the sensitive nature of the topic under discussion and the detailed data collection process, it may evoke some emotions, the debriefing session with the Social Worker will be arranged who may also refer to a Psychologist where necessary.

### ***Ethical considerations***

Please be advised that your identity and information will be treated with the utmost confidentiality. Please feel free to ask any questions you may have so that you are clear with what is expected of you. Please note that:

- You are free not to participate
- You are free to withdraw at any stage without any compulsion
- Your name will not be used nor will you be identified with any comment made when the data is published.
- There will be no risk attached to your participation

### ***Advantages to you as a respondent:***

The findings of the study will be made available to you on completion. The study *may* benefit you in informing the leaders about your experiences so that they may effect changes to your advantage.

Thank you

If you need further information, please DON'T hesitate to contact us:

Supervisor: Prof B R Bhengu .

Contact No: 0836615563

E mail: [bhengub2@ukzn.ac.za](mailto:bhengub2@ukzn.ac.za)

Researcher; E Z Gumede  
Contact No: 0722605376  
E mail: [gumede@ukzn.ac.za](mailto:gumede@ukzn.ac.za)

Research Officer: P Ximba  
Contact No: 0312603587  
E mail: [ximbap@ukzn.ac.za](mailto:ximbap@ukzn.ac.za)

## **APPENDIX 4**

### **INFORMED CONSENT FOR CHILDREN**

Title: An analysis of the health behavior of children from child headed household in a selected health district, KwaZulu-Natal: An Ethnographic study.

My name is Emelda Zandile Gumede, student no: 208529792, I am a student at the University of KwaZulu-Natal and currently registered *for* my PhD degree, and this research project is part of the requirement.

#### **Purpose of the Study:**

**The purpose of the study is to analyze the health behavior of children from child headed families with the aim of developing the health care framework for dealing with such children.**

#### **Inclusion criteria:**

**You have been approached to participate in the study because you meet the eligibility criteria which are:**

- **You must be a child from the child headed household**
- **You must be 12years of age and above**
- **You must be staying under the care/supervision of the caregiver**
- **You may either be staying in the institution, foster care hostels or in your parental home**

#### **Description of the Procedure:**

Your participation is requested as you *are* representative of the target population under study. As part of the research process, you will be required to avail yourself for data collection processes which may be in the form of participant's observation in their natural settings, focus group and interviews. The interviews will take about 20-30 minutes to complete, but there might be more than one sessions, this process is guided by saturation. All the data collection will be conducted in the participant's environment at a time convenient to them. For the focus group and interviews, the researcher will also request the permission for digital recording of the conversation.

The recordings will be transcribed into text and given to participants for corrections and feedback.

All the collected will be treated with utmost respect, no names or places will appear in the document.

Participant's anonymity and confidentiality will be maintained throughout the process. Participation in the study is purely voluntary and they are free to participate and disengage at any time with no penalty or prejudice in the future. There are no financial /monetary rewards for engaging with the study.

There will be no physical harm/risk to participants, but due to the sensitive nature of the topic under discussion and the detailed data collection process, it may evoke some emotions, the debriefing session with the Social Worker will be arranged who may also refer to a Psychologist where necessary.

### ***Ethical considerations***

Please be advised that your identity and information will be treated with the utmost confidentiality. Please feel free to ask any questions you may have so that you are clear with what is expected of you. Please note that:

- You are free not to participate
- You are free to withdraw at any stage without any compulsion
- Your name will not be used nor will you be identified with any comment made when the data is published.
- There will be no risk attached to your participation

### ***Advantages to you as a respondent:***

The findings of the study will be made available to you on completion. The study may benefit you in informing the leaders about your experiences so that they may effect changes to your advantage.

Thank you

---

If you need further information, please DON'T hesitate to contact us:

Supervisor: Prof B R Bhengu

Contact No: 0836615563

E mail: bhengub2@ukzn.ac.za.

Researcher; E Z Gumede

Contact No: 0722605376

E mail: gumedez@ukzn.ac.za.

Research Officer: P Ximba

Contact No: 0312603587

E mail: ximbap@ukzn.ac.za

## DECLARATION

I ..... (Full names of participant) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participate in the research project.

I understand that I am at liberty to withdraw from the project at any time, should I so desire.

.....

Signature of the participant

.....

Date

.....

Signature of the witness

.....

Date

.....

Signature of the researcher

.....

Date

## **Interview guide for children**

### **A: Demographic data:**

- Choose a pseudo name to be used for the data collection:
- Age in numbers:
- Who is the eldest?
- How many are you:

### **B: Open ended questions:**

1. Who are you living with at home?
2. Why are you living alone?
3. Now that you are living alone, tell me about your daily living activities at home (from morning till evening)
4. Have you had a health problem before, if yes, what was your experience in the health care center
5. Is there any help /assistance that you are receiving from the government, community, extended family, church or any organization?
6. Are there any problems that you need to be assisted with?

## INCWADI YOLWAZI YABANTWANA

ISIHLOKO: UKUBUKEZWA KWENDLELA YEMPI LO NOKUZIPHATHA KWABANTWANA ABAHLALA NGABODWANA BENGENABAZALI; ESIFUNDENI SEZEMPILO KWAZULU-NATAL.

IGAMA LAMI NGINGU EMELDA ZANDILE GUMEDE STUDENT N0:208529792,NGIFUNDA ENYUVESI YAKWAZULU -NATAL, ETHEKWINI, NGENZA IZJFUNDO EZIBHEKELA IMPILO NENHLALO YABANTWANA ABAKHULA BEHLALA BODWA BENGENABO ABAZALI

INHLOSO YALOLUCWANINGO UKUTHOLA ULWAZI, IZIDINGO ,KANYE NEZINGQJNAMBA(IZINKINGA) ABABHEKANA NAZO UMA BEGULA BEYA EMTHOLAMPILO ESIFUNDENJ SEZEMPILO ESITHILE SAKWAZULU- NATAL

UYACELWA UKUBA UBE YINGXENYE YALOLUCWAN INGO NGOBA LUQONDENE NABANTWANA ABASESI MWENI ESINJENGALESISAKHO

- ABANTWANA ASEBASHONELWA ABAZALI
- ABANTWANA ABAHLALA NGABODWANA,NGAPHANDLE KOMUNTU OMDALA EKHAYA
- ABANTWANA ABAPHANSI KWESO LIKA NOMPILO

UMA UVUMA UKUBAMBA IQHAZA KULOLUCWANINGO,KUSHO UKUTHI UZOSIPHA INGXENYE ETHILE YESIKHATHI SAKHO UKUZE SIXOXISANE NAWE SIBUZE IMIBUZO.KUNGENZEKA FUTHI NGESINYE ISIKHATHI SICELE UKUQOPHA INKULUMO YETHU UKUZE IQONDE KAHLE KUNGABI KHONA OKUSALA NGEPHUTHA. ISIKHATHI SOKUXOXA NEMIBUZO SIYOKWENZI WA NGOLIMI LWAKHO OLUQONDA KAHLE, NANGESIKHATHI ESIVUMELANA NAWE. KUNGENZEKA SIBE NEZINGXOXO EZIKHASHANA EZININGANA,KODWA ZOBE ZIHLUKENE,NGEKE KWENZEKE NGELANGA ELILODWA,UYOLINIKWA ITHUBA LOKUPHUMULA.

INGXOXO YETHU IZOBA PHAKATHI KWAMI NAWE, AKEKHO OMUNYE UYOBA NELUNGELO LOKUYITHOLA .NGEKE IGAMA LAKHO NENDAWO OHLALA KUYONA IBHALWE NDAWO KULOLUCWANI NGO. UMA KUFANELE SIBIZANE NGAMAGAMA SOQAMBANA AMAGAMA OKUDLALA KUPHELA NJE AYOPHELELA KITHINA ,NAWO NGEKE AZIWE MUNTU.

UKUBA YINGXENYE YOCWANI NGO NGOBA UTHANDA,AWUPHOQWE MUNTU,FUTHI UMA USUFUNA UKUYEKA ,UNGAYEKA NOMA ININI NGAPHANDLE KOKUBA UCWASEKE/INHLOWULO. AYIKHO INKOKHELO,KUMBE IZIPHO EZITHOLAKALA NGOKUBA YI NGXENYE YALOLUCWANI NGO.ABUKHO UBUNGOZI ONGABHEKANA NABO NGOBA ASITHI NTI INYAMA,KODWA SIBUZA IMIBUZO NGOKUJULILE,YILOKHO KE OKUNGENZEKA KUVUSE UMUNYU NOBUHLUNGU OSEBADLULA. USONHLALAKAHLE NOCHWEPHESHE BEZENGQONDO BOBE BEKHONA UKUBHEKELELA LESO SIMO UMA SIBA KHONA.

IMINININGWANE YABANTU ONGABATHI NTA MAYELANA NOCWANI NGO UKUZE UBUZE NOMA YINI ONGAYIZWANGA KAHLE NANSI:

UMPHATHI: Prof B R Bhengu  
UCINGO: 0836615563  
E mail: bhengub2@ukzn.ac.za.

UMCWANINGI; E Z Gumede  
UCINGO: 0722605376  
E mail: gumedez@ukzn.ac.za.

IHOVISI LOCWANINGO: P Ximba  
UCINGO: 0312603587  
E mail: ximbap@ukzn.ac.za

NGIYABONGA

.....

MRS E Z GUMEDE

## INCWADI YEMININGWANE NOLWAZI NESIFUNGO SABANTWANA

ISIHLOKO: UKUBUKEZWA KWENDLELA VEMPI LO NOKUZI PHATHA KWABANTWANA ABAHLALA NGABODWANA BENGENABAZALI; ESIFUNDENI SEZEMPILO KWAZULU-NATAN.

IGAMA LAMI NGINGU EMELDA ZANDILE GUMEDE STUDENT NO:208529792,NGIFUNDA ENYUVESI YAKWAZULU-NATAL, EThekwini, NGENZA IZIFUNDO EZIBHEKELA IMPILO NENHLALO YABANTWANA ABAKHULA BEHLALA BODWA BENGENABO ABAZALI

INHLOSO YALOLUCWANI NGO UKUTHOLA ULWAZI, IZIDINGO ,KANYE NEZINGQINAMBA(IZINKINGA) ABABHEKANA NAZO UMA BEGULA BEYA EMTHOLAMPI LO ESIFUNDENI SEZEMPILO ESITHILE SAKWAZULU- NATAL

UYACELWA UKUBA UBE YINGXENYE YALOLUCWANINGO NGOBA LUQONDENE NABANTWANA ABASESI MWENI ESINJENGALESI SAKHO:

- ABANTWANA ASEBASHONELWA ABAZALI
- ABANTWANA ABAHLALA NGABODWANA, NGAPHANDLE KOMUNTU OMDALA EKHAYA
- ABANTWANA ABAPHANSI KWESO LIKA NOMPILO

UMA UVUMA UKUBAMBA IQHAZA KULOLUCWANINGO,KUSHO UKUTHI UZOSIPHA INGXENYE ETHILE YESIKHATHI SAKHO UKUZE SIXOXISANE NAWE SIBUZE IMIBUZO .KUNGENZEKA FUTHI NGESINYE

ISIKHATHI SICELE UKUQOPHA INKULUMO VETHU UKUZE IQONDE KAHLE KUNGABIKHONA OKUSALA NGEPHUTHA. ISIKHATHI SOKUXOXA NEMIBUZO SIYOKWENZIWA NGOLIMI LWAKHO OLUQONDA KAHLE, NANGESIKHATHI ESIVUMELANA NAWE. KUNGENZEKA SIBE NEZINGXOXO EZIKHASHANA EZININGANA,KODWA ZOBE ZIHLUKENE,NGEKE KWENZEKE NGELANGA ELILODWA,UYOLINIKWA ITHUBA LOKUPHUMULA

INGXOXO YETHU IZOBA PHAKATHI KWAMINAWE, AKEKHO OMUNYE UYOBA NELUNGELO LOKUYITHOLA. NGEKE IGAMA LAKHO NENDAWO OHLALA KUYONA IBHALWE NDAWO KULOLUCWANINGO. UMA KUFANELE SIBIZANE NGAMAGAMA SOQAMBANA AMAGAMA OKUDLALA KUPHELA NJE AYOPHELELA KITHINA,NAWO NGEKE AZIWE MUNTU.

UKUBA YINGXENYE YOCWANINGO NGOBA UTHANDA,AWUPHOQWE MUNTU,FUTHI UMA USUFUNA UKUYEKA ,UNGAYEKA NOMA ININI NGAPHANDLE KOKUBA UCWASEKE/INHLOWULO. AYIKHO INKOKHELO, KUMBE IZIPHO EZITHOLAKALA NGOKUBA YINGXENYE YALOLUCWANI NGO. ABUKHO UBUNGOZI ONGABHEKANA NABO NGOBA ASITHINTI INYAMA,KODWA SIBUZA IMIBUZO NGOKUJULILE, YILOKHO KE OKUNGENZEKA KUVUSE UMUNYU NOBUHLUNGU OSEBADLULA. USONHLALAKAHLE NOCHWEPHESHE BEZENGQONDO BOBE BEKHONA UKUBHEKELELA LESO SIMO UMA SIBA KHONA.

IMINININGWANE YABANTU ONGABATHINTA MAYELANA NOCWANINGO UKUZE UBUZE NOMA YINI ONGAYIZWANGA KAHLE NANSI:

UMPHATHI: Prof B R Bhengu  
UCINGO: 0836615563  
E mail: bhengub2@ukzn.ac.za.

UMCWANINGI: E Z Gumede  
UCINGO: 0722605376  
E mail: gumedez@ukzn.ac.za.

IHOVISI LOCWANINGO: P Ximba  
UCINGO: 0312603587  
E mail: ximbap@ukzn.ac.za

NGIYABONGA

.....

MRS E Z GUMEDE

**ISIFUNGO**

MINA .....(amagama agcwele) NGIYAVUMA UKUBA  
YINGXENYE YOCWANINGO OLUBHEKELA ABANTWANA ABAHLALA NGABODWANA  
ASEBASHONELWA ABAZALI. NGIYAZI UKUTHI NGINGAYEKA NOMA NGASIPHI ISIKHATHI  
UMA NGINGASATHAN01 UKUZIBANDAKANYA NOCWANINGO NGAPHANOLE  
KOKUHLUKUMEZEKA.

.....

SAYINA

.....

USUKU

.....

UFAKAZI

.....

USUKU

.....

UMCWANINGI

.....

USUKA

## **Imibuzo yabantu abafanelekile kulolucwaningo**

OKUNGEZIWE: 4

### ***Imibuzo yezingane***

#### **A: Imininingwane Yakho:**

- Khetha igama okungelona elizosetshenzi swa ngokutholwa kolwazi
- Imnyaka, ibe inombolo.
- Ngubani omdala phakathikwenu.
- Nibangaki seninonke

#### **B: Imibuzo evulelekile:**

1. Ubani enihlala naye lapha ekhaya?
2. Kungani nihlala nodwa?
3. Ngoba nihlala nodwa, ngicela ningitshela izinto enizenzayo ukuze niphile(ekuseni kuze kubesebusuku)
4. Ingabe wake wagula ngaphambilini,uma kungu yebo,ingabe impatho yasemthol ampilo yayinjanl?
5. Ingabe lokhona usizo olutholayo kuhulumeni,emphakathini,emndenini,esontweninoma
6. enhlanganweni?
7. Ingabe unayo inkinga ongathanda ukuba usizwe ngayo?

## APPENDIX 5

### INFORMATION SHEET FOR CAREGIVERS

**Title:** An analysis of the health behavior of children from child headed household in a selected health district, KwaZulu-Natal: An Ethnographic study.

My name is Emelda Zandile Gumede, student no: 208529792, I am a student at the University of Kwazulu-Natal and currently registered for my PhD degree, and this research project is part of the requirement.

#### **Purpose of the Study:**

The purpose of the study to analyze the health behavior of children from child headed families with the aim of developing the health care framework for dealing with such children.

#### **Inclusion criteria:**

You have been approached to participate in the study because you meet the eligibility criteria which are:

- You are responsible for the day to day care of the children who are from the child headed household
- You are the care caregiver working for the institution
- You are a relative who is entrusted with the supervision of such children

#### **Description of the Procedure:**

Your participation is requested as you are representative of the target population under study. As part of the research process, you will be required to avail yourself for data collection processes which may be *in* the form of participant's observation in their natural settings, focus group and interviews. The interviews will take about 20- 30 minutes to complete, but there might be more than one sessions, this process is guided by saturation. All the data collection will be conducted in the participant's environment at a time convenient to them. For the focus group and interviews, the researcher will also request the permission for digital recording of the conversation.

The recordings will be transcribed into text and given to participants for corrections and feedback.

All the collected will be treated *with* utmost respect, no names or places will appear in the document.

Participant's anonymity and confidentiality will be maintained throughout the process. Participation in the study is purely voluntary and they are free to participate and disengage at *any* time with no penalty or prejudice in the future. There are no financial /monetary rewards for engaging with the study

There will be no physical harm/risk to participants, but due to the sensitive nature of the topic under discussion and the detailed data collection process, it may evoke some emotions, the debriefing session with the Social Worker will be arranged who may also refer to a Psychologist where necessary.

#### Ethical considerations

Please be advised that your identity and information will be treated with the utmost confidentiality. Please feel free to ask any questions you may have so that you are clear with what is expected of you. Please note that:

- You are free not to participate
- You are free to withdraw at any stage without any compulsion
- Your name will not be used nor will you be identified with any comment made when the data is published.
- There will be no risk attached to your participation

#### **Advantages to you as a respondent:**

The findings of the study will be made available to you on completion. The study may benefit you in informing the leaders about your experiences so that they may effect changes to your advantage.

Thank you

---

If you need further information, please DON'T hesitate to contact us:

Supervisor: Prof B R Bhengu  
Contact No: 0836615563  
E mail: bhengub2@ukzn.ac.za.

Researcher; E Z Gumede  
Contact No: 0722605376  
E mail: gumedez@ukzn.ac.za.

Research Officer: P Ximba  
Contact No: 0312603587  
E mail: ximbap@ukzn.ac.za

## **APPENDIX 6**

### **INFORMED CONSENT FOR CAREGIVERS**

**Title:** An analysis of the health behavior of children from child headed household in a selected health district, KwaZulu-Natal: An Ethnographic study.

My name is Emelda Zandile Gumede, student no: 208529792, I am a student at the University of KwaZulu-Natal and currently registered for my PhD degree, and this research project is part of the requirement.

#### **Purpose of the Study:**

The purpose of the study is to analyze the health behavior of children from child headed families with the aim of developing the health care framework for dealing with 1;uch children.

#### **Inclusion criteria:**

You have been approached to participate in the study because you meet the eligibility criteria which are:

- You are responsible for the day to day care of the children who are from the child headed household
- You are the care caregiver working for the institution
- You are a relative who is entrusted with the supervision of such children

#### **Description of the Procedure:**

Your participation is requested as you are representative of the target population under study. As part of the research process, you will be required to avail yourself for data collection processes which may be in the form of participant's observation in their natural settings, focus group and interviews. The interviews will take about 20- 30 minutes to complete, but there might be more

than one sessions, this process is guided by saturation. All the data collection will be conducted in the participant's environment at a time convenient to them. For the focus group and interviews, the researcher will also request the permission for digital recording of the conversation.

The recordings will be transcribed into text and given to participants for corrections and feedback.

All the collected will be treated with utmost respect, no names or places will appear in the document. Participant's anonymity and confidentiality will be maintained throughout the process. Participation in the study is purely voluntary and they are free to participate and disengage at any time with no penalty or prejudice in the future. There are no financial /monetary rewards for engaging with the study

Supervisor: Prof B R Bhengu  
Contact No: 0836615563  
E mail: bhengub2@ukzn.ac.za.

Researcher; E Z Gumede  
Contact No: 0722605376  
E mail: gumedez@ukzn.ac.za.

Research Officer: P Ximba  
Contact No: 0312603587  
E mail: ximbap@ukzn.ac.za

## DECLARATION

I ..... (full names of participant) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participate in the research project.

I understand that I am at liberty to withdraw from the project at any time, should I so desire.

.....

Signature of the participant

.....

Date

## **Appendix: 7**

### **Interview guide for care giver**

#### **A: Demographic data**

- Choose a pseudo name to be used for data collection
- Age
- Gender
- Sector

#### **B: Open ended questions**

1. Since you are a care giver dealing with child headed household, would you please give us your experiences in this regard?
2. What has been your experience with respect of extended family members absorbing such children into their families?
3. What support is given to children from government, non-governmental organization, the church and families?
4. What do you suggest should be done to enhance the welfare of these children?
5. From a health perspective, what do you think can be done to enhance their access to clinic? (Experiences in terms of clinic attendance)

## INCWADI YOLWAZI YONOMPILO

ISIHLOKO: UKUBUKEZWA KWENDLELA YEMPILO- NOKUZIPHATHA KWABANTWANA  
ABAHLALA NGABODWANA BENGENABAZALI: ESIFUNDENI SEZEMPILO KWAZULU-NATAL.

IGAMA LAMI NGINGU EMELDA ZANDILE GUMEDE STUDENT N0:208529792,NGIFUNDA ENYUVESI  
YAKWAZULU-NATAL, ETHEKWIN, I NGENZA IZIFUNDO EZIBHEKELA IMPILO NENHLALO  
YABAN1WANA ABAKHULA BEHLALA BODWA BENGENABO ABAZALI

INHLOSO YALOLUCWANINGO UKUTHOLA ULWAZI, IZIDINGO ,KANYE EZINGQINAMBA(IZINKINGA)  
ABABHEKANA NAZO UMA BEGULA BEYA EMTHOLAMPILO ESIFUNDENI SEZEMPILO ESITHILE  
SAKWAZULU-NATAL

UYACELWA UKUBA UBE YINGXENYE YALOLUCWANINGO NGOBA LUQONDENE  
NONOMPILO ABABHEKELELA IMPILO NENDLELA YOKUZIPHATHA KWABANTWANA  
ABAPHILA BODWA BENGENABO ABAZAU:

- USEBENZA NJENGNOM PILO KULESIKHUNGO
- UBHEKELA IMPILO NEZIDINGO ZABANTWANA ABANGENABO ABAZAU

UMA UVUMA UKUBAMBA IQHAZA KULOLUCWANINGO,KUSHO UKUTHIUZOSIPHAINGXENYE  
ETHILE YESIKHATHI SAKHO UKUZE SIXOXISANE NAWA SIBUZE IMIBUZO .KUNGENZEKA FUTHI  
NGESINYE ISIKHATHI SICELE UKUQOPHA INKULUMO YETHU UKUZE IQONOE KAHLE  
KUNGABIKHONA OKUSALA NGEPHUTHA .SIKHATHISOKUXOXA NEMIBUZO SIYOKWENZIWA  
NGOLIMI LWAKHO OLUQONDA KAHLE,NANGESIKHATHI ESIVUMELANA NAWA. KUNGENZEKA  
SIBE NEZINGXOXO EZIKHASHANA EZININGANA,KOOWA ZOBE ZIHLUKENE,NGEKE KWENZEKE  
NGELANGA EULODWA,UYOLINIKWA ITHUBA LOKUPHUMULA

INGXOXO YETHUIZOBA PHAKATHI KWAMINAWA, AKEKHO OMUNYE UYOBA NELUNGELO  
LOKUYITHOLA NGEKE IGAMA LAKHO NENDAWO OHLALA KUYONA IBHALWE NOAWO  
KULOLUCWANINGO. UMA KUFANELE SIBIZANE NGAMAGAMA SOQAMBANA AMAGAMA  
OKUOLALA KUPHELA NJE AYOPHELELA KITHINA, NAWO NGEKE ASIWE MUNTU

UKUBA YINGXENYE YOCWANI NGO NGOBA UTHANDA,AWUPHOQWE MUNTU,FUTHI UMA  
USUFUNA UKUYEKA,UNGAYEKA NOMA ININI NGAPHANDLE KOKUBA UCWASEKE/INHLOWULO.

AYIKHO INKOKHELO, KUMBE IZIPHO EZITHOLAKALA NGOKUBA YINGXENYE YALOLUCWANINGO. ABUKHO UBUNGOZI ONGABHEKANA NABO NGOBA ASITHINTI INYAMA,KOOWA SIBUZA IMIBUZO NGOKUJUULE ,YILOKHO KE OKUNGENZEKA KUVUSE UMUNYU NOBUHLUNGU OSEBADLULA. USONHLALAKAHLE NOCHWEPHESHE BEZENQONDO BOBE BEKHONA UKUBHEKELELA LESO SIMO

UMA SIBA KHONA.

IMINININGWANE YABANTU ONGABATHINTA MAYELANA NOCWANINGO UKUZE UBUZE NOMA YINI ONGAVIZWANGA KAHLE NANSI:

UMPHATHI: Prof B R Bhengu  
UCINGO: 0836615563  
E mail: bhengub2@ukzn.ac.za.

UMCWANINGI: E Z Gumede  
UCINGO: 0722605376  
E mail: gumedez@ukzn.ac.za.

IHOVISI LOCWANINGO: P Ximba  
UCINGO: 0312603587  
E mail: ximbap@ukzn.ac.za

NGIYABONGA

.....

MRS E Z GUMEDE

## **INCWADI YOLWAZI NEMININGWANE NESIFUNGO YONOMPILO**

**ISIHLOKO:** UKUBUKEZWA KWENDLELA YEMPILO NOKUZIPHATHA KWABANTWANA ABAHLALA NGABODWANA BENGENABAZALI; ESIFUNDENI SEZEMPILO KWAZULU-NATAL.

IGAMA LAMI NGINGU EMELDA ZANDILE GUMEDE STUDENT NO: 208529792,NGIFUNDA ENYUVESI YAKWAZULU-NATAL, ETHEKWINI, NGENZA IZIFUNDO EZIBHEKELAIMPILO NENHLALO YABANTWANA ABAKHULA BEHLALA BODWA BENGENABO ABAZALI

INHLOSO YALOLUCWANI NGO UKUTHOLA ULWAZI, IZIIDINGO, KANYE NEZINGQINAMBA (IZINKINGA) ABABHEKANA NAZO UMA BEGULA BEYA EMTHOLAMPI LO ESIFUNOENISEZEMPILO ESITHILE SAKWAZULU- NATAL

UYACELWA UKUBA UBE YINGXENYE YALOLUCWANI NGO NGOBA LUQONOENE NONOMPILO ABABHEKELELA IMPILO NENDLELA YOKUZIPHATHA KWABANTWANA ABAPHILA BODWA BENGENABO ABAZALI :

- USEBENZA NJENGNOMPILO KULESIKHUNGO
- UBHEKELA IMPILO NEZIOINGO ZABANTWANA ABANGENABO ABAZALI

UMA UVUMA UKUBAMBA IQHAZA KULOLUCWANINGO,KUSHO UKUTHI UZOSIPHA INGXENYE ETHILE YESIKHATHI SAKHO UKUZE SIXOXISANE NAWE SIBUZE IMIBUZO .KUNGENZEKA FUTHI NGESINYE

ISIKHATHI SICELE UKUQOPHA INKULUMO YETHU UKUZE IQONDE KAHLE KUNGABIKHONA OKUSALA NGEPHUTHA. ISIKHATHI SOKUXOXA NEMIBUZO SIYOKWENZI WA NGOLIMI LWAKHO OLUQONDA KAHLE, NANGESIKHATHI ESIVUMELANA NAWE. KUNGENZEKA SIBE NEZINGXOXO EZIKHASHANA EZININGANA,KOOWA ZOBE ZIHLUKENE,NGEKE KWENZEKE NGELANGA ELILODWA,UYOUNIKWA ITHUBA LOKUPHUMULA.

INGXOXO YETHUIZOBA PHAKATHI KWAMINAWE, AKEKHO OMUNYE UYOBA NELUNGELO LOKUYITHOLA. NGEKE IGAMA LAKHO NENDAWO OHLALA KUYONA IBHALWE NDAWO KULOLUCWANINGO. UMA KUFANELE SIBIZANE NGAMAGAMA SOQAMBANA AMAGAMA OKUDLALA KUPHELA NJE AYOPHELELA KITHINA ,NAWO NGEKE AZIWE MUNTU

UKUBA YINGXENYE YOCWANINGO NGOBA UTHANOA,AWUPHOQWE MUNTU,FUTHI UMA USUFUNA UKUYEKA ,UNGAYEKA NOMA INININGAPHANDLE KOKUBA UCWASEKE/INHLOWULO. AYIKHO

INKOKHELO,KUMBEIZIPHONGAZITHOLAKALA NGOKUBA YINGXENYE YALOLUCWANI NGO.ABUKHO UBUNGOZI ONGABHEKANA NABO NGOBA ASITHINTI INYAMA,KODWA SIBUZA IMIBUZO NGOKUJULILE, YILOKHO KE OKUNGENZEKA KUVUSE UMUNYU NOBUHLUNGU OSEBADLULA. USONHLALAKAHLE NOCHWEPHESHE BEZENQONDO BOBE BEKHONA UKUBHEKELELA LESO SIMO UMA SIBA KHONA.

IMINININGWANE YABANTUONGABATHINTA MAYELANA NOCWANINGO UKUZE U8UZE NOMA YINI ONGAYIZWANGA KAHLE NANSI:

UMPHATHI: Prof B R Bhengu  
UCINGO: 0836615563  
E mail: bhengub2@ukzn.ac.za.

UMCWANINGI: E Z Gumede  
UCINGO: 0722605376  
E mail: gumedez@ukzn.ac.za.

IHOVISI LOCWANINGO: P Ximba  
UCINGO: 0312603587  
E mail: ximbap@ukzn.ac.za

NGIYABONGA

.....

MRS E Z GUMEDE

## ISIFUNGO

MINA ..... (amagama agcwele) NGIYAVUMA UKUBA  
YINGXENYE YOCWANINGO OLUBHEKELA ABANTWANA ABAHLALA NGABOOWANA  
ASEBASHONELWA ABAZALI. NGIYAZI UKUTHI NGINGAYEKA NOMA NGASIPHI ISIKHATHI UMA  
NGINGASATHANDI UKUZIBANDAKANYA NOCWANINGO NGAPHANDLE KOKUHLUKUMEZEKA.

.....

SAYINA

.....

USUKU

OKUNGEZJWE:

***Imibuzo yonompilo***

**A: Imininingwane Yakho:**

- *Khetho igomo okungelono esizolisebenziso*
- *tminyako*
- *Ubulili "Isigobo*

**B: Imibuzo evulelekile**

1. Njengoba ungunompi o osebenza nezIngane ezihlala zodwana, siyacela ukuba usitshela ngesimo sakho sokusebenza.
2. Sicela usicazele ngesimo sezingane esezithathwe imindeni ukuba zihlale nabo?
3. Ingabe lukhona usizo olutholakala kuhulumeni, kuzinhlango zomphakathi, kanye nasemasontweni?
4. Ikuphi ongakusho okungasiza noma engathuthukisa ukuphathwa kwalezizingane?
5. Ngokwezempilo, ikuphi ocabanga ukuthikungenziwa baye emtholampilo?