## Citation:

Syacumpi, M. (2015) Changing Family Roles: Coping Mechanism of Family Carers in Home Based Care in Zambia [Online]. Leeds Beckett University. Available from: <https://figshare.leedsbeckett.ac.uk/articles/thesis/Changing_Family_Roles_Coping_Mechanism_of_Family_Carers_in_Home_Based_Care_in_Zambia/21842175/1> [Accessed 9 January 2023]. - Link

## Link to Leeds Beckett University Research Data and Thesis Repository record:

10.25448/lbu.21842175.v1

## Item Type:

Thesis

## Licence:

# Changing Family Roles: Coping Mechanism of Family Carers in Home Based Care in Zambia

---

Muriel Muwaika Syacumpi

A thesis submitted in partial fulfilment of the requirements of Leeds Beckett University for the degree of Doctor of Philosophy

JANUARY 2015

## *ABSTRACT*

Home based care is one important health care strategy to provide health care services to chronically ill individuals in households away from health facilities. In the advent of the HIV/AIDS epidemic, there are an increased number of individuals affected and infected. The chronicity of the disease has exerted different form of pressure on those who may find themselves caring for the infected.

This interpretive phenomelogical study was conducted in Zambia. The study explored and described how family carers reconstructed their lived care life experiences as they dealt with them, how they coped or didn't cope with care demands. Data was generated, transcribed and translated over a period of 10 months through 16 in-depth interviews with family carers, and 10 focus group discussions (3 with Key Informants and 7 with family carers). Data was analysed using thematic analysis and NVIVO software was used to create models. The study adapted the salutogenic model and symbolic interactionism to describe the lived experiences of family carers in HBC situations.

The study findings show that family members especially women and/or girls were key in the provision of care in households. However, there may be situations where men also became involved in care work. Family carers constructed their care lives based on the confirmed identity of being caregivers whose desire to provide care was mostly based on meaningfulness attached to the relationship with the patient, and derived satisfaction from their input to the health of their patient. There were strong interlinkages between comprehensibility, manageability and meaningfulness (the Generalised Resistance Resources components of the salutogenic model) and emotional closeness in the care situations.

In the construction of their lived care experiences, one common coping factor was Godly devotions with strong relationship with spirituality and religion which was linked to the three aspects of the GRR. Other coping factors such as “training”, ‘love for the patient’, “piece work” and “patient is a relative” were mostly linked to comprehensibility. Caregivers strived to find knowledge and skills to deal with any challenging care situation, and most caregivers lacked these attributes.

However, their perceived identity as a caregiver generated and strengthened their desire to do something for the patient. In addition, self-identity as caregivers and the sense of filial piety encouraged the motivation to go on despite difficulties faced. Caregivers constructed their care lives based on the meaning the care input meant for the patient, and to those they were

confirming their identity to as caregivers. Hence meaningfulness was one key component that was observed to be high amongst all as this resource provided them with the desire to go on caring, there were weakness found in comprehensibility and manageability. There were weaknesses felt in comprehensibility as a resource to facilitate cognitive elements of care. Caregivers felt that care work was ordered but not predictable as situations and conditions related to the patient and households were dynamic. They did not have easy access to resources to support their work. Those who devised any coping mechanisms did so within the boundaries of “suffering” with care work. Their care life was viewed as difficult and subjected them to different situations in the health of the patients which they could not provide. Family carers found coping with care giving not easy to attain.

Family carers made cognisant of the care environment, which did not make available supportive structures to enhance coping with care work. As result of the breakdown of family structures especially the extended families from HIV/AIDS, most family carers experienced an environment that was not conducive to provision of care for chronically ill patients.

The findings challenge the implementation of HBC as a strategy to help chronically ill PLWHA as health care service at the household. The study suggests that the country’s recognition of HBC strategy through different policy pronouncement will require concerted efforts to ensure that those providing care in households are provided with effective and efficient support mechanisms to improve care of patients.

## *Candidate's Declaration*

I confirm that this thesis is my own work and that all published or other sources of material consulted have been acknowledged in notes to the text or the bibliography.

I can confirm that the thesis has not been submitted for a comparable academic award.

Muriel Muwaika Syacumpi

January 2015

**Acknowledgment**
In every life encounter there are key players that make the interactions related to those encounters more meaningful and make what may have seemed challenging in life become more bearable. In this journey there were many that moved with me from the beginning and continued on with resilience and motivation. Others joined and continued with me, while others fell along the way but had made invaluable contribution to my PhD journey.

I would like to thank Leeds Beckett University for opening up this opportunity for me through the centenary award for this PhD. My sincere appreciation goes to my supervisory team which comprised of Professor Rachael Dixey, Dr. Sally Hayes, and Dr. Tony Wane from Leeds Beckett University, and Dr. Mima Cattan formerly with Leeds Becket University and now with Northumbria University, Newcastle. I wish to mention that Professor Mubiana Macwa'ngi from the University Of Zambia Institute of Research and, who always found time there taking charge of the process and ensuring that I received the much needed academic guidance, encouragement and support.

Rachael though so far away in the UK, yet so near, as to me she was always visible urging me to do more and more. She was a pillar especially in situations when I thought things were getting too complicated and the journey seemed rough. Her challenging questions helped me think academically and propelled me to do more. Whenever she visited Zambia, she provided and created an academic environment during which we extensively discussed my thesis and shaping the progression of the works therefore providing for my health promotion and well-being. She made the writing process which to me looked challenging be more enjoyable.

Sally, thanks for coming in the picture when you did, my trips to the UK and your availability to work with me and review my thesis by using a special “Lens” provided me with a different understanding of how my best to approach the drafting of my thesis and move to be an academician. I enjoyed our interactions in the UK and in Zambia you were God sent.

Mima, thank you for everything as you were with me from the beginning of the whole process. Sometimes I wondered who between was the student between the two of us. Mima spent long hours working with me helping me grasp academic and be inducted in academic thinking and behaviour. This untiring support helped me go through the initial academic hurdles to the next

stage of my PhD journey. Even after leaving Leeds Beckett University, Mima continued to provide that guidance that made so much difference in the progression of my work.

I wish to thank Dr. Tony Wane, whose short lived interaction did help me view my study from a different perspective. He helped me understand that the burden of care was equally a responsibility of the elderly and not only of the young adults.

Prof Mubiana Macwan'gi was always there in every step I took in this journey for my PhD. I wish to appreciate your efforts in helping accomplish taught courses in Research Training Programme. These courses helped create my own research environment to understand the different faces of research in general and in the academic world. Her input and guidance in understanding the social science research and her guidance and encouragement on how to proceed with field work gave me the impetus to go on and on.

I wish to thank the Executive Director Mrs. Chola and her staff who gave me ideas on the environment of home based care in Chazanga compound. The team gave me support and facilitated identification of gate keepers in the communities and homes with chronically ill patients with HIV and AIDS.

Dr. Ruth Cross, Dr. Bornwell Sikateyo, Dr. Lonia Mwape, Dr. Oliver Mweemba and Dr. Rose Ndonyo Likwa for your support and guidance at different times of my struggle to understand what was expected my research journey.

I would like to thank my colleagues from my workplaces:  at Support to HIV/AIDS Response in Zambia (SHARE) and Zambia Integrated System Strengthening Programme (ZISSP) for the continued support and encouragement that kept me smiling all the time. I also say thank you to Abt Associates for funding some part of my PhD programme. Further appreciations go to my many friends and associates who had faith in my abilities.

I also say thank you to the research participants to this study. They had a special role to play as they made it possible to interact and help me learn and understand their lived experiences as they cared for their loved ones. I would like to thank Mr Bisalomo Mwanza for his untiring support as a research assistant, and also proof reading the written work.  I wish to thank Mr

Patrick Chanda, Ms Ireen Chimbwe and Mr Million Phiri for their understanding and support in special ways.

A special mention is made of the contribution made by the team at Lumia farm comprising my children: *Muluwa, Malunga, Sarah, Cecilia, Lubona* and grandchildren: *Kasonde, Domia, Bupe and Ngosa*. They always wanted to know when I will be addressed as a Doctor and asked questions why it was taking me that long. It was a long journey and we had stopped socialising and they did not like it, I love you all for your wonderful support and understanding.

Muriel Muwaika Syacumpi
(January, 2015)

Dedication: This Thesis is dedicated to my late father- Shadreck Ben Muwaika and my Mother – Elizabeth Mawini Muwaika who were both educationists and would have shared this happy moment of my PhD achievement, I miss you.

## Table of Contents

## List of Figures

## List of Tables

## List of Maps

## List of Abbreviations

| | |
|---|---|
| AIDS | Acquired Immune Deficiency Syndrome |
| ARV | Antiretrovirus |
| CBO | Community Based Organisation |
| CBOH | Central Board of Health |
| CHBC | Community/Home-based care |
| CHW | Community Health Worker |
| CSO | Central Statistics Office |
| DHMT | District Health Management Team |
| DHO | District Health Office |
| DOTS | Directly Observed Treatment System |
| FBO | Faith Based Organisation |
| FC | Family Carer |
| FGD | Focus Group Discussion |
| GRR | General Resistance Resources |
| HBC | Home Based Care |
| HC | Health Centre |
| HIV | Human Immuno Deficiency Virus |
| HMIS | Health Management Information System |
| IDI | In-depth Interview |
| IMCI | Integrated Management of Childhood Infections |
| IGA | Income Generating Activity |
| KI | Key Informant |
| MDG | Millennium Development Goals |
| MoH | Ministry of Health |
| MCDMC | Ministry of Community Development Mother and Child |
| NAC | National AIDS/TB/STI Council |
| NASF | National ADIS Strategic Framework |
| NHSP | National Health Strategic Plan |
| NGO | Non –governmental Organisation |
| OVC | Orphans and Vulnerable Children |
| PLWHA | Persons Living with HIV and AIDS |
| RA | Research Assistant |
| SI | Symbolic Interactionism |

| | |
|---|---|
| SOC | Sense of Coherence |
| SSA | Sub-Saharan Africa |
| STI | Sexually Transmitted Infections |
| TB | Tuberculosis |
| UNAIDS | United Nation Programme on HIV/AIDS |
| UNDP | United Nations Development Programme |
| UNICEF | United Nations Children Fund |
| UNZA | University of Zambia |
| VCT | Voluntary Counseling and Testing |
| VSO | Volunteer Service Organisation |
| WHO | World Health Organisation |
| SWAAZ | Society for Women against AIDS in Zambia |
| PMCTC | Prevention of Mother- to- Child Transmission |
| SOC | Sense of Coherence |
| ZSBS | Zambia Sexual and Behaviour Survey |
| ZDHS | Zambia Health Demographic Survey |

# CHAPTER ONE: Introduction and Overview of the Thesis

## Introduction

In this chapter the background of the study is discussed, and why it was undertaken, briefly highlighting home based care in the Zambian context as it relates to caring for chronically ill patients from the HIV/AIDS. I further introduce the family carer involved in providing care for chronically ill AIDS patients.

*The Post of Wednesday October 2, 2013, one of the daily newspaper in Zambia reported the Deputy Minister in the Ministry of Community Development Mother and Child Health (Hon. Jean Kapata) as having said that "caregiving though time consuming had been deemed a free resource that did not attract benefits to the providers of such services, adding that it was largely considered as a role to be undertaken by women and girls". Katebe Beauty of Zambia National Women's Lobby Chairperson said that "the sacrifice by women and children of taking care of the sick had gone untold and did not have any impact on socio-economic development of the country". She added that once the care giver policy was adopted in Zambia, there would be increased school attendance by the children who are usually left to care for the sick. Baroness Jay urged the government to adopt a new health policy that would help volunteer care givers for people living with illness and reduce the burden of care on women and girls in communities across the nation*

Quote from one of the Zambia daily newspaper: The Post News Paper, October 2, 2013

The Government of the Republic of Zambia has formulated a number of health related policies and guidelines aimed at fulfilling the vision "A Nation of Healthy Productive People". Strategies were developed to guide the implementation of health care provision and for giving direction on how to improve health care services. The National HIV and AIDS/STI/TB Policy (2005) were formulated and the National HIV/AIDS Strategic Framework (2011-2015) is reviewed annually to provide policy direction in addressing the HIV/AIDS pandemic. Research findings in a study on scaling up HIV/AIDS prevention, treatment, care and support in community and home based care programmes by Reducing the burden of HIV/AIDS Care on women, girls and older carers in Southern Africa Development Communities(SADC) revealed that, although policies and guidelines and standards exist they “had not been translated into language that could be understood by care providers and that Care providers are not adequately involved in the formulation and review of policies and hence do not sufficiently address their needs and rights” (Isaacs. Mundeta and Masunda, 2010, p 11).

This research was undertaken to explore and provide an understanding of the implementation of home based care services in households. The study sought to provide information on how those involved in providing that care addressed issues related to caring for chronically ill patients with HIV/AIDS.,

The study sought to answer specific questions aimed at facilitating this understanding whilst examining the care environment and the family carers’ perception of caring for chronically ill AIDS patients.

The main research questions I ask in this study is: What psychosocial factors are associated with coping mechanisms devised by Family Carers(FC) to address the needs of family members and the wider family who are chronically ill with HIV/AIDS? And the sub questions derived from the main research question include:

1. What challenges do Family Carers face or report in the course of providing care to chronically ill family members with HIV/AIDS?
2. What are the key psychosocial factors that contribute to coping (or not coping) with caring roles for chronically ill family members with HIV/AIDS?
3. How does resiliency play a role in Family Carer’s ability to care for family members who are chronically ill with HIV/AIDS?
4. What role do filial norms play in structuring the coping process of family carers of chronically ill family members?

The aim of this study is to identify and analyse key attributes of coping mechanisms of family carers who are coping (or failing to cope) with caring functions. The study will therefore develop, disseminate and share models/theories of coping that are devised by family carers of chronically ill family members with HIV/AIDS in HBC settings. And will further inform the policy formulation process to guide the establishment of support structure for HBC programmes.

## Outline of the Thesis

This thesis is organised in ten chapters.

Chapter one provides and discusses the basic information related to the study, gives an overview of the thesis, and sets the scene that describes the underlying factors and the reasons that led to the undertaking of this study. I have included an introduction to the key concepts that form the basis of the study, and the structure of thesis

Chapter two discusses the HIV/AIDS pandemic and tries to give detailed account of different social and psychological factors associated with the disease and more especially how care for patients with HIV/AIDS evolved into home based care (HBC) which is the main focus of this study.

Chapter three provides a comprehensive discourse on caring as a key concept in the provision of HBC in light of HIV/AIDS and other factors that may affect the outcome of caring functions in the households.

Chapter four gives an account of the two main theories of symbolic interactionism and the salutogenic models that provides explanation of Salutogenic model, highlighting the Sense of Coherence (SOC) and Generalised Resistance Resources (GRR) as key operational factors in understanding how FCs construct their lived care experiences and cope with care work in the households. Further how Symbolic Interactionism (SI) provides meaning to the behaviour of FCs and how the two theories are adapted in the theoretical framework to explain this behaviour.

Chapter five, which outlines the theoretical framework, is structured to provide a guide for describing the discussions related to this research. It provides key concepts in caring and coping, how they are interlinked and relate to each other and how they influence coping mechanisms at the household level.

Chapter six describes the methodology and study design and the rationale to the study process. The chapter further provides detailed information of the study site and characteristics of the study population. The methods of data generation, and procedures followed during the study are also described, including data validity and reliability. The limitations of the study, data management and data analysis procedures are also provided to assist the reader to understand the different processes that were followed as a way of ensuring that the study results provided key information that add value to the body of knowledge this study aims to contribute. Ethical considerations guiding the process are also described in detail.

Chapters seven presents findings which include details of demographic information and profile of FC and patients and of the activities in the locality being implemented. They also set the ground to understand the environment within which HBC activities are implemented. I present the general characteristics of households and the environment within which the patient is being cared for and how they access to social amenities that facilitate the provision of care.

Chapter eight presents findings of information pertaining to care work, general preparedness of family carers for care functions, and their feelings about care work or functions are discussed. Family Carer's stand in the midst of the effects and impact of HIV/AIDS in households, the type of challenges faced during care work, the perceived source of challenges and how they cope with those challenges. The chapter also describes the attributes the FCs possess that make it easy or difficult to provide care to patients and how such attributes contribute to coping mechanisms. Finally provides information on the kind of needed resources, perceived source or resources and also gives a short brief on organisations involved in provision of Home Based Care services in the study area.

*C*hapter nine summarises the main findings and therefore provides a detailed discussion of the study results, and draw on the results to adapt into Antonovsky's Salutogenic model of SOC and GRR in coping with care functions and symbolic interactionism to understand the behaviour and language associated with caring. It is therefore divided into four interrelated sections dealing with (a) Empowerment of caregivers to manage care work (b) The Role of Self-Esteem as a coping tool, (c) Filial Obligation as a factor in coping mechanism, (d) Spirituality and Faith as a coping tool and (e) the role of Social support in care work. The chapter further brings to light the different theories of coping based on the salutogenic model that relate to family carers in the day-to-day care of chronically ill HIV/AIDS patients.

Chapter Ten presents the study conclusion and recommendations. It describes the various limitations associated with the study and how some of those limitations were addressed. I also make recognition of different opportunities for further research to increase on the body of knowledge. It further provides a summary of the main findings and draws recommendations for future action from the findings drawn from this thesis.

In the context of Zambian and other countries especially as this relates to caring for patients with HIV/AIDS. It describes the context within which care for chronically ill patients with HIV/AIDS is discussed and introduces the concept of coping in the care situation in the household. The chapter further demonstrates the care situations of those who provide care in households.

## Overview of the Study

This is an exploratory study focusing on care and coping mechanisms devised by Family Carers in HBC settings. HBC for patients with HIV/AIDS is one of the care strategies that were slowly introduced in Zambia, as in other Southern African countries, to cater for those many patients with HIV/AIDS who were at the time being discharged to be cared for by family members at home. The HIV/ AIDS epidemic in Zambia continues to be one of the major health problems and was declared a national emergency requiring a multisectoral and a decentralized response (NAC, 2010). The high numbers of patients being discharged from the hospital in some cases, it can be argued, occurring before the family was ready for care functions, meant that someone in a home had to assume the responsibility of providing that care. In this study the carers at household level are referred to as FCs who may also be referred to as Caregivers (I will give a detailed discussion on FCs later in this thesis). In view of the roles and the various tasks that FCs may be expected to carry out and the challenging situations in care work, the study hence explores evidence related to how caregivers act and cope in HIV/AIDS HBC situations. Further, the study serves as an orientation into the coping mechanisms of Family carers, whilst also trying to understand factors within the individuals and the community that govern different responses of caregivers to care situations.

The study therefore, explores the different experiences of caregivers, especially those factors that guide their interrelationships with the patient being cared for, the interplay with the external factors in the environment within which the family carers have to provide care, and which in most situations they have no control over as they provide care to their patient. In essence, the study focuses on the way caregivers understand the environment around them, how they make sense of care situations and events they find themselves in and taking appropriate action to meet these challenges.

The ability of the caregiver to respond or react to the confronting care situations in the care environment or the lack of this ability remains the main focus of this study. The often unique and different situations in which care is provided to HIV/ AIDS patients and other chronically ill patients, and the way different cultures of care in such situations is hence discussed at length. The study also looks at the caregiver’s ability to recognise, understand and source different physical, social, psychological and other resources appropriate to addressing the challenges of care.

By adapting Antonovsky's Salutogenesis model, (1987, 1979) the study explores and sets the scene on how care is actualized by FCs. The model sets the parameters for describing and understanding the care environment at the community level. This model further underpins specific behaviour of family carers as a framework to analyse the specific realities in caring for chronically ill patients with AIDS.

Antonovsky's SOC (1987) is a measure describing the ability of how an individual is able to deal with a confronting situation which can have positive or negative effect on the individual (details of the salutogenic model are described in chapter 3). In this context therefore, the individual is managing situations they encounter or they are trying to make sense of their world.

SOC according to the Salutogenic model is a state of being said to protect people from stress by virtue of their feelings that life events are challenges that occur for a reason (Antonovsky, 1979; 1987; Forsberg-Warleby et al., 2002; Feldt et al., 2005), and that SOC is based on an individual's life experiences grounded in their ontological being. Further, SOC is believed to have its origin in the individual's socio-cultural background which is a determinant of the construct of his/her internal and external general resilience that could be a force in addressing care issues (Antonovsky, 1979; 1987;Forsberg-Warleby et al., 2002; Feldt et al., 2005). Cultural factors are therefore contructions that make caring an active engagement of a Caregiver meeting the needs of the patient. However, Lazarus and Folkman (1984) also acknowledge Antonovsky's work as it emphasises the integration and union of the self and the world. This is the environment within which a family carer has to interact on a day-today basis.

A caregiver may for example believe in the active role of caring when they understand and value what they are doing for the patient and may subsequently view this engagement as a meaningful contribution to the welfare of the patient. The engagement between the FC and the patient would possibly result in appreciation of the care by the patient, other relatives and give meaning and hope to the patient. Further, this engagement may also provide meaning to the family carer who may derive some form of social and mental satisfaction in what they may be doing for the patient.

The study therefore, provides a unique opportunity to investigate the understanding of how the culture of care giving at the household level is, contextualised, conceptualized, and managed by FCs by applying the Salutogenic model to describe and examine coping mechanisms during the management of care functions at the household level.

### Social significance of the study to Zambia

I do recall that during a two week stay in hospital, nursing my relative as a "bedside" helper, at no time did any nurse come to find out or help me understand what was going on with my patient. What I did not also understand or maybe I was too quick to make judgment of the attitude of nurses, was maybe because I was a senior nurse and taking care of a patient who was HIV positive. I did not understand the observed behavior, and I may have felt I was being stigmatised, though I will never know but can only speculate.

I always waited for the Doctor in charge of my patient for detailed information. I constantly had rather worrying thoughts especially for those who were not nurses but "bedsiders" helping their patients. Upon discharge from the hospital, I was to buy expensive drugs to inject my patient for a three-week period. But no nurse approached me or assessed my ability to provide that procedure at home.

This experience led me to question the experiences of carers and the support received in order to provide an account of the social significance of such support (provision or absence) and associated implications for Zambia. Given the estimated HIV prevalence of 14.3% in the age group 15 – 49 in Zambia is one of the highest in the Sub-Saharan region (MOH 2005; NAC 2006, 2010), very little effort has been directed at addressing issues impacting on households and communities caring for AIDS patients in Zambia (UNDP 2007).

Empirical studies show that when a patient is discharged from hospital more often than not someone within the family or from the community will take on the responsibility of providing care for them (Ogden et.al., 2004; Akintola, 2006, 2008, 2010; UNAIDS, 2008; Andersen, 2012). These families or community members however may not be prepared to assume the caring role personally but will nonetheless initiate care in homes. The study of coping mechanisms of family carers in HBC is therefore an important focus of research in Zambia, and such a study has not been undertaken before. The study has the potential of building on studies that have looked at coping in caring for HIV/AIDS patients in HBC, and at the situation of FCs in environments where resources are inadequate to meet the needs of carers, patients, communities and the health care delivery system. Studies on HBC have not been adequately linked to other services in communities (Isaacs, Mundeta and Masunda, 2010; Mwewa et al., 2013). If coping mechanisms by family carers are found to be related to a strong ability to deal with adverse situation and social factors' influence in coping, HBC support organisations and the government sector can use the information to plan and manage the support structure of HBC activities.

The findings on coping mechanisms will bring to the HBC programme in Zambia new knowledge that will ultimately bring understanding on how family carers deal with internal and external factors affecting care. The study will work towards providing information that may subsequently help address HBC programme intervention issues that may support HBC operational systems and structures that may enhance care functions at household level.

### Introducing Family Carers in caring for chronically ill patients

The paradigm shift in care for chronically ill patients from hospitals to homes in Zambia has created a category of carers mostly referred to as "Family Carers". In this study "Family carers" will be used and "Caregiver" is also used interchangeably in other documents as the titles referring to those caring for patients in the homes. The term "Family carers" is used in the context of those family members and volunteers in communities taking care of chronically ill patients. Studies have observed that in most cases FCs are not trained and are non- medical, while some FCs do receive some orientation to the basics of health care in the homes ( Akintola 2008, 2013;  Chaava, 2005).  In addition becoming a caregiver is not a decision family members make, it is just a role they simply take on because of an illness within the family (Knodel 2010; Esu-William et al., 2006)

Some family members feel they could not conceive of another approach of caring for their terminally or chronically ill family member (Ogden et al., 2004; Cheung and Hocking 2004). It is further observed that family members who are carers provide the bulk of care, and for the vast majority of AIDS affected families, these caregivers are not linked to, nor adequately supported by formal HIV/AIDS programmes (Nsutebu et al., 2001;

Ogden et al., 2004; MoH 2005; Esu-Williams et al., 2006), while in remote areas health care services are mostly inaccessible to HIV infected persons (Andersen, 2012).

Family carers according to Akintola (2008) play a major role in providing home care to people living with HIV/AIDS the world over and especially in the SSA. These caregivers are mostly family members providing care to siblings, parents, spouses, and this care is outside the formal health care setting, and in most cases not remunerated (Akintola, 2006). Another emerging group is those providing cares to orphans of HIV/AIDS are grandparents. The caregiving burden of orphans by grandparents is increasing. Zambia, has the second highest number of orphans and vulnerable children (OVC) in Africa (NAC, 2010). Zambian records show that an estimated 1.3 million orphans were as a result of the HIV/AIDS epidemic. The reports further show that the elderly and in particular women were providing care to OVC and PLHIV. The epidemic has resulted in social and financial stress on the elderly and caregiver of vulnerable households and has deepened poverty levels (NAC 2010). The burden of care has therefore contributed to a diminished capacity of care givers to cope with care work. Female-headed households are disproportionately affected and least likely to be able to economically sustain orphans.

Orner (2006) observed that FCs experience a range of demands from clients (like need for good nutrition, water and sanitation, medications, counseling and other needs), but with no competencies to address them (also Olenja, 1999; Held and Brann, 2007). Caregivers are often distressed with social, emotional, physical, economical and spiritual demands of care functions and that of the fear of contracting HIV/AIDs. Fears expressed by some FCs include being stigmatised when seen interacting with people living with HIV/AIDS (PLWHA) (Demmer, 2006,). Caring for anyone with chronic illness can be a physical and emotional challenge for even the most dedicated carers. Caregivers take on the caring role for their relatives in homes mostly because they have little alternative.

However, in view of the observed burden of care of AIDS patients on households, there is need to explore how HBC activities may be impacting on caregivers' quest to provide care for the chronically ill AIDS patients. This study explores the different coping mechanisms of FCs, especially where government support may be inadequate or lacking, where caregivers are not compensated for services provided or where no structure exists to provide meaningful support to care services. The lack of studies on how HBC programming affects the provision of HBC services and how those providing services, cope with the burden and dictates of caring functions, what makes them continue caring for patients, suggests the need for this study.

A study of this nature will provide empirical data that can be used to improve support for family carers, thereby improving health and socio-economic outcomes for volunteers, family caregivers and their patients (Akintola, 2008). The study has the potential of building upon already existing data as it relates to how individuals found in difficult situations or adverse conditions are able to cope or not cope. The study objective is to provide impetus for social policy interventions that provide opportunities for supporting HBC development. This includes helping to address the mental health needs of carers.

## Statement of the problem

The effect of the HIV/AIDS pandemic in Zambia continues to impact negatively on the socio-economic situation of the population. This has resulted in the breakdown of family social structures, social service delivery, and reduction in household incomes (NAC 2006, 2010.). The prevalence rates are higher (20%) in urban areas  and lower (10%) in rural areas  with women (18%) being more vulnerable than men (13%) whilst prevalence among males (12.3%) and females (16.1%) and it has been estimated that at least one in five in the general population is HIV positive (MoH 2005; ZDHS 2007; NAC, 2010; MOH, 2013).

The increase in morbidity and mortality rates related to HIV/AIDS is altering the Zambian population structure and the functioning of the productive sectors by limiting both productivity and the supply of services National AIDS Council (NAC 2006). Approximately 80,000 Zambians are infected with HIV every year, 535,828   clients on antiretroviral treatment in 2011 and Prevention of Mother to Child Transmission (PMTCT) services have also reached 80,607 clients in Zambia (MOH, 2013).

The following factors were highlighted as the main drivers of the epidemic: Multiple and concurrent partners, inconsistent use of the condom, low rates of male circumcision, mobility and labour migration vulnerability especially poverty situations in most households (MOH, 2013). Households have been the hardest hit by this epidemic especially as heads of households are being affected, thereby affecting household incomes (UNDP 2007). The health care system has also been adversely affected by pressures related to HIV/AIDS morbidity and mortality (UNDP 2007; Kiragu et al., 2007;

NAC 2006, 2010). At the same time, hospital and health care workers are also dying and are overtaxed by the epidemic in their own personal capacities (Kiragu et al., 2007; Chaava 2005). The HIV/AIDS pandemic has therefore placed a heavy strain on the health care services arising from high numbers of chronically ill patients with AIDS. The high demand for hospitalisation by AIDS patients and the chronic nature of the disease, and the high staff attrition, have resulted in more patients being discharged home to be cared for by family members (Ncama, 2005).

Zambia recognises the important role played by HBC in meeting the needs of patients with AIDS and other chronic illnesses, and has strengthened the treatment, care and support services to address HBC (NAC 2006). Despite this recognition, the HBC activities are inadequately being implemented (Ncama, 2005; Ministry of Health, 2006; NAC, 2005/6, Mwewa et al., 2013). HBC, as part of the treatment, care and support for HIV/AIDS patients, is one of the main strategies adopted by the Zambian government to address the needs of such patients. The HBC strategy was established though mostly by Non-governmental organisations (NGO) and Faith based organisations (FBO) to provide for the physical, psychological and social needs of FCs and their patients. The expected care to patients may be overwhelming especially where the HBC support structure is not well defined (this is discussed in detail later in the thesis). However, despite a not so well defined support structure, HBC caregivers are expected to provide nursing and counselling services to their clients.

There is evidence in Zambia that institutional support, where deliberate efforts are made by institutions to provide for carers in HBC from the public or other private institutions, was not reaching many caregivers (MOH, 2005, 2010). However, efforts are being made to reach more chronically ill patients (NAC 2010), however there is no data showing the number of vulnerable households receiving a free basic external support, although related report state that some households were receiving some form of support from mostly FBOs (NAC 2010)

While some strides are being made in policy and programming around HIV/AIDS-related care, much more needs to be known and done to enable individuals, families and households to survive in a world shaken by AIDS (Ogden et al., 2004). It is further argued that HBC can be a strategy of downloading responsibility for care on to women, families and communities, which now can no longer be a viable, appropriate or sustainable response (Ogden et al., 2004; Orner 2006; Omaswa, 2006).

Although research exists on how family carers in homes cope with providing care for the chronically ill patient there is no specific emphasis on how the mental health aspect of the carer is addressed. This is more so for Zambia where no specific research has been conducted to document how carers in homes utilise different resources to meet their physical, social and psychological needs and those of patients.  In addition there is inadequate empirical evidence that addresses how FCs in Zambia deal with the environment within which they are expected to provide care. It is therefore important to explore the physical and mental factors that facilitate provision of care and how these factors are harnessed in making appropriate care choices and managing care functions.

Given the situation described above, the purpose of the study is to explore how those providing HBC services cope with the burden and dictates of caring functions. It will consider ideas that condense and organise knowledge on coping in care situations of chronically ill patients of HIV/AIDS in HBC situations, and as such will serve as an orientation into the coping mechanisms of home based carers. In this study I endeavour to provide a descriptive account of coping mechanisms as FCs meet the needs of their chronically ill AIDS patients in home based care settings. I therefore emphasize that the study explores the different experiences of caregivers as they interact with the internal and external environment in care functions. I also focus on the way caregivers understand the environment around them, believing that they can make sense out of care situations and events they find themselves in and taking appropriate action to meet these challenges.

## Conclusion

In this chapter I was able to set the scene of the context within which this study was conceptualised. The chapter provided a guide on the statement of the problem, an understanding of whom the family carer was the general overview and the outline of the thesis. In the next three chapters I have provided empirical data related to the study.

## CHAPTER TWO: The HIV /AIDS Situation and Home base Care Services in Zambia

### Introduction

This chapter describes the situation of HIV/AIDS from the global, regional as in the case of Sub-Saharan Africa and finally the Zambian perspective. It provides related information that puts HBC in the context of HIV/AIDS, as HBC environment forms the main focus of my thesis. Different search strategies in locating both published and unpublished studies were performed and also used the most cited journal articles, the following database were used to locating articles: BioMed, PubMed using key words like Home based care, HIV/AIDS, Zambia, Sub-Sahara Africa.

### The HIV/AIDS epidemic

The AIDS pandemic has had its devastating effects on the general population the world over and has continued to take its toll on families and communities worldwide. UNAIDS ( yearly reports) has reported that the epidemic has continued to be one of the most destructive health crises of modern times, ravaging families and communities throughout the world and that globally there about 35.3 million people were living with HIV by the end of 2012. However, the UNAIDS report (2013) show positive progress in addressing HIV epidemic globally. There was a downward trend of new infection at 2.3 million in 2012 from 3.4 million in 2001, with deaths declining from 2.3 million in 2005 to 1.6 million in 2012.

AIDS has been ranked fourth among the leading causes of death worldwide and first in SSA (Isaacs, Mundeta and Masunda, 2010; Ashford, 2006; Manchester and Barnes, 2000). Sub-Saharan Africa (SSA) has experienced the worst effects of the pandemic in most developmental areas like education, economic growth, health, agriculture, as the most affected are the productive age groups (UNAIDS, 2008; Akintola, 2004). Costs of running industries have risen as more and more individuals seek medical attention, stay away from work for longer periods, hospitals admit more patients with the virus, and the cost of treating those that are sick being higher than budgets would allow (Akintola, 2008; Isaacs, Mundeta and Masunda, 2010)

The chronic nature of the disease therefore is meant that caring should aim at enabling the sick to live their lives fully and as rewardingly as possible (Guyer, 2008). It then becomes imperative and a necessity for the caregivers to adequately provide for needs of the patient including adequate nutrition, cash incomes and psycho-social support (Aantjes et al., 2014). Due to poverty levels that usually are associated with protracted caring roles for the chronically ill, households are known to have developed situational related actions and decide to sell off some property/assets in order to meet financial obligations to address the different needs of the patient (Knodel, 2008; Knodel et al., 2009, Knodel and Im-Em, 2004). Care giving has been observed to inflict undue hardships on already strained households who may easily slide into poverty (Akintola, 2004, 2013; Lindsey et al., 2003) Research carried out in SSA region has shown that the care environment in the era of HIV/AIDS has sometimes not been favourable to enhance care work. For example, women have talked of lack of health and welfare support, poverty, family conflicts, and relationship difficulties, including societal expectations on filial obligation to provide social support (Burgess and Campbell, 2014) poor infection prevention facilities ( Akintola et al ., 2014), there has been breakdown of extended family structures with less social support to those in need and stigma against those connected to PLWA( Akintola et al., 2014; Cheng and Siankam, 2009; Aidoo and Harpham, 2001) with care work continuing to be exploitative in nature( Thabethe, 2011) and leading to loneliness, isolation and luck of social support for those who do not want others to know about the HIV in the household(Singh et al., 2011).

Zambia is one country in SSA that has been hardest hit by the HIV epidemic. The most common mode of transmission in Zambia is through heterosexual sex and mother-to-child transmission, with rates being higher in urban areas than rural. The Zambia situation registers at least one in every six persons were infected, with some cultural practices being associated with the spread of HIV. According to the NHSF: 2011-2015, resources for Zambia health services had continued to be poor more especially in form of resources to manage health facilities for the purpose of meeting the nation vision of “equity of access to cost effective and quality of health services as close to the family as possible”. Partners have therefore “continued to significantly contribute to the health sector development through leveraging financial, technical, material and logistical support” MOH (NHSF 2011-2015 p.9). The framework also recognises the contribution of the household in this scenario, and that households form the top three financiers of health care. However, Guyer (2008) observed that HIV/AIDS does put significant stress on individuals, families, communities and nations regardless of where they are located, with the grassroots being made poorer, as the effects of the pandemic continue to have its devastating toll. Large numbers of such communities therefore continue to be affected by poverty as the meager resources to sustain them are in most situations used on meeting the medical bills or other related costs of medical care of their patient who then becomes chronically ill. As the WHO (2000) observed, “the aim of such care is not simply to look after the sick but to enable those with long-term illness or disabilities to live their lives as fully and as rewardingly as possible” (Guyer, 2008, p.1). The current poor infrastructure currently existing in Zambia provides a “not so attractive but may be viewed as hostile” environment to assist families and communities meet the needs of their patients in households. This environment may be viewed as “hostile” to provision of quality care as observed by other empirical studies (also Akintola et al., 2013; Singh et al 2011; Fox, 2010; Thabethe, 2011; Opiyo et al., 2008). Only 50% in rural areas in Zambia have a health centre within 5Km radius, whereas 90% in urban areas live within 5Km radius of a health centre. The situation has been compounded with capacity constraints, which include inadequate and inequitable distribution of human resources for health services (MOH –NHSF 2011-2015). The current doctor and nurse ratios stand at 1 to 15,000 and 1 to 5,000 respectively which are far short of WHO recommendation of 1 to 5,000 for doctors and 1 to 700 for nurses (Makasa, 2008).

Zambia has seen a growing number of people living with HIV/AIDS as observed from the data above. Care and support for patients afflicted with AIDS becomes a need for those requiring protracted care demands. The introduction of ART in 2005 (Musheke et al., 2013) and subsequent free roll out in 2006 (Patterson, 2010) has made the disease chronic in nature as clients are living longer and hence families and communities are now being required to care for AIDS patients much longer than the time when they died much earlier (Esu-William et al., 2006; Akintola, 2008). Although the individuals with HIV/AIDS on ART were living longer, they also generate a new development, in that periods of PLWHA being exposed to opportunistic infections has become longer. This situation therefore requires that family members continue to take care of the individuals during times of poor health (Mwewa, et al., 2013) we should note that despite the availability of ART in Zambia only 68.4% are accessing (Musheke et al., 2013) the majority of patients in need of ART especially those in rural areas are unable to access

ART services (Chiwele and Syampungani 2011; MOH 2010. NHSP 2011-2015) as most ART services are found mainly in urban areas with trained staff to provide specialized related services. Sites providing ART services have increased from 355 in 2009 to 564 in 2012 and 580, 118 children and adult receiving ART (MOH/NAC, 2013).

Although Zambia has recorded some positive results in treatment of individuals with HIV/AIDS, as over 580,118 adults and children were receiving treatment NAC/MOH Revised National AIDS Strategic Framework (RNASF) 2014 -2016, the fight is far from being won.  1.6 of adult population become newly infected each year however, this has reduced 0.8% in 2012.

Zambia report states that although the figures for new infections appear to show some downward trend, programmatically it also becomes a major area of focus to reduce the number of new individuals being infected. The prevalence rate continues to be high (although this showed marginal reduction from 16% to 14.3% - with females at 16.1% and males 12.3%) ZDHS 2007; MOH/NAC 2013) and consequently has a number of implications at household level, more especially that people with AIDS are living longer (NAC 2010), and there is a financial cost associated with longevity for those caring for the sick relatives.

Treatment for HIV/AIDS, therefore continue to be out of reach of the many Zambians requiring the service. There are more services addressing pregnant mothers and children with HIV/AIDS, but the reach remain a major concern for the government. The diversity in the care and support needs of individuals with symptomatic HIV infection vary according to factors including stage of illness and availability of services. As disease progresses and physical capacity diminishes, individuals require increased assistance with domestic chores (e.g. cooking, laundry, fetching water and firewood) and personal tasks e.g. bathing, (Esu-William et al., 2006, Akintola, 2008; Mwewa et al., 2013).

It was important to make recognition of the fact that HIV/AIDS was interlinked with poverty, socio-economic inequalities between men and women and long standing cultural behaviour and beliefs (Thabethe, 2011; Opiyo et al., 2008). These factors have consequently resulted in situations that lead to households being overwhelmed with caring needs and not having adequate preparations to assume the roles.

## The effects of HIV/AIDS on the population in Zambia

The effects of HIV/AIDS continue to be evidenced by the number of orphans, child headed households, and households headed by widows (Macwan'gi et al., 1994: Society for Women and AIDS 2007; NAC 2010)  Further, such families also experience poor livelihood, widespread malnutrition as bread winners are affected more with the HIV/AIDS. Chiwele and Syampungani (2011) and UNDP (2013) acknowledge in the Millennium Development Goal progress reports that challenges such as distances to health facilities and cost of transport that make it difficult for families to move their patients to the nearest health facility for medical attention (Fox et al., 2010: Aantjes et al., 2014). Poor nutrition status of household affects the initiation of ART as people express concern and fear of taking ARV when they do not have enough food (Fox et al., 2010). Others have doubted the potency of ARVs when they have not taken food (Musheke et al., 2013).

There are many countries today coming up with strategies to mitigate the impact of the HIV/AIDS epidemic on their population. In the wake of the AIDS pandemic lies a growing burden of caring for the sick, the dying, and those left behind (UNAIDS, 2006; Ashford, 2006). This is more so for resource poor countries where medical facilities are not able to cope with the number of chronically ill patients. Zambia is one of these countries where the pandemic has left medical facilities overstretched and is one of the Sub-Saharan African countries worst affected by HIV/AIDS (Nsutebu et al., 2001; MoH, 2005; Bengtsson and Bengtsson, 2005).

As HIV infection rates rise, the burden of care on hospitals also increases. Evidence shows that increasing number of hospital beds in Central and Southern Africa (Zambia, Kenya, Swaziland, South Africa and Uganda in particular) were occupied by people suffering from HIV/AIDS related illnesses and that hospitals cannot cope with these numbers (Akintola, 2006; 2008; Thabethe, 2011; Opiyo et al., 2008; Lindsey at al., 2003; Nsutebu et al., 2001; AIDS Action/Health link Worldwide, 2000; PANOS, 1996; AVERT nd,).  With the increasing numbers of HIV/AIDS patients, there is arguably a failure of the hospitals to cope with the number of patients (Isaacs, Mundeta and Masunda, 2010; Akintola, 2008; 2004). The onus is therefore on households to care for chronically ill patients (Homan et al., 2005). It would therefore suffice to say that as more AIDS patients are discharged from the hospital the more families are tasked to care for the chronically ill. Families therefore have to cope with the needs of the patients and those of the carers. It has also been observed that as the epidemic matures the strain on those caring for people with HIV/ AIDS in homes is high (UNAIDS, 2008).

Despite the numbers of patients with HIV/AIDS increasing the world over, families do not openly talk about HIV/AIDS health related situation in their homes and hence hide the fact when one of the close family members is afflicted for fear of being stigmatised and discriminated against (Fox et al., 2010; Klemz et al., 2014; Akintola et al., 2013; Mieh et al., 2013). Although there is now high level of general awareness of HIV/AIDS, stigma and discrimination continue to be causal factors discouraging families coming to openly talk about HIV/AIDS in their households. This fact has contributed to lower numbers of people for example in Zambia, who know their HIV status (in 2008 was 511, 266 with an upward trend to 1,772.043 in 2011(NAC 2012) against the projected population of age 15 and older, in 2010 was 7,326,449 million.

### Home Based Care an apparent answer for chronically ill HIV/AIDS patients

*"Home-based care is taking us back to the root of human coexistence. It*
*reminds us that we all have the responsibility to one another. If we hold*
*hands through this tragedy ... we will be able to retain our humanity and will*
*come out of this epidemic as a stronger community."*
*Joy Phumaphi, Minister of Health, Botswana* **(WHO 2002: p 8)**

Home Based care(HBC) services involving FC who are the carers at household level are more and more becoming an option to hospital care and considered valuable to PLWHA as the patient is discharged from public health facilities to the households (PANOS, 1996; Held and Bran, 2007; Nsutebu et al., 2001; Akintola, 2008, 2010). The major underlying factor of HBC being an option in the care of those suffering from AIDS has been the failure of health institutions to cope with the increased numbers of patients, poor staffing levels, and medical, social and psychological needs of PLWHA in health facilities (Esu-Williams, et al., 2006; Ncama, 2005; Lindsey, et al, 2003; Akintola, 2010). However, Guyer (2008) observes that although HBC was recognised as a strategy to address the chronic nature of the disease, very little attention had been paid to supporting HBC services. He further notes that a search for peer reviewed articles on phrases "home-based care" and "HIV/AIDS" yielded only 46 articles from PubMed and

98 from Web of Science, but with more documentation on contributions made by non-governmental organisation (NGO) supported programs (Guyer, 2008)

### Models of Community/Home-based care

HIV is now a chronic disease as a result of the availability of ART and PLWA are exposed to HIV longer. The chronic nature of the disease has resulted in an emergence of different models of HBC service provision in most parts of SSA The nature of models are mostly based on who was initiating the programme (Ncama 2005). Schneider and Russell (2000) had earlier made observations of models being implemented by different organisations in SSA. The formal models of caregiving initiated and implemented mostly by recognised structures and informal care models provided by unpaid family members.

Formal HBC are classified into service models and include home visiting during which volunteers participate in meeting different social, physical and psychological need of the patient (Russell and Schneider, 2000). They also identified a comprehensive HBC model providing some degree of palliative care, this model is associated mostly with NGOs and is sometimes referred to as hospice care (Ncama 2005). Hospice care services are found in most countries in SSA and managed mainly by FBOs (anecdotal evidence).

Structural model (Formal) of HBC is specialized/private and integrated. They are linked to health care system and have a mix of providers who can be volunteers or remunerated, trained employees (Ncama, 2005). Singh et al., (2011) report that the integrated models in South Africa provide continuum of care with emphasis on palliative care whilst, the isolated models are mostly initiated by NGOs and reported not to have a formal referral system and not linked to a formal health care system, home visiting is their major way of linking with patients (Ncama, 2005). All these models of HBC are tailored to the needs of the patient and not the care provider as observed by Thabethe, (2011). In addition to services mentioned above, the comprehensive model in Malawi has included care of orphans, income generating activities (IGA) and social support (Ncama, 2005). According to Campbelle and Foulis (2004) the comprehensive model in South Africa was administered by professional trained staff, who educated family members on palliative care and linking families to referral networks of health facilities and welfare. Swaziland and Lesotho have gone further by formalizing HBC care provision as salaried job (Guyer, 2008)

It is further argued that despite these efforts in reaching more households with care and support, there are empirical literatures revealing the different conditions caregivers find themselves in.  For example, some of the sick and their caregivers in South Africa continue to hide the HIV status for fear of being stigmatised and discriminated and the secrecy leading to social isolation and subsequent lack of support (Mieh et al., 2013; Akintola et al., 2013; Singh et al., 2011; Klemz et al., 2010). While in Zambia those with HIV have failed to initiate treatment as a result of fear of being stigmatised (Fox et al., 2010). Thabethe (2011) observed that despite all the efforts in HBC services, models of care in South Africa focused mainly on the needs of PLWHA, whilst the needs of caregivers were ignored. This scenario can also be true of the Zambian situation (anecdotal evidence).

Zambia was one of the first country in SSA to initiate HBC services through the Chikankata HBC programme, and was one of the famous HBC programme in Africa (Nsutebu et al., 2001) The initial programme was based on hospital- led home visiting by a mobile medical health teams (Mwewa et al., 2013; Chaava, 2005, Nsutebu et al., 2001), which later proved to be costly and had to be suspended however, they continued with volunteer caregivers (Aantjes et al., 2014)..  During the home visits, the team provided services ranging from treatment of minor conditions, counselling and support, education on HIV and general hygiene, infection prevention. The Zambia HBC services continue to be implemented by NGO, FBOs and CBOs through hospices and volunteer caregiving (Pattersen, 2010; NAC 2008), whilst the government has supposedly assumed the coordination role and provision of oversight.

When resources were available the HBC programmes in Zambia, caregivers / HBC teams also distributed food (and personal communication with programme officer, Chikankata hospital 2009). Zambia has implemented both formal and informal models of HBC services (personal communication with programme manager HBC/NGO Lusaka, October 2010).

Despite the many improvements in the provision of HBC services in Zambia, the programme continues to face challenges for both caregivers and their clients. The Zambian government has for long recognised the value of HBC as key to community based services (Mwewa, et al., 2013 ) the HBC policy document that is expected to guide and regulate organisation implementing HBC activities is still in draft form. This has resulted in poor coordination and harmonisation of CHBC activities (Mwewa et al., 2013). The previous supports for caregivers in form of HBC Kits (containing basic essentials) to support caregiver were externally supported and have since stopped (personal communication, programme manager, Lusaka 2010). Due to poor funding caregivers and their patients are no longer receiving food pack and HBC kits which had motivating effect. The MOH/NAC National AIDS Strategic framework (NASF) document (NASF 2011 -2015 p.42), has placed emphasis on the following strategies to improve CHBC activities in Zambia: Conduct mapping of CHBC services and service providers, Strengthen coordination of CHBC, Strengthen community systems to support the implementation of CHBC services- this will entail recruitment and retention of experienced volunteers, financial support and capacity building, Revise the home based care guidelines given the impact of ART on patients in CHBC, Standardise training for community CHBC providers, Training volunteers in basic palliative care skills and Procuring and supplying home based care kits.

These strategies were aimed at ensuring a comprehensive support structure for HBC activities, but despite the existence of strategies, there has been very little effort made on ensuring the operationalization mechanisms.

The HIV/AIDS pandemic in Zambia has continued to cause high morbidity and mortality among the productive age group across the country. The burden of care for health institutions has over the years faced different hardships that have resulted in a compromise in the quality, access and availability of health care services (Isaacs, Mundeta and Masunda, 2010). Isaacs et al., (2010) for example in their study in Malawi, Mozambique, Namibia, South Africa, Zambia and Zimbabwe, recognised the burden of HIV/AIDS of care on families especially women and girls (also Akintola et al., 2013; Andersen, 2012; Singh et al., 2011; Opiyo et al., 2008)

Available literature on CHBC suggests that home care programmes for people living with HIV/AIDS (PLWHA) were mainly initiated in North America and Europe in the late 1980s, Spier and Edwards, 1990 in Ncama 2005; Cullinan, 2000; WHO, 2002). It was, at that time observed that, if care for PLWHA was to be comprehensive and cost-effective, it had to be conducted as much as possible within the community (Ncama, 2005). With more people and individuals living with AIDS, the care continuum for such clients has changed its course to that of chronic nature.

HBC therefore is one of the strategies adopted in some countries in Southern Africa to address issues of chronic illness associated with HIV/AIDS. In SSA and other developing countries, HBC has been adopted in systematic and need-based effort necessary to deal with effects of HIV/AIDS (WHO 2002) as one of the strategies adopted to address issues of chronic illness associated with HIV/AIDS (Mwewa et al., 2013; Singh et al, 2011; Opiyo et al., 2008; Lindsey et al., 2003; NAC, 2006, 2010; Ncama, 2005). Most HBC programmes were initiated by NGOs, CBOs, FBOs and concerned individuals who formed organisations or groupings with the objective of helping and providing support to patients being discharged from hospitals and families taking care of such patients. Caregivers have continued to provide care and support to their loved ones. This dedicated service is without doubt, one that is expected from family members regardless of their preparedness to take on the caring tasks (Esu-William et al., 2006; Akintola, 2004).

However, PANOS(or Panos East Africa, 1996) expressed a fear that in as much as HBC was an answer to care for chronically ill patients, health care institutions could be seen as opting out of providing care to AIDS patients and placing the burden on the family and or community (Singh et al., 2011 argues that despite the positives of HBC as complimentary to health care, there is associated stigma to caregivers who also feel burdened with the care workload, experience mental and physical health problems. They further observe an attitude of secrecy on HIV status resulting in social isolation, loneliness and lack of support from social networks (Singh et al., 2011; ) as caregivers experience more stress when they perceive the care demands were more that their coping resources would accommodate, Pearlin et al., (1990). There were expressed fears of contracting the disease as their knowledge levels on infection prevention were poor and there were no adequate resources to ensure hygiene and protective equipment to support care in households which were also crowded with poor conditions (Akintola and Hangulu, 2014). Thabethe (2011) argues that the burden of care should not all be shifted to communities as they may not cope at all as was the current situation in South Africa.

The view of the Zambia health sector is however different. This is evidenced in the HBC manual developed by the MOH where HBC is described as “a system of providing prevention, care and support services beyond the clinic walls to meet the overall needs of people suffering from prolonged/chronic illness and families, within the home environment of the affected” (MoH HBC Manual, February 2005 p. 7). This definition appears to prescribe that chronically ill patients are expected to be provided with holistic care in a home setting, making the home and the family key elements of care.

HBC is therefore seen as an extension of the formal health care system and not an isolated strategy. For example the Zambia's National AIDS Strategic Framework (NASF) 2006 - 2010 and NASF 2011 - 2015 (NAC 2006, 2010) recognised the important role HBC plays in expanding the care continuum for treatment, care and support and mitigating the socio-economic impact of HIV/AIDS (NAC, 2006, 2010). As observed by WHO (2000) and Ulys, (2003) up to 90% of illness care is provided in the home.
The NHSP 2011 - 20115, in relation to care for persons infected and affected with HIV/AIDS, clearly emphasises as one of the strategies to include HBC and various other economic empowerment activities. To support the implementation of the plan, the Ministry of Health plans to do the following: Strengthening and scaling up HIV/AIDS treatment, care, and support through: amongst other strategies, Improve adherence to treatment; Strengthen and increase access to community- home based care /palliative care, improve adherence to treatment, increasing access to and enrolment on ART, for both adults and children" (MOH, NHSP 2011 – 2015, p. 52)

The strategic framework also supported the creation of an environment that facilitates broad based ownership of the response by all partners. This was expected to bring about cohesion, resulting in a uniform approach to HBC and its implementation. This however, is not the case as the different players in the provision such as FBO and CBO have their own approaches to this strategy although the MOH has tried to standardise HBC training materials and is working on the policy (Mwewa et al., 2013). This clearly demonstrates that cohesion has not been achieved as the approaches used are dependent on the organisation supporting the programme and may not always be in line with government guidelines. With all these approaches, one begins to wonder how caregivers cope, especially in the absence of a formal support system. We now see HBC services involving caregivers increasingly becoming more and more common as families are now assuming the responsibility of caring for their siblings, parents, spouses and other family members (Akintola, 2008) and especially where the culture of the extended family is a norm and family members need to conform to caring roles. HBC therefore has regionally in Southern Africa, become an alternative to hospital care and valuable to PLWA as local health facilities may not have the capacity to care for increasing number of PLWA PANOS, 1996; Held and Brann, 2007; Nsutebu et al., 2001; Akintola, 2008), while UNAIDS (2008) recognises HBC as a cost –effective strategy for governments but which give little considerations to the effects of care giving to those involved at the household level.

With the coming of ART, most patients are now spending longer time in their homes with the family members, bringing into the care scenario another dimension of care work, that of ensuring that the patient is adhering to treatment programme. This includes observing appointment dates, resupply of medication, special or regular tests at the health facility, bathing, feeding, changing bed linen, washing, turning position of patient if bed ridden and others. Hence the success of such added roles will depend on the type of support – social and psychological, the ability to encourage the patient, and the way the family is monitoring the adherence and the patient's response to such interventions (Knodel, et al., 2010)

For example in the study conducted by Akintola (2004) in Uganda and South Africa focusing on burden of care of chronically ill HIV/AIDS patients on family and volunteer caregivers, findings show that due to the chronic nature of HIV/AIDS, most caregivers experience physical, psychological, emotional, economic and social stress. Symptoms such as general body weakness, fatigue, backaches, sleeplessness, (Akintola 2004) make the life of caregivers more complicated, making caring a challenge to caregivers at household level.

## Conclusion:

In this chapter I presented key information relating to HIV/AIDS at regional and local levels, and allowing the reader to localize the epidemic in Zambian. The localization of the epidemic provided for an insight for one to understand the different parameters related to the epidemic and providing this study with the context within which HIV/AIDS in the HBC service provision is discussed including the different models being used in the implementation of related HBC services. In the next chapter I will give concise discourse of the tenents related to caring for patients with HIVAIDS especially in households.

## CHAPTER THREE: The Concept and Discourse on Caring

Nelson Mandela said "*Women don't only bear the burden of HIV; they also bear the burden of HIV care. Grandmothers are looking after their children. Women are caring for their dying husbands. Children are looking after their dying parents and surviving siblings". From 46664 HIV/AIDS Awareness Concert, March 2005, (cited in VSO 2006).*

In this chapter I introduce the family carers (FC) and discuss literature that describes caring in different contexts and provide different parameters that constitute nursing from both professional perspective and from non-professional. I also discuss and bring to light what was involved in caring for PLWHA and initiate discussion on how coping with caring can be or is not actualized. I used different databases through the following search engines CINAHL, SychINFO, MEDLINE via EBSCO, Google scholarly articles, followed up with more referenced articles and from bibliography. Key words used were caring, nursing, filial obligation, social support, gender, empowerment, and coping.

### The Discourse on Caring

Caring in the community exists at different levels: caring by lay carers, caring by professionals- but with similarities in the care provision process. Those charged with the responsibility of providing care, have directed their efforts towards meeting the needs of the one being cared for, conversely those being cared for also have certain expectations from caregivers. In one aspect the caregiver should possess understanding of what constitutes caring and knowledge of the appropriate actions to be taken to achieve positive results. Whilst at the other end of the continuum of care the "being cared for" maybe in anticipation for some level of understanding of the care input from the caregiver. Sargent (2012) argues the difficult in locating the conceptual definition of caring but with a number of explanations as to what constitute caring. For example, Caring involves interpersonal process, sensitivity in an environment conducive to caring (Hogan, 2013). Mitchel and Oakley (1986) attempt to describe caring as a range of human experiences having to do with feeling concern for, and taking charge of, the wellbeing of others. Whereas, caring can also mean anything and everything done for a person who previously had usually done things for her/himself, but as a result of illness, those actions are done by someone else. Caring therefore constitutes dealing with physical, psychological and emotional needs for both the caregiver and the one being cared for.

Further, caring is also set in the formal economy of care services happening in social institutions like health care services and the informal care services as the kind that is happening and being offered in the households and communities (Hayes and Llewellyn, 2008).

Further, Hayes and Llewellyn (2008) describes caring as having two distinct scenarios: the "Cognitive aspect – if one cares about something, one sees it as of value, concern or interest- see something good in it, The Emotional aspect – if one cares about something, one feels or is disposed to feel an array of emotions in relations to it" (p 22-23).

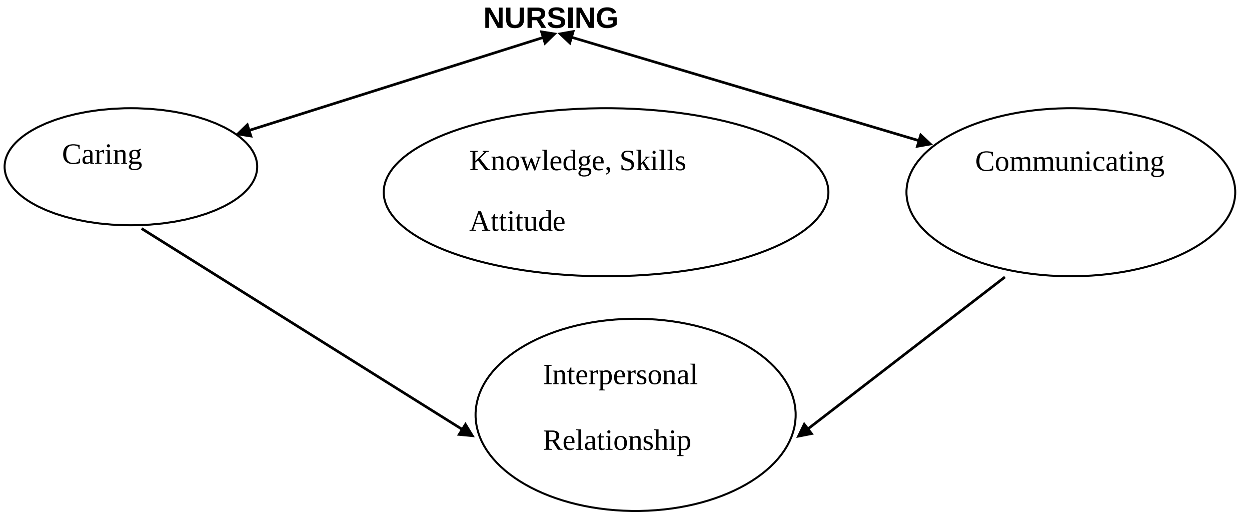
### Caring and care attributes

Caring is provided at different levels e.g. parents caring for their children and vice versa, friends caring for each other. In this context someone shows concern or is concerned about the other person's needs. Caring is therefore entrenched in the way individuals take on the challenge to provide for the other person in need. In any caring situation there is an established relationship between the carer and the one receiving care. Caring in nursing according to Morrison and Burnard (1997), will include the following elements: Knowledge, learning from experience, patience, honesty, trust, humility and courage. Sargent (2012) argues that caring was central to nursing practice, however, it was difficult to locate the conceptual definition of what caring may mean to an individual. Programmes in nursing allow that learners be knowledgeable and skilled to provide care to their patients. These attributes are learned as compared to caring at household level where knowledge and skills in caring is mostly informally acquired and learnt. Caring is further argued to be subjective, intersubjective and mutually felt (Sargent, 2012).

Caring according to the reviewed literature also has different meanings as this depends on the context within which it was being used. For example, it may be argued that nurses are taught how to care for their patients and this prescribed taught programme takes a specified period of time to acquire nursing knowledge and skills. Others may also argue that caring even at household level can be taught through the socialization process. These views require in depth discussion to extract the understanding of what determines caring in the household and caring that is provided for by professional nurses. Griffins (1983) in Morrison and Burnard (1997) describes caring in nursing as one involving interpersonal processes in which the nurse is required to carry out specific role- related activities in a way that conveys to the recipient the expression of certain emotions.

Figure 3.1 below shows a model that describes the different fields that constitute nursing and the linkages between the fields. For nursing to be happening at professional level, the central elements of the care interaction and links is determined by the knowledge, related skills and the attitude of the health care provider (nurse in this context),who during this interaction, is expected to build some level of interpersonal relationship through language and action. This process provides the patient with opportunity to understand what was being or to be done for them so they participate in the care process. This model can also be applied even to other professions as the health care provider should be in constant interaction with her "self" and the expectation of others on her/his behaviour relating to caring.

**Figure 3.1: A simple model in caring and communication in the nursing field has the following planes.**



(Adapted from Morrison and Burnard (1997, p 4).

These different planes Figure 3.1 determine the individual's level of understanding when carrying out nursing care roles. For example, the planes form the interplay between what one is in terms of their position in level of knowledge and skills in nursing, more especially what they already know and that to be learned. FCs will also be expected to provide care to patients in households and function through the same planes as what is expected of professional nurses.

To ensure success in adherence to medications requires that the FC has some depth of understanding of what is and what is not to be in caring. Caring is enhanced by the strength or the degree of the relationship between the carer and the patient and each care day bring different experiences (Hogan, 2013). For example parents according to Knodel et al., (2010), recognise their obligation to ensure the wellbeing of their adult children, thus prolonging/supporting intergenerational support and what needs to be done to support the other members of the family.

## The Culture of Caring

Culture is a social heritage of a group of people, and involves a number of attributes in the form of knowledge, language, values, customs, behaviour that govern the way of life of that people (Kendal 2002). Culture according to Antonovsky, (1980) gives human beings a sense of belonging, our place in the world, language we speak - by learning it or by acquisition, norms and values that guide our existence and how each individual fits or not into the world . Therefore when we care for others or receive care each individual brings into focus those attributes that constitute internal and external environment responsible for understanding the world.

The understanding of caring and its relationship with culture are some of the topics that have received widespread attention, more especially in the medical field where caring was the mainstay of the profession. Caring in the nursing field is articulated differently as it also depended on the branch of nursing one was dealing with. Caring is seen to be provided at different levels like; care by health professionals, care at health clinics and provided by health professionals, and Care provided in the households (Muñoz, 2007). Just as care may be provided at different levels, it may also have different meaning depending on the context it was being used Literature talks about “Caring” or “to care”, “to provide care” in different context and with differing meanings (Lazarus and Folkman, 1984, p.158). The concept of caring to date remains a very complex phenomenon, which requires different interpretation when an “Act of Caring” was committed by an individual. For example, anecdotal evidence has showed that sometimes parents have killed their children because they “care” for them and do not want to see them suffer especially in situations where there is abject poverty or provocation. Where nurses, for example, are trained to care for their patients, family members are informally socialized to care for their siblings and family members especially in most African situations. Many religions have been known to teach their congregation the importance of caring for one another, as noted by Griffin (1983) caring was paramount in most religions and has to some extent became an essential “regulation” of religious faith. Some religions have established some form of structured programmes where, especially women groups take the lead and responsibilities to visit homes of those congregants who are sick.

Muñoz (2007) in his argument about Culturally Responsive Caring observes that people learn from their cultural issues related to health and how to remain healthy, how to define illness and what to do to remain healthy.  Culture also guides and dictates to individuals where to seek help and sometimes culture will also prescribe sanctions when certain procedures are not followed by individuals or family members when trying to access health related help especially when help is not sought from recognised community structures. There are cultural variations in the way caring is perceived, and interpreted by families and communities. Cultural beliefs, sometimes combined with religious beliefs, are viewed as significant in the life of an individual and are factors in management of life events (Cattan and Tilford, 2006). How life events are coped with and managed relate to health and wellbeing.

WHO define health as not merely the absence of illness but a positive sense of well-being (WHO 2005).  Differences between people mean that there are differences in how they “define illness and what to do to get better and when and from whom to seek help” (Muñoz, 2007, p. 256). Individuals learn about health through the process of learning culture. It is further argued that, the same culture tries to dictate where to seek help when ill. Sometimes culture will also guide an individual and even prescribe sanctions if one does not seek help from recognised structures in the community (Muñoz, 2007). FC are therefore faced with the dilemma of making decisions when challenged with health issues that sometimes are culturally sensitive for example nursing/providing care to own child more especially when the caregiver and the care recipient were of different gender.

The cultural or social aspects of caring have been further examined for example by Lanre-Abassi (2008) who found that it was not about the general feelings of positive willingness to provide care to others, but that it was about tangible or specific interactions between particular persons.  Care can be viewed as a basic need in everyday life, where others give or provide care and others receive the care. Nodding (1984) viewed caring as a moral response during which one responds to a natural expressed or observed need out of love or natural inclination (Aboderin, 2006). Caring requires responsiveness to the patient's experiences and interactive feedback based on of factors that related to unfolding relationships (Hogan, 2013). The ethics of caring share some features with the traditional African communal values, where in some African communities the collective approach to living still prevails as everyone may continue to be viewed as the brother's keeper, as a societal value (Klemz et al., 2010; Cheng and Siankam 2009; Aboderin, 2006; Lanre-Abassi, 2008; ). Where such positive values exist, they were to be encouraged as the African traditions always promoted communalistic way of living. The socialisation process brought up children to believe and understand the importance of developing a sense of belonging and solidarity, which was based in the system and belief of reciprocity- a wider understanding of which individuals has obligations to a larger community (Lanre-Abassi 2008; Aboderin, 2006; Akintola, 2010; Tselebis, et al., 2001). Keller et al., (2005) observe that individuals are implicitly or explicitly socialised through interactions with others and hence actively construct the meaning of relationships and moral norms. For example Scharlach et al., (2006) say that caring was seen as a responsibility that fulfilled cultural norms, maintained cultural continuity and strengthened family ties.

African societies did and to some extent still have, shared values and existence. It can also be noted that during the socialization process, culturally, an individual is taught from the beginning to have a sense of belonging and shared aims.  This fact may confirm the basis of reciprocity and filial obligations within the family and other individuals in the family (Akintola, 2010; Nodding, 1984; Aboderin, 2006; Lowenstein and Daatland 2006). Values of connections, relationships and reciprocity are some of the factors in care ethics as the individual is considered a part of social web designed to create harmonious interactions (Lanre-Abassi, 2008). Aboderin (2006) also observes a natural sense of love, a growing sense of affection taking on the care function was dictated by some unwritten force, during which members of the family grew up believing that children were expected to provide for others.

According to Lanre-Abassi (2008), caring was not about the general feelings of positive willingness to provide care to others, but about tangible or specific interactions between particular persons.  Care can be viewed as a basic need in everyday life, where others give or provide care and others receive the care. Generally people want to be cared for; Nodding (1984) viewed caring as a moral response during which one responds to a natural expressed or observed need out of love or natural inclination (also in Aboderin, 2006). In some African communities the collective approach to living still prevails as everyone may continue to be viewed as the brother's keeper which could be a societal value (Aboderin, 2006; Lanre-Abassi 2008). African societies to some extent still have the beliefs of shared values and existence, summed up by the *Ubuntu* concept. The concept promotes  the idea of helping one another, and  which is almost universal in most families as  parents will always encourage their children to provide help to those who are less privileged and in need. The Ubuntu concept which is defined as "art of being a human being" (Bhengu, 1996 in Broodryk, 2006 p.2) is based on primary African values of humanness, caring, sharing respect, compassion, and associated values, ensuring a happy and qualitative community life in the spirit of family (Broodryk, 2002 in Broodryk, 2006, p. 2). Freeman and Nkomo (2006) observe that Ubuntu among the Xhosa and Zulu in South Africa, stresses that interpersonal relationships, caring for each other and sharing and self-sacrifice should be harmonious. Hence their elders were expected to provide for their families. However, due to high rates of HIV/AIDS the practice has changed due to stigma affecting care provided (Klemz et al., 2010)

The concept of helping can be learnt from other people as Morrison and Burnard (1997) argue, through a process of social learning through the mechanism of reinforcement, observation and role modeling, and thus helping behaviour may be conditioned through sanctions. Studies have further showed that there is some consistency in helping behaviour, grounded in the sense of moral obligations to help (Keller et al., 2005). It was common for the nuclear family to care for all in the family including the disabled, orphans, the elderly and the extended family and vice versa (Mugumbate and Nyanguru, 2013).

It can also be noted that during the socialization process, it is culturally acceptable for an individual to be taught from early childhood to have a sense of belonging and shared aims within the family and community, confirming the basis of reciprocity and filial obligations within the family and other individuals in the family (Akintola, 2010; Nodding, 1984; Aboderin, 2006; Lowenstein and Daatland, 2006). It is the cultural factors on how children especially girls are socialised on their expected caring roles for others, that makes caring an active engagement of carers meeting the needs of the patient. A caregiver can believe in caring when they value what they are doing for the patient. The engagement between the caregiver and the patient would possibly result in appreciation of the care and give meaning and hope to the patient. The cultural expectations of family members to provide care or look after the sick or those in need also bring to this discussion the issue of filial obligations within the family structures (Manthorpe, 2007; Aboderin, 2006) which will be discussed later.

Aboderin (2006), observes a natural sense of love, and a growing sense of affection were some factors that propelled one to taking on the care function and the act of caring was dictated by some unwritten force, during which members of the family grew up believing that children who provided care were well socialized or properly brought up with good morals and behaviour.

The love and concern that an individual has for others will in most cases dictate the quality of care to be provided and the outcome of the care intervention. An individual having been socialized to provide for others will feel obliged to care for others in need. Caring requires an input of different attributes, and some family members feel they could not conceive of another approach of caring for their terminally or chronically ill family member other than to take on the role themselves (Muecke, 2001; Sankar, 1999; Ogden et al., 2004; Cheung and Hocking, 2004). It is further observed that family members who are caregivers continue to provide the bulk of care, and for the majority of AIDS affected families, their caregivers are not linked to, nor adequately supported by formal HIV/AIDS programmes (Nsutebu et al., 2001; Ogden et al., 2004;Thabethe, 2011).

The sense of affection therefore propels one to desire to provide care most probably because others before have done so and did set unwritten examples to be followed or observed. For example a girl child has seen her mother or elderly women take on responsibilities to take care of the sick, that child will grow to believe that she too was required to do the same. In the Zambian context as evidenced in past studies as the Zambia Sexual and Behaviour Survey (ZSBS) of 2005 had showed the desire to nurse or take care of the sick especially those with AIDS was quite high; among females for example it was 95% and 93% among men, which has showed some degree of decline in of ZSBS (2009), of men 91% and women 90%. (Also a study by Sehume et al., 2012). However, this could be the result of the process of gendered child rearing practices where mothers will teach female children how to manage a home whereas boys will be attached to other men for the purpose of learning those skills that maintain their supremacy over the women folk (Opiyo et al., 2008).

When I was growing up for example, I spent more time carrying out household chores and often the boys (my brothers) went out sometimes hunting for birds, wild animals, fishing while I waited at home preparing meals for the whole family. It therefore meant that I had to help my mum take charge of activities in the household. Effects of socialization do negatively contribute to perpetuation of some gender roles. For example, Creig et al., (2000 in Johnson et al., 2003) recognise the roles played by both men and women as both consumers and creators of a gender spectrum, to include concepts of masculinity. Whilst Johnson et al., (2003) observe that both men and women played a role in promotion of ideas about feminity and masculinity and the socialization process was a major base for such developments. Women have been known not to allow men to take primary care responsibilities, which in most cases is not by choice but because society expects them to do so also observed by Mweemba (2014).(The gendered aspect of HBC will be examined later in this study)

In caring there is the understanding that you do so because you love or that you have a sense of duty and that you will labour to meet the needs of the cared for (Akintola, 2004, 2006; Hogan, 2013; Rose, 1986). However, despite the circumstances involved in caring whether one has been prepared to provide that care or not, or that actual caring demanding total investment of energy and dedication by those providing care, it has been described by many as not an easy task (Pirraglia et al., 2005; Kipp et al., 2006; Guyer, 2008).

Caring has been viewed as burdensome, stressful for most involved in the provision of such care to others (Akintola et al., 2013; Singh et al., 2011; Kipp et al., 2006; Guyer, 2008; Pirraglia et al., 2005) Caregivers have described caring as burdensome, as it emotionally involves a process of analysing the care situation. This process demands that the caregiver, reviews options available to institute a response to the expressed care need. Hence, in response, the caregiver will take physical action to address the need, and will require being economically able to provide for resources required to meet the needs of the patient. (Akintola 2004; Pirraglia et al., 2005; Kipp et al., 2006; Guyer, 2008). As studies have showed that caring was burdensome, structures were needed to be in place to offer relief to those experiencing stressful situations connected to the act of caregiving (Akintola, 2004, 2006, 2008; Odgen et al., 2004; Demmer, 2006; Esu-William, et al., 2006; Pirralgia, et al,. 2005).

Other research shows that the burden of caring had different psychosocial effects on different individuals (Akintola, 2004, 2006, 2008; Odgen et al., 2004; Demmer, 2006; Esu-William, et al., 2006; Pirralgia, et al., 2005; Lazarus and Folkman, 1984; Nolan, et al., 1996; Cassidy,1999). In view of the different perceptions and reaction of each individual when confronted with a stressful situation and also based on the appraisal mechanisms, individuals will label differently how they view caring work and more especially that of chronically ill patients. Caregivers will make efforts to try and make sense of care situations in the world around them, and will perform a quick analysis of their internal and external environment to ascertain the kind and level of available resources to address the care needs. Hence, arising from this process, a caregiver will, and may view caring as burdensome or not, based on the appraisal process employed.

A FC may provide care because of cultural dictates and one may have no choice because the community expects one to do so. In this context the cultural expectations of family members to provide care or look after the sick or those in need also bring to this discussion the issue of filial obligations within the family structures (Manthorpe, 2007; Aboderin, 2006). Accordingly Aboderin (2006) observed that the religious, familial or economic authority and functions of the old people in the extended family system were some of the key factors in ensuring that children conformed to their filial obligation regardless of the children’s situation.

Aboderin (2006) further argues that filial support was driven by an externally constructed public ideology of caregiving and that familism wrongly portrayed family caregiving as a “natural” responsibility especially for women (also in Cheung and Hocking, 2004; Esu-William et al., 2006) However, with modernisation and the state of material constraints affecting families to-day, there has been an observed weakening in the traditional norms and values. The weakening of such important factors therefore meant that most families became more individualistic resulting in the weakening filial obligation (Aboderin, 2006; Nodding, 1984). Although there was some experience in the weakening of the ideology of filial obligation in some families, the ideology was internalized and thus was compelling women to provide care. For example, those individuals who did not or were not seen providing care to their sick relatives feared eliciting social disapproval and feeling of guilt as they were seen as not conforming to the societal norms or expectations (Keller et al., 2005: Aboderin, 2006; Manthorpe, 2007).

### The Role of Filial obligation/responsibility in Care

A number of studies reviewed by Manthorpe (2007) revealed the enduring strength of the family as a care unit and is not only a simple social unit linked by economic and cultural norms. He further observed and argued that those giving care and those receiving care were distinct units, with for example spouses supporting each other, and inculcating an interdependence of family members (Cheng and Siankam, 2009), as none of them would predict which spouse would need help first or most. Caregiving can involve physically maintaining the household and family members which is instrumental in nature and facilitating psychological well-being of the family which is emotional caregiving (Kuperminc et al., 2009). Caregiving was viewed and described to be an act that needed to be done and that it was seen to provide for stronger family ties and done as part of culture (Scharlach et al., 2006). In addition, in Asian cultures, Wangmo (2010) observed that children were repeatedly taught and reminded of their duties towards their parents and family members. Children were therefore seen as primary caregivers for their ageing parents and parents received more support from children in whom they had invested more.

The natural sense of love and affection on the part of children was one value that is consistently being reinforced during the socialization process. During the childhood period there is a developed emotional attachment to parents by and from children. This sense of attachment to parents is said to originate in early child-parent interaction Cirelli, (1983 in Aboderin, 2006). The interaction referred to in Midwifery as mother-baby bonding is encouraged and is expected to initiate at birth of the baby. This interaction uses symbolic actions like cuddling, smiling, and some verbal language by the mother.

This is continuously being nurtured up to the time a child starts to use language to communicate. The social setting therefore is a major factor in the development of the positive social interactions amongst people in a social setting. The affection model was observed to be the prime role of the affection that compelled and motivates support in the family (Aboderin, 2006). However, the result of the affection model may also be associated with the levels and the kind of child-parent interaction especially the care, love, emotional support provided to their children (Aboderin, 2006; Keller et al., 2005). Children will reciprocate and feel obliged to reciprocate in providing support to their parents depending on how the child-parent interactions and relationships were nurtured. For example, Aboderin (2006) further observes that motivation to support parents was an act of showing appreciation for what parents may have provided for their children. Children felt obliged to provide support to their parents in return for a good favour. The ideology of filial obligation and reciprocity, according to Aboderin (2006) was internalized more especially during the socialization process and thus was compelling women to provide care or risk eliciting social disapproval and feeling of guilt where they, for some reason, did not conform to societal expectations (also Keller et al., 2005; )

Care cultures may also vary between different social groups and communities who have different social structures and construction that may result therefore in differences in how care is scrutinized and addressed, as issues of beliefs, priorities and preferences will be factors in how individuals will manage health and illnesses (Muñoz 2007). As caring exists in all cultures, research has demonstrated a relationship between culture and care and, some important factors like gender role practices within the family and religious activities have also been observed to exert influence on care (Halligan, 2005; Akintola 2006; Ogden et al., 2004). The culture of care demands where those providing care do so within the realm of cultural expectations in society, and individual behaviour in care situations needs to be consistent with these requirements. Deducing from these arguments about caring and circumstances to caring, we can see how socially or culturally ‘organised’ or determined caring can be. According to Scharlach et al., (2006) families were considered responsible for provision of care, and that caring was an enactment of cultural tradition regarding family roles and activities. These were the expectations that were handed down from ancestors from generation to generation.

In this context therefore any social change in communities can effect change and with some segments of the population in communities in Zambia experiencing economic stagnation or decline of living standards, this can effect declining family support to families, especially to older people. When children grow and have their own children, there appear to be a shift in the focus of support from the elderly or parents to their own children (Wangmo, 2010), hence the reduction in the support to the elderly. This development appears to be common in most caregivers. According to Aboderin (2006) the decline of filial obligation is seen as a product of change in material circumstances and situations, though this does not explain how at the individual family level may lead to decline in the support for the elderly-for example and nuclear families becoming a common feature (Cheng and Siankam, 2009). Thus it can be argued that filial obligation is not always based on the affection model or the reciprocity, as that was not a necessary pre-condition for provision of support to parents but was mostly based on the fact that children's sense of general normative obligation or duty may have required them to assist parents in whatever form possible (Aboderin, 2006).

## The concept of filial caring

Lowenstein and Daatland (2006) suggest that studies on filial obligations show some degree of consistent high involvement of families in care giving to older people and a modest input of care for weak older people. However, Aboderin (2006) observed a decline in family support and her findings also suggest a decline in customary filial obligations norms. The declines, Aboderin (2006) suggests, have been compounded by a decrease in resource capacity from economic strain, and rising retaliation resulting from embitterment about the past behaviour of the patient/person in need of such help. Hence care and support in those circumstances may not be forthcoming (Keller et al., 2005; Scharlach et al., 2006).

Knodel et al., (2010) also observed that filial support was driven by an externally constructed public ideology of caregiving and familism that wrongly portrayed family caregiving as a natural responsibility especially for women, hence the ideology was internalized and compelled women to provide care or eliciting social disapproval and feeling of guilt where, for some reason did not conform (Keller et al., 2005). For example according to Knodel, et al., (2010), observed that parents recognise their obligation to ensure the wellbeing of their children. Most parents take this responsibility seriously and will take any appropriate action conceivable to ensure that their children are provided with the very basics of their survival. The bond between parent and children provides the basics for strengthening this realization.  Aboderin (2006) argues that the religious, familial or economic authority and functions of the old people in the extended family system were major factors in ensuring that children conformed to their filial obligation regardless of the children's situation. The coming of modernisation resulting from urbanization and industralisation has led to individualism, secularisation, thus weakening the traditional norms of filial obligation and consequently reducing the enforcing mechanism that may have existed against those who disobeyed (Aboderin, 2006). The era of universal education where nearly all children are expected to receive some form of education, and especially in urban areas, urbanisation and the development of new technologies have contributed and resulted in an apparent erosion of the power of the parent to enforce filial obligations norms on the children.

Having received help in the past was a motivator for reciprocity which can be associated with the desire to provide caregiving Harowitz and Shindelman (1983) and especially when that help was coming from a relative or a family member whether extended or immediate.  Spousal caring can be linked to what could be understood to be the long standing cultural tradition that defined family obligations. Hence caring for ill, disabled, or elderly family members were seen as responsibilities that needed to be observed by members of the family. Caring as an expressed behaviour did fulfill cultural norms, maintained cultural continuity and strengthened family ties (Scharlach et al., 2006). However, Manthorpe (2007) talks about interdependence, past relationships and emotions as some key factors involved in caring for family members especially in spousal caring. The caring roles changed for example Cheung and Hocking (2004) observed caring in spousal situation to have been worrying and very stressful  in the sense that the spouse taking care of the other will constantly worry about the partner, their relationship and the future, more especially when the disease is chronic in nature. In a situation like HIV/AIDS issues of vulnerability to contracting the disease becomes a concern sometimes to both (the patient and the carer).

### Caring for the chronically ill PLWA patients

Providing care to chronically ill patients means caring for protracted periods, with no or very little hope of the patient recovering as there is no known cure for AIDS to-date. Before the introduction of ARVs, patients with HIV did not have long to live as they died early. However, this picture had changed as the condition now becomes a chronic disease (Guyer, 2008). The nature of this chronicity is meant that, firstly, it affects mostly those who are employable for example age group 25 - 44. When they are infected, they lose the ability to provide for the family, which can result in some level of poverty in the affected household (However, with access to ARVs, this picture is seemingly changing although very few infected individuals (as seen earlier in this study) in Zambia have access to ARVs.

Secondly, someone within the household takes over the responsibility of providing for the family. This expectation spreads out for a long period of time, and which may become a burden for those that take on this responsibility.

Further the chronic nature of the disease means that if it is the wife or husband (though quite often a female relative in the Zambian context would take care of a sick wife {anecdotal evidence}) who is taking on the care function and possible sourcing for food and other family requisites, the stress of trying to source for funds and other resources, may begin to have effects on their physical, mental and social wellbeing and probably experience difficulties in the process of providing care.

PLWAs will continue to experience symptoms of opportunistic infections more especially during time of lowered immunity, with episodes of feeling unwell and exchanging with periods of improved condition and wellbeing. As disease progresses and the patient's physical capacity diminish, individuals require increased assistance with domestic chores (e.g. cooking, laundry, fetching water and firewood) and personal tasks e.g. bathing, (Esu-William et al., 2006).

### Experiences of care giving and roles defined

In care functions, the carer makes deliberate efforts and takes calculated actions that are believed will meet the overt and hidden needs of the patient. Caring can be understood to imply a distinct way of being, thinking, believing and acting that calls for commitment, knowledge and skill (Roach 1987; Benner and Wrubel, 1989; Cheung, 1998). Caring is further viewed by Cheung and Hocking (2004) as one way of expressing respect for, and response to human expression of need. The way the caregiver values "caring" is the motivating factor that propels the carer to give meaning and structure to life of the patient under care. It can thus be argued that a caregiver with a high SOC will view and devise ways of dealing with the internal and external world as logical, clear and easy to understand and use this perception to avoid transformation of tension into stress (Forsberg-Warleby, 2002).

Social, psychological and physiological issues are some factors and challenges to consider when caring for an HIV infected individual. Caring for such patients brings with it different experiences, which can be positive or negative. For example, studies in Brazil found that caregivers experienced emotional difficulties such as fear of infections, revulsion, pity, grief, and guilt from being helpless in the face of death (De Figueiredo and Turato, 2001). A study in South Africa also revealed that care giving impacted on family caregivers' physical and mental health (Orner, 2006). Further, a study in Ghana, Tanzania, South Africa and Democratic Republic of Congo has documented family caregivers' experience of stigma and discrimination, isolation, and lack of support. Other studies in South Africa have shown that caregiving can create major time burdens for caregiver, worsening the poverty levels among those caregivers who were already poor (Isaacs, Mundeta and Masunda, 2010; Akintola, 2004; Lindsey et al., 2003).

Many of those providing care at the household level are not professionals but family members, friends or volunteers (Ncama, 2006).These are the FCs facing different challenges in coping with caring for patients, in situations where they do not have adequate knowledge, skills and resources of how to look after and meet the patients' needs. There is no defined support structure at household level for FCs to leverage basic resources to enhance provision of care especially in Zambia (UNDP, 2007, Mwewa et al., 2013), and in SSA (Akintola, 2004; 2008).

Meeting the health needs of the chronically ill may include making decisions of when and where to take the patient for health or medical attention, adhering to drug regimen, and providing psychological care like counseling, and encouraging. Generally, care giving activities as noted in this literature, include provision of physical and emotional support to patients, and this work which may vary from patient to patient, may include activities like lifting, bathing, feeding, cleaning after bouts of diarrhea, or taking the patient to the toilet, talking to the patient, walking the patients. Sometimes caregivers are made to stay awake at night attending to patients who are in the terminal stages of their illness (Orner, 2006; Demmer, 2006; Chepngeno-Langat, et al., 2009; Akintola 2008, 2010).

Care giving continues to be very demanding for the family. Care work leads to physical, emotional, psychological, social and economic stress as they experience physical stress related symptoms such as headaches, backaches from lifting patients, and general body weakness and fatigue due to lack of rest (Akintola, 2004, 2008). Some of the family members also face the risk of infection like TB because of frequent close contact with patients and also risk of HIV infection because they do not use protective devices. The act of caregiving can result in carers not having enough time to socialize with other members of the community thus resulting in the feeling of being alienated from friends and other social activities and also straining the caregiver-care recipient relationship. Furthermore, men rarely assist with care giving because they are usually involved in formal or informal activities to earn an income for the family, they do not see it as their role, while some however deliberately shirk their responsibilities (Akintola, 2004). However, Esu-Williams et al., (2006) argues that caregiving at the household was a difficult and intensely personal task whose effectiveness relies on the sensitivity of the caregiver, the caring skills, the environments existing in the household in terms of communication, and openness by the family.

However, Akintola (2010) observes that available literature on family caregiving appears to have focused mostly on the negative implications of caring for the caregiver. He further argues that family caregiving results in poor health and socio-economic outcomes. This may further result in stigma and discrimination against those caring for PLWHA and hence will be isolated from the source of support. Literature has also shown that these negative effects of care giving are evident at household level (Lindsey, et al., 2003). Other literature however, has shown some family caregivers do experience some form of reward resulting from caring for patients, for example those who are elderly, chronically ill, the mentally ill. In addition to the feeling of being stressed, caregivers experience some form of rewards derived from care work. Feeling of obligations, pleasures, satisfaction, gratifications of caregiving have been noted from literature

(Akintola, 2010). Others have shown a great feeling of satisfaction as they would consider such moments of caring as ways of fulfilling their obligations, duties. It is natural that when one exerts efforts in the hope of achieving positive results, when that happens, the feeling of self- satisfaction is actualized. These rewards could hence be viewed as coping resource that would serve as a buffer between caregiver burden and negative health consequences Lawton, et al., (1991 in Akintola, 2010).

### Factors associated with caring for the chronically ill AIDS patients

In caring for HIV/AIDS patients, factors that affect the quality of care need to be considered. These may include, among others, social, psychological and physiological factors such as willingness and readiness to care, availability of resources like money to meet different needs for the patient and for the caregiver, people to help, time, knowledge and skills that make it easy or difficult for a caregiver to meet the patient's needs (Isaacs, Mundeta and Masunda 2010; Singh et al., 2012; Morwe, Klu and Tugli, 2013)

Care is related to those interactions between the caregiver and the one receiving care. The process of stimuli and response is a factor that makes the one providing care responds to the expressed (verbal or non-verbal) need because of love or natural fondness. Nodding (1984) observes that the caregiver will recognise this effort of the caregiver as being seen as one of a good moral and the individual will strive to provide that care. Through phenomenological analysis Nodding (1984) discovered that when engaging in caring encounters, caregivers were found to be receptive and attentive in a special way to their patients. Further he observed that by being open to what the patient is saying and experiencing, the caregiver would reflect upon what the cared for was going through.

A caregiver can believe in the active role of caring when they understand and value what they are doing for the patient and may subsequently view this engagement as a meaningful contribution to the welfare of the patient. The engagement between the caregiver and the patient would possibly result in appreciation of the care by the patient, and other relatives, and give meaning and hope to the patient. Further this engagement may also provide meaning to the caregiver who may derive some form of social and mental satisfaction in what they may be doing for the patient.

Caring for others more especially the sick is in most scenarios one that demands for an in depth understanding of what caring means when used in different context. It is therefore, within the process of contextualising caring that it becomes one of the factors that ultimately prescribe the outcome of the care input. Caring takes on different characteristics when viewed from the psychological, sociological and even medical perspectives.

These are some of the factors that FCs have to contend with on a daily basis. In caring for family members, there are factors like filial obligations that one needs to respect, relationship with the being care for, who can be spouse, daughter, son, in-law these relationships demand different behaviour disposition to manage care functions. The anticipated demands, when caring for such family relationships are in most cases different and the approach to appraise the care situations further put the carers in a position that may be sometimes be difficult to comprehend. Firstly, families can be potential sources of stress as Nolan et al., (1997), observed, that negative social exchanges can occur between members, the care situations demand for long hours of work, carrying out a wide range of care activities and most times without help or any support structure (Mwewa et al., 2013; Isaacs, Mundeta and Masunda 2010; Guyer, 2008).

Caring involves providing for those in need as earlier discussed, and further compounded with long hours of providing this care, with a wide range of activities that include both personal as further reported by Nolan et al., (1997), that it is taking place in the same household, with the form of caring that may involve not receiving any support or little help from other members of the family. This is the caring that has been observed to be provided by some members of the family, like women, girls, young and old.

### The role of gender and age in caring for chronically ill family members

The effects of HIV/AIDS on households continue to exert different effects on those that are affected, for example individuals, families, households and the community in general. A household, which is a unit in any community, can be comprised of nuclear family members, where the father, mother and children live under one roof (This is not common in Zambia as most households include members of the extended families). However, there are also other family structures like the extended family system that over a period of time have been viewed to be part of the nuclear family and are hence traditionally recognised.

When caring is taking place at the household, mostly family members would be the ones responsible for providing that care. Hayes and Llewellyn (2008) talk about cognitive and emotional domain and orientation of the carers towards the cared for. Generally, when care is being provided, tasks performed can be considered skill-based and are visible to the recipient. However, there are emotional orientations during the appraisal and interaction processes that may be affected by the status of the relationship between the caregiver and the patient/cared for. These factors may include, age, gender, relationship, diagnosis, the anticipated disease progression and prognosis. Demmer (2006) also asserts that caring for relatives with AIDS forces caregivers to be secretive about their loved ones reasons for being ill, for fear of stigma and discrimination. Families may be talking about AIDS in their families but will not comfortably disclose the presence of AIDS when the disease “hits” their households. Other social scientists further claim that family carer experiences include fear of contracting the disease, issues of stigma to the extent that the cultural of silence sometimes becomes part of the family carers.

According to Nolan et al., (1997) in widening the horizons for family caring, the notion of purpose for caring or just the intent for doing so are important factors in care situations. Should help in form of caring be a right or should it be a duty that one is expected to provide to another. They propose that it was wrong to expect help as a right and therefore the related negotiations should have happened well in advance of the time when the help was needed. Further, Nolan et al., (1996) observe that these negotiations did depend on real and anticipated situations, for example parents will need some form of help from their children especially when in older age group and even other older family members. The same authors continue to argue that factors like gender, ethnicity, culture or income did not explain support in any straightforward way. The issue of filial obligations was a guideline for action and not related to a right or duty. To be able to provide for or care for others, one requires to be empowered with knowledge and skill and have specific resources to do so (also Guyer, 2008). It is this acquisition by individuals that allow for enhancing capacities for making a difference in families and communities.

The role that gender plays in care provision, has in the past decade been receiving a lot of attention and research work has been carried to ascertain the level of male involvement in caring for patients especially in the households. Nolan et al.,(1997) observed that, it was the feminist approach to care, and maybe, writings at that time focusing on gender that may have reviewed gender in relation to care. During these reviews, although men did participate in care work in the households, they may have been relegated to positions that depict their low input into care work and their care contributions not be recognised as active and/ or their input in caring perceived but ignored.

The ZSBS (CSO, 2009) did observe that willingness to care in the Zambia context in men and women was high 94% in urban areas and 85% in rural areas. However, it is further observed that according to traditional stereotypes in Zambia as in other African countries, women take the lead in providing care for example for the sick at the household (Esu-Williams et al., 2006). This can further be argued that the role that men and boys may be playing as providers of care in the context of the HIV/AIDS epidemic has been poorly documented and inadequately understood in Zambia especially. As in most instances, when one talks about or suggests that a boy child or man be useful in a home by participating in some female-viewed household chores, like cooking, sweeping, washing dishes, such demands were seen to be related to gender equality and not as desire to help a boy child also learn some of the chores in the household. The study conducted by Esu-Williams et al., (2006) in Luapula province of Zambia, determining which care and support needs could be met by trained young people, explored how young males and females would react to the ideas of active involvement in caregiving. The study revealed that males and females were already actively involved in caring within the households and that they were already caring for patients with HIV/AIDS. Although the finding further shows evidence of special preference for same-sex patients and that special tasks like those that were more difficult and strenuous like fetching firewood, roof repairs were more suitable to be carried out by males. While females, were left to be more responsible for household chores. Generally they also felt that some nursing and medical tasks like wound dressing, general cleaning could be carried out by both males and females (Esu-Williams et al., 2006). However, it is generally recognized that women and girls are the principal caregivers in the vast majority of homes and bear the greatest degree of responsibility for the psychosocial and physical care of family and community members (Ogden et al., 2004).

Changes in family structures that may arise from different factors, like deaths from HIV/AIDS, resulting in the deaths of ‘bread winners’, mostly when death involves the young leaves the elderly with the responsibility of caring for others ( Harrison and Short 2014; Klemz et al., 2010; Cheng and Siankam 2009; Aidoo and Harpham, 2001). Caring is a life event which according to Cattan and Tilford, (2006) can have impact on the well-being of the whole family, and women are one and half times more likely to provide care than men. Female-headed households are disproportionately affected and least likely to be able to sustain orphans economically for example. With the advent of HIV/AIDS grandparents in Africa are active participants in the care of grandchildren and are now taking on a new level of responsibility as they become the sole caregivers (Ice et al., 2009).

Studies indicate that when men participate in caring activities, their level of effort, and even the length of concentration on care activities differed considerably to that of women. For example, the study by Parker and Lawton (1994) revealed that men could not be viewed as the main carers as they observably spent less time on care work as compared to women (Nolan et al., 1996). Further, there is the notion that men are required to spend less time on care work as compared to the women folk as they are in most cases involved in paid work outside the home, and sometimes, women will intuitively make it a woman’s responsibility to provide care in the household.  Patriarchal ideology promotes men as beings with a higher status in the family and as such they hold power and are more privileged (Thabethe, 2011).  This ideology appears to have been a distorted development, which according to the analysis by Maroney, Heather, Jon (in Mitchel and Oakley, 1986), seen to place male-female relationship on sexuality, marriage and family and as such was at the centre of the arguments (also Mweemba, 2014).

Nolan, et al., (1996) also suggest that although gender was significant in the care phenomenon, it was just one of the major factors in hierarchy of obligations about caring if not the only one factor. From the feminist point of view, gender has been seen in terms of sex of an individual, with biological understanding of the specific roles ascribed to that individual related to biological attributes, so women as mothers and men more undertaking physically demanding work.

Furthermore, culturally there are clear divisions of what roles were ascribed to men and those to women. For this reason, the socialisation process strengthened and ensured that the strong values, norms and beliefs on gender, referred to as - sex roles were offered in an environment where they were seen to be perpetuated. For example, women as  result of their biological standing were expected to give birth to babies and nurture such babies, men  for example in our village setting in Zambia, had the responsibility of ensuring that the woman was provided for during pregnancy and  after delivery of the baby. Women, were thus intuitively believed to be charged with the responsibilities of taking care/nursing of the other woman who may have given birth to a baby.  Mothering as argued by Ehrenreich and English, (1997), was seen as an intuitively acquired skill, an ability that was believed to come with informal training (socialisation of girls) during child rearing and the associated expertise evolves with subsequent birth of other children. But it was also important to note that each child in the family brought different dimensions of the mothering experiences and therefore, we can talk about mothering being a dynamic process.

The recognition of caring as a woman's issue and mainly a feminine concern may have resulted in men, even when they could have been active players in caring functions being ignored as they were not considered as the main carers as women were tied to homemaking, hence them being main carers (Nolan et al., 1996) .   Twigg and Atkins (1994) argued that men found it easy to separate themselves from caring roles and set limits to their involvement in caring. While men would look forward to help with caring roles, women would be determined to continue working without help from men as such work would be viewed as an extension of domestic work (Twigg and Atkins, 1994).

At times in rural communities and in some urban areas it was common practice that,  a pregnant woman would move and live with her parents (mother) whilst waiting for the birth of the baby or vice versa the mother to the pregnant woman or an elderly woman would move in in anticipation for the birth of the baby. However, it was generally acceptable in communities to have specific roles for men and those for women. The youth in a study conducted in Zambia, (Esu-Williams et al., 2006), expressed their desire to challenge the traditional gender norms that perpetuated the stereotypical way of thinking especially in relation to gender. They did feel that some roles cannot be carried out by males, especially when caring for patients (with HIV/AIDS) in households.

In caring roles, the literature describes the phenomenon where caring and nurturing are characterised by women as one of their key roles in relation to others in the family (Knodel et al., 2010; Mitchel and Oakley 1986), thereby strengthening the practice that for example nursing and midwifery were women's profession. It took many years for Zambia to recognise and accept male nurses and midwives, and to date, in some rural health centres, men are not allowed to conduct deliveries in maternity wards or rooms (Govende, and Penn-Kekana, 2007; anecdotal evidence). Women in Zambia, which may be true of other women in the region, have been groomed and socialised to carry out tasks that are female oriented and this is clear to all in the community as gender roles are very specific and clear to all. However, although women are ready to take on the care responsibility, studies show that they are in most cases ill equipped to do so as they may not have adequate knowledge and skills to carry out some care demands. The literature review has highlighted the extent to which caring demands knowledge and skills (Hayes and Llewellyn, 2008; Nolan, et al., 1996; Morrison and Burnard, 1997; Macwan'gi et al., 1994) and therefore, FCs will require some depth of understanding of what is expected of them, but evidently the caring task has been reported to be enormous (Nolan et al., 1996; Bandura, 1995; Cassidy, 1999; Morrison and Burnard, 1997).

Emotional attributes like commitment, obligation, dissociation, and repudiation (Opie, 1994) further alludes to the fact that caring is strongly influenced by individual life histories irrespective of gender. Govende and Penn-Kekana, (2007) have argued that gender dynamics alongside age, race, class have been factors in shaping how providers will communicate to and listen to their patients, and how they will believe and interpret what the patient tells them. Gender therefore can be said to play a critical role in influencing the anticipated outcomes of caregiving based on the levels of interactions, care activities and the type of information shared with the cared for.

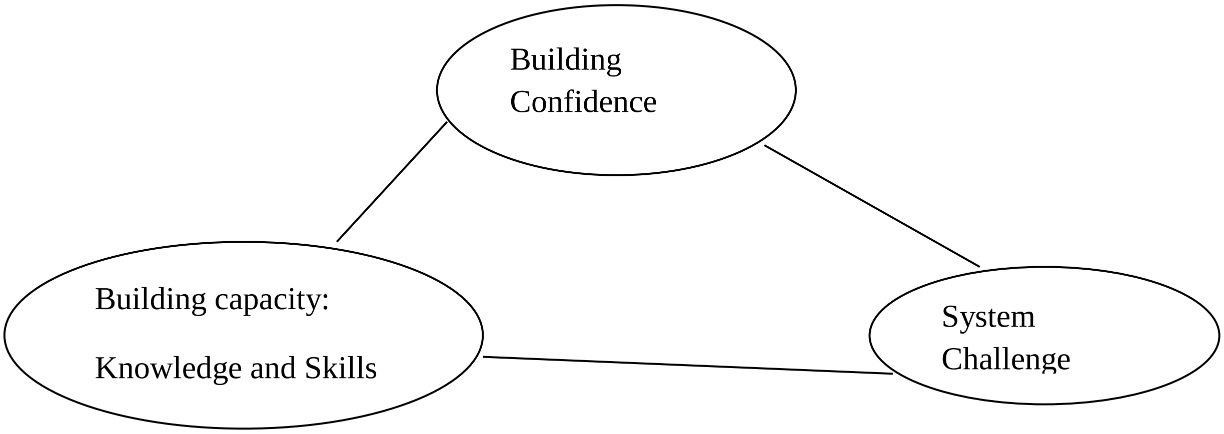
### Empowerment and Caring for family members

To provide care to anyone requires that the caregiver is well equipped with knowledge and skills and other resources to be able to actualise the care programme (Dixey et al., 2013). One can go to school to train as a nurse and be empowered with knowledge and skills in caring for someone or a patient. Whilst it is known that others use the traditional approach of acquiring knowledge and skills through the socialisation process or through trial-and error approach to learning, learned experiences. In all these approaches an individual is learning how to master some skills to provide care to those needing it, and being empowered to act.

Rowland (1997) argues that empowerment should be viewed as a development process that enables people to gain self-confidence and self-esteem, thereby allowing both men and women to actively participate in decision making. To strengthen the argument further, an empowerment approach, according to Momsen (2010), was a term that described the enhancement of efficiency and productivity without changing the status quo. She further argues that alternative development literature looks to empowerment as a method of social transformation.

The empowerment model according to South and Woodward (2010), talks about building capacity like acquisition of knowledge and skills, building confidence and system challenge as key factors and variable that describe the key tenets of empowerment.

**Figure 3.2: Empowerment Model.**



Adapted from Woodall et al., (2010).

The above model was designed on the understanding that when people or individuals are equipped with knowledge and skills, they will be capable of making a difference in communities. Empowerment therefore, happens at different levels in any society- this could be at individual, Organisational or community level and can be about environment, organisation or systems. When embracing empowerment issues according to Barry (2001) it is important to pay attention not only to the individual but the wider community and social forces. It has been argued that empowering individuals facilitates their ability to make contributions to their communities in a way that such communities also benefit from such empowerment processes (Woodall et al., 2010). Dixey (2013)(ed) add that empowerment fits with humanistic approaches, where we assume that people are competent and capable of making changes in their own lives, and that competence was gained through life experiences and is not about being told what to do. Empowerment in caring for someone therefore means having the capability to take on the responsibility to provide psychological, physical and social needs of the person in need.

Taking on such responsibility requires that one has to be empowered to do so or this may not be the case at all as someone finds themselves being “forced” to take and provide care to a patient as Mitchell and Oakley (1986 p. 170) claimed it was “enforced caring extracted from the woman”.  Arguably, traditional life-skills training, although situational based, have diminished and these are reported to be individually focused and based on the need. Therefore, when an individual shows interest or reaches the age of learning an aspect of life survival skills, that aspect of need would be recognised appropriately. Elders therefore took the responsibility to teach and the individual would be taught accordingly. This kind of the taught processes according to Walsh (2002) have been known to be linked to the concept of empowerment. Therefore, where families are not well versed with the key traditional knowledge and skills may result in family members missing out on the empowerment process and being inadequately equipped for roles such as caring roles especially for the sick.  Furthermore, these are the skills that contribute to individual attaining some form of control in what is evolving around their lives, and attainment of high-esteem in taking care of others in need.

### The role of social support in caring for chronically ill patients with HIV/AIDS

Support is an element of communal living and existence and each individual expects to be provided with support at different levels of stages of development as a child or an adult Support networks especially have been known to have a positive effect on the general wellbeing of individuals in individuals and families. (Cattan and Tilford, 2006; Nolan, et al., 1997; Antonovsky, 1980; Lazarus and Folkman, 1984). Support can be formal when it is organised in a particular format with set objectives and is structured, it can be informal and is not overtly structured but community members know about its existence. Support networks provide physical, emotional, psychological and sometimes material support and are known to be received from families, neighbours and formal organisations (Nolan, et al., 1997). Social support has over the years received much attention from sociologists who have conducted research to explore human relationships in greater detail (Cassidy 1999) and that being isolated has been associated with loneliness, coldness, sadness, ill-health and evil, while being with friends has been associated with general good health, warmth, and happiness. The studies of social support are linked to the seminal works of Cassel (1976) and Cobb (1976), the two sociologists whose research papers argued that social support was a major factor in countering and buffering the negative effects of stress. As far back as in the 1960s, social support was closely connected to, and was viewed as an important element in mental health (Cassidy, 1999).

Social support therefore is a strong resource in coping with stress (Cattan and Tilford, 2006; Cassidy, 1999; Nolan et al., 1997; Antonovsky, 1980; Bandura, 1995; Lazarus and Folkman, 1984). Continued debates on social support highlight the fact that it contributed to coping, as discussed by Antonovsky (1980), revealing the results of a study focusing on the relationships and between social support and health outcomes and measured the four measures of social ties vis: marriage, close friends and relatives, church membership and informal and formal group associations, and these factors accordingly predicted mortality differently. The results of the study showed that people with more social contacts had experienced the lowest mortality. While it is noted that Antonovsky (1980) equated the four factors to GRR. Similarly, Lazarus and Folkman (1984) also viewed social support as one of the resources that one could draw upon to survive and flourish. However, Lazarus and Folkman (1984) still argue that social support in relation to health outcomes still lacks the definition on the process and how health is affected.

People and individuals with tangible social support within their internal and external social environment have less likelihood of suffering ill health (Antonovsky 1987). Interestingly, Nolan et al., (1997) observe that social network structures could be construed as potential pathways for transmitting forms of care and support, being viewed as an opportunity framework which could be a constellation of relationships that may not guarantee support to those needing it. However, further discussions focusing on social networks and social support do suggest that the theories were concerned with understanding the relationships between families, individuals and community dynamics that prescribe and play a bigger role in the functioning of these structures. Social support is anchored in the concept of friendliness, loving, caring relationships (Akintola, 2010; Aboderin, 2006; Lazarus and Folkman, 1984; Antonovsky, 1987).

### Social Support and Coping

Social support has been argued to have positive effects on individuals experiencing some form of stress. For example, simply being with others reduces anxiety, and in addition friends and family may help in solving problems. Bengtsson and Bengtsson (2005) further argue that social support is valuable for a healthy life as it helps people avoid getting into stressful situations and events (Langeland, et al., 2007; Klepp et al., 2007). The act of talking to someone is also a source of help especially when such discussions focus on talking about difficulties one is experiencing (Baron and Bryne, 2006). Clarke and Stone (2007 pp. 209) report that Sussan Folkman 1984 observed a third type of coping referred to as "meaning type coping". This is where patients facing impending death from AIDS interpreted the situation positively by employing positive reappraisal which included- "finding meaning in daily life events, revising goals for the future, and activated spiritual beliefs". However, as the type of appraised process is going on, the individual may experience conflicting situation in the approach of dealing with the stressor. For example, when individuals are confronted with a conflicting situation, the appraisal process may demand that decision on the course of action to take and presenting choices may be favourable and attractive to the individual. At times the individual finds him/herself in a situation where after appraisal, finds that the alternatives are both not attractive and taking action may result into some form of cost to him/her or those around. These are some of the factors that constitute conflict during the appraisal processes and may even result in delayed action or decision (Lazarus and Folkman, 1984; Schneider, 2008).

### Coping as a Care Attribute

The care situation for chronically ill patients in this study is discussed and understood in the context of the Salutogenic model and how informal carers cope with challenges related to care at the household level. Antonovsky's model of Salutogenesis, (1979, 1987) in this study, is used as a framework to explore and further understand the mental process of how FCs interact with the internal (within the self) and externally in the environment in coping with care functions. Antonovsky's SOC is a measure of the level of ability to deal with a confronting situation (Antonovsky's idea will be looked at in more depth later in this chapter).

Coping, which is the ability to deal successfully with a difficult situation (Hornby, 2000), can be positive or negative depending on circumstances one is confronted to deal with. Monan and Lazarus (1991) also define coping as the way an individual physically and mentally deals with or adapts to a threat, whilst Lazarus and Folkman(1984) define coping as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" p. 141. The ability of an individual to cope will also be dependent on the Carer's mental and physical health status that may also be an attribute in counteracting the effects of stressors (Bengtsson and Bengtsson , 2005; Cattan and Tilford, 2006).

Literature over the past two decades shows an explosion of research investigating how people cope with everyday life stressors (e.g. lack of finances, employment, and disease). This may be due in part to the important role coping is thought to have in mediating or moderating the relationship between health-related stressors and psychological or physical health (Oxland, Miller-Lewis, and Wade, 2004). Coping, as evidenced by research, is also determined by the kind of resources available to support his/her desire to take action and accordingly these resources may include health, and energy, existential beliefs about God, general beliefs about control, commitments, and these have been observed to harbour some motivational factors or properties that will support and sustain coping for example: problem solving skills, social skills, social support and materials resources (Lazarus and Folkman, 1984).

Evidence shows that an individual's ability to cope is assumed to lie in the fact that when faced with stressors, he/she is capable of reviewing, make clear and structure the nature of the stressor to believe that appropriate resources are available to cope and will mobilise resources to choose appropriate strategy to cope (Forsberg-Warleby et al., 2002; Kloosterhouse and Ames, 2002; Bengtsson and Bengtsson, 2005) When confronted with an event, the reaction to that event in most cases depends on an individual's past experience and beliefs. Clarke and Stone (2007) argue that, when a person was exposed to a harsh childhood for example, they may tend to grow up with negative beliefs and with a general sense of pessimism and tend to always see things as threats while this maybe the opposite for others. They have further argued that individuals will assess their internal resources, like strength of character and coping mechanisms to deal with the situation. People will also review the external resources like networks, finances, and information and decide on the best approach to deal with a confronting threat. Clarke and Stone (2007) further observe that past experiences, and personality, as well as current social support and circumstances, will influence actions to be undertaken. Salutogenic model (Antonovsky's, 1987) purports that, life in general is meaningful, manageable and comprehensible, and hence action to address the stressor will be influenced by those life beliefs (Sammallahti et al., 2003; Klepp et al., 2007).

The ability of an individual caregiver to cope will also be dependent on their mental and physical health status that may also be an attribute in counteracting the effects of stressors (Bengtsson and Bengtsson, 2005; Cattan and Tilford, 2006). Bengtsson and Bengtsson (2005) have observed that social support is valuable for a healthy life as it helps people avoid getting into stressful situations. For example, the ability to deal with or not deal with a stressful situation may depend on one's resilience. An individual's skill to recognise, find meaning and adjust to social support can be factors in the ability to cope with stressful situations (Klepp et al., 2007; Love, Irani, and Themistocleous, 2001).

According to Cattan and Tilford (2006), the capacity to manage life change comes from a combination of individual and societal factors. The life changes which involve anxiety, reduction in self-esteem and sometimes depression may sometimes be of short duration but others may last longer and may even form part of or be associated with the learning process. The process may provide an individual with basic understanding of the cognitive effects life changes may have had on that particular individual. In similar studies on cognitive theory of stress and coping, Lazarus and Folkman (1984) state that coping originates with the everyday appraisal and reappraisal of a person's transactions within their environment.

Lazarus and Folkman (1984) observe the number of arguments related to the appraisal process in coping, suggesting it is inherent in every individual and is influenced by beliefs, values, goals and how emotions are triggered by the presenting event. The appraisal process helps the individual galvanise both internal and external resources appropriate for fight or flight. From the earlier writings, appraisal was seen as a process that required mental activity involving judgment, discrimination, and choice of activity based on past experience (Lazarus and Folkman 1984).They further argue that the cognitive appraisal process was actualised in two distinct phases and that the vulnerability was different between individuals, as their minds are working at determining the type of stress they are faced with, and will also handle such stressful situation differently.

Lazarus and Folkman (1984) clearly identify the primary phase of appraisal during which the individual faced with a stressful situation will take time to analyse and interpret the stressor whilst also trying to determine the level of danger or how benign it was to the individual. During the second phase of the appraisal process, the individual is trying to evaluate the available resources available in themselves or in the immediate environment that will enhance coping with the stressor.

Whilst the literature does show various arguments and research conducted in field of stress, appraisal and coping and how people cope with stress, the works of Richard S. Lazarus and Susan Folkman (1984) were of interest in this study as the related literature helped set the study environment within which Antonovsky's model of Sense of Coherence (SOC) (to be discussed in detail later in the thesis) is adapted as the focus of the data generation and analysis. Lazarus and Folkman (1984) do acknowledge the works of Antonovsky's on the SOC and further argue that Antonovsky's SOC "being as one with the world should have emotionally supportive functions and that it was probably a positive factor in social and work functioning and health" (p. 67). Lazarus and Folkman (1984) are quick to mention that the concept views personal factors without due regard to the society the person lives in. Another theoretical framework by Dr. Susan Kobasa in the late 1970s, on the theory of hardy personality style as a moderator of the effects of life on illness was also mentioned in Lazarus and Folkman (1984). Kobasa's theory arguably does not offer much ground to support the current study, and was therefore not considered favourably by the researcher in selecting the framework to adopt in ascertaining the coping mechanisms of FC. Further, although Lazarus's and Folkman's theories of coping vis: "problem-focused coping" during which an individual tries to manage or alter the environment that has distressing effect, and "emotion-focused coping" where an individual is trying to regulate the emotional response to the identified problem at hand, are mentioned in this study, they do not take the central role in determining the coping mechanisms amongst caregivers.

These two models of coping (i.e. problem focused and emotion focused) according to Lazarus and Folkman (1984) serve two overriding functions as stated above. The two models arguably have influence on the other throughout the period during which an individual experiences a stress encounter, and they are also known to facilitate or impede each other. Whilst this conclusion may be positive and probably favourable, it may not provide an easy way to apply to my research process. According to my assessment, the kind of understanding of care at household level, coping with care and new knowledge to how Caregivers cope with caring work at household level may not be accomplished. The Salutogenic model of coping was therefore more favourable in my view. The description of the SOC with the components of GRR and how this can be applied to my research in understanding the day to-day functions of the carer was more favourable and was found to be easy to apply. The discussion of SOC by Antonovsky therefore justifies the arguments therein and that the themes focus on the (Comprehensibility) locus of control during which self-reliance in the face of challenge was an attribute an individual adopted, (Manageability) Self-confidence, self-efficacy were factors in the potency to deal with a demanding encounter and (Meaningfulness) which echoes motivation to go on and on and with basic trust placed in life events (Antonovsky, 1979).

Antonovsky (1979, 1987) further uses the term GRR that can be used to facilitate possible management of stress as maybe experienced by the caregiver. Whilst we understand Lazarus and Folkman’s argument about Antonovsky’s theory of Salutogenesis, related factors that are arguably essential for resistance to stress and sees resources as buffers of stress, whilst Lazarus and Folkman (1984) view coping as “process that evolves from resources” and see them as factors that proceed and influence coping. However, the salutogenic model was attractive, easier to understand and use in the sense that it was also a health promotion theory and facilitates the establishment of how people continue to remain healthy even when exposed to adverse situations of similar nature, whilst others fail and are negatively affected. In this study, I am examining the mental factors associated with FCs’ lived experiences in caring for chronically ill patients, and highlighting how they used their internal and external resources in health promoting way (Lindström and Eriksson, 2012).

The salutogenic model was according to Antonovsky (1996 p. 13) not a theory which focused on keeping people “well” rather in that it derives from studying the strength and the weakness of promotive,  and rehabilitative ideas and practices in public health. It is a theory of the health of that complex system of the human being.  Lazarus’s and Folkman’s theory of coping, was argued to be based on the emotional and behaviour aspects of coping, and was mostly culturally bound (Antonovsky, 1996). In my opinion and in my effort to analyse the lived experiences of caregivers, Antonovsky’s salutogenic model provided more favoured parameters or frameworks for understanding the effects of GRR and SOC of the caregiver. It was important to understand how caregivers’ life experiences helped them (caregivers) “make sense” cognitively, instrumentally and emotionally (Antonovsky, 1996 p15) of their care responsibilities.  SOC is not a culturally bound construct (as that of Lazarus and Folkman) but, one that was driven by a combination of cognitive, behavioural and motivational factors.

## Conclusions

In this chapter I synthesised literature that examines the concept of caring and explores caring in different contexts.  I looked at caring from different perspectives, as it relates to professional knowledge and skills, and from the perspective of an individual taking care of others at the household level. I further discussed the different parameters that constitute what it takes to care for others like, knowledge and skills, filial obligations and responsibilities, associated culture issues. I then linked these parameters to the concepts of caring for the chronically ill especially PLWHA and how gender, age, empowerment, and social support as resources contribute to caring. Finally I reviewed literature that discussed coping issues related to caring for the chronically ill and how individuals cope with different situations. In the next chapter, I will discuss in detail selected theories that form the basis for coping in different individuals and how they relate to this thesis and form the background information on how FCs devise coping mechanisms in care work.  In the next chapter I will give a detailed account of the salutogenic model.

## CHAPTER FOUR: The Concept of Salutogenic Model: Origin, its application and Implications

### Introduction

This chapter provides a review of related literature that forms the epistemological frame for discussing the reconstruction of caregivers' care environment. I have reviewed literature on Salutogenesis model and theories of coping. I have provided a brief insight into how the theories of Symbolic Interactionism can be used as a basis for the study framework which focuses on SOC, describing how FCs reconstruct their daily lives in relation to the social interactions which contribute to their sense of self. I shall expand on this introduction in the theoretical chapters and applied in the chapter discussing the research findings. I used different databases through the following search engines CINAHL, MEDLINE via EBSCO, Google scholarly articles, followed up with more referenced articles and from bibliography appropriate literature. Key words Salutogenesis, coping, symbolic interactionism, and general resistance resources.

### The Concept of Salutogenesis: Origin, Application and Implications

### Origins of salutogenic

The origin and application of the concept of Salutogenesis and the GRR were introduced by Aaron Antonovsky in the 70s and 80s. Antonovsky (December, 1923 – July, 1994) was trying to understand why some people regardless of the major stressful situations and severe hardships stayed healthy, while others did not (Antonovsky, 1979; 1987; Eriksson and Lindstrom, 2007). Salutogenesis according to Antonovsky (1987) is a concept concerned with exploring the origin of health or source of health. It is explained further by Lindström, Eriksson (2005 in Billings and Hashem, 2010) that is was a deep personal way of being, thinking and acting, a feeling of inner trust that things will be in order no matter what circumstances and independent of whatever happens. Salutogenesis highlights the attributes that enable an individual to display strength and capacity to do well and maintain good health even when exposed to adversity (Antonovsky, 1987).

Antonovsky viewed stress as a negative event that increased the susceptibility and risk of breaking down an individual. He observed that disease and stress existed and occurs everywhere and all the time and concluded that chaos and stress were part of life's natural condition (Lindström and Eriksson, 2006). Antonovsky's approach to stress and illness was Salutogenic, during which questions like "why do people stay healthy?" becomes the focus of the approach to dealing with stress and illness as compared to questions like "why do people get sick?" (Antonovsky, 1979; Johnson, 2004), which could be described as a pathogenic approach. Antonovsky's introduction of the salutogenic model was initially posed with a question like; what are the factors that produce health? (as opposed to asking what are those factors that produce ill health?). Antonovsky came up with key salutogenic concepts as generalized resistance resources (GRR) and a sense of coherence (SOC). While according to Billings and Hashem (2010) GRR could be considered biological, material and psychological factors that make it easier for an individual to understand and structure their lives, the SOC provides the capabilities to use the GRR. The GRR are money, social support, knowledge, experience, intelligence and traditions (Antonovsky, 1979, 1987). Antonovsky (1987, p.19) identified SOC with three main resources that may help facilitate individual's positive adjustment, how they deal with challenges, and how they cope with difficulties: these resources are the central component of SOC and are revealed by the extent to which one has the pervasive, enduring though dynamic, feeling of confidence that (1) *Comprehensibility: perception of* the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable and that when they came as surprises they will be ordered and explicable. (2) *Manageability: extent to which one perceives that* resources are available at one's disposal to meet the demands posed by these stimuli. These resources maybe under one's control or are controlled by others; and (3) *Meaningfulness: the perception that life makes sense emotionally and that* the demands are challenges worthy of investment and engagement (Antonovsky, 1979,).

Eriksson and Lindström (2007) and other researchers further observed that these two resources according to Antonovsky, refer to an enduring attitude and measure how people view life and, in stressful situations, identify and use their GRR to maintain and develop their health (Wennerberg et al., 2012; Johnson, 2004; Lindström and Eriksson, 2006; Eriksson and Lindström,2007, Klepp et al. 2007) . The SOC concept was therefore devised to describe the general orientation to life of an individual especially in the context of public health where one needs to explore the different characteristics existing in same communities where some individuals (who could be said to have a good or strong SOC) are able to cope better and remain in good health (Cowley and Billings, 1999; Lindström and Eriksson, 2006). SOC is thought according to Johnson, (2004) to mirror the quality of life of an individual in terms of internal responses, and that it precedes or enables adaptive coping with situations that are difficult and uncertain. Antonovsky according to Langeland, et al. (2007) views health as a continuum which regards a person to be understood to be an open system in active interaction, with different factors, experiences or occurrences within the environment as a source of both stressors and resistance resources. The concept therefore as argued by Antonovsky, (1987), has emphasis in human life which people need to invest in if they do not want to lose resources and meaning over time like  inner feelings, immediate personal relations, major activity, and existential issues.

This orientation is further argued to mean a reflection of self-esteem and perceived control over life events (Kalimo and Vuori, 1990; Underhill, Motzer and Stewart, 1996(in Johnson, 2004), self – identity, self-efficiency, self-regulation (Langeland, et al., 2007). The Salutogenic model provides the basis for explaining how health may be enabled. The Salutogenic orientation as provided by Antonovsky, offers the basis for a person's perception of the world around him/her, which is a factor in health promotion, where one with strong SOC is less likely to perceive a situation as less stressful as compared to one with weak SOC (Heiman, 2004).

Hence Feldt, at al., (2005; 2007) observe that SOC was not a personality trait or pointer to specific coping strategy, but argue that, the levels of SOC appear to be dependent on factors in cultures that provide the basis for coping processes. Feldt, et al., (2007), show the interrelated sets of beliefs in these cultures (reflected below) that make SOC low or high in an individual.

These beliefs are said to mirror internal factors of which the first dimension refers to locus of control, translated into sense of self-reliance; the second belief brings about the attribute of an individuals' ability of self- confidence to deal with the challenge or difficulty and the last belief is said to motivate the individual to go on despite the many challenges being faced. Meaningfulness is believed to be the heart of SOC (Heiman, 2004; Johnson, 2004; Feldt et al., 2007; Andershed and Ternesterdt, 2001). Therefore according to Antonovsky, these beliefs are the three main resources that may help an individual to adjust his/her sense of being at the time and be capable to deal with the challenge and further be able to cope with any difficulties (Johnson, 2004). However, despite the interrelatedness between comprehensibility, meaningfulness and manageability, Antonovsky still observes that its psychological constitution and health-relevant potential was still unclear. Other findings by Antonovsky, (1996) and Feldt, (2000) have indicated only moderate levels of long term stability, questioning further the trait nature of the concept.

Debate on the relevance of SOC and its relatedness to physical health and more especially mental health promotion continue. For example, Flensborg-Madsen, et al., (2006) in their reviews of Antonovsky's work, concluded that SOC as developed by Antonovsky 1923-1994 was unable to prove the association between SOC and physical health empirically. Although in their earlier paper Sense of Coherence and physical health: A review of previous findings conducted in 2005, did conclude that SOC scale was correlated with physical health. But was a weak predictor of physical health but powerful predictor of psychological measures including stress and behaviour aspect, hence not able to measure SOC correctly. They finally tried to improve the SOC scale to strengthen the correlation between SOC and physical health by revising the SOC scale. Erickson and Lindström (2006) further argued that contemporary global evidence base showed that strong SOC protect against anxiety, depression, burnout and hopelessness, and that is was positively related to health resources such as optimism, hardiness, control and coping. It predicts good health and quality of life from childhood to adulthood, the stronger the SOC the fewer the symptoms of mental health, and they concluded therefore that those with a strong SOC also have a better quality of health and mental health (Erickson and Lindström, 2006).They considered mental aspects as a factor in determining an individual's psychological health and the emotional aspect that was responsible for determining physical health (Flensborg-Madsen, 2006a; 2006b)

Barry (2001) views mental health as an integral part of overall health and also a factor in health promotion. She argued that mental health promotion focuses on positive mental health and that it aimed at building strengths, competences and resources. Mental health can be viewed as a community and individual resource during which there is interaction between person and social settings and systems including the structure of social support. (Oxford 1992 in Barry, 2001)

Barry (2001) further observes that comprehensive programmes that focus on young people and the environment, within which socialization takes place, do produce long lasting positive effects on mental, social and behaviour development. SOC is a long-life process, as maintaining health is a life-long learning process (Lindström and Eriksson 2012). Antonovsky's SOC therefore involves the ability for one to identify and use resources, a key element to the ability of gaining health and health promotion (Wennerberg et al., 2012). In a way, Lindström and Eriksson 2012 is in agreement that there is a stronger correlation between SOC and mental health and perceived wellbeing than objective physical health state of health and SOC correlates strongly to good mental health than perceived quality of life. In addition, Cattan and Tilford (2006) observed the strong association between behavioural factors and mental health for example in maintaining well-being and as a coping mechanism.

Horowitz (2000) observed that people who were optimistic in life live 19% longer than those who were pessimistic (Baron and Bryne, 2006). There has been awareness of people's own inherent coping and mastering abilities in recent decades (Klepp et al., 2007). In his argument (Klepp et al., 2007) refers to Antonovsky (1979) who viewed the world as a source of varied internal and external stressors that individuals deal with and explored the resistance factors responsible for protecting people from disease as they deal with stressful situations. Hence when faced with a challenge the individual will be expected to mobilize any resources available to address the challenge or the difficulty (Wennerberg, et al., 2012; Heiman, 2004).

Andershed and Ternesterdt (2001) observe that some of the problems and demands posed by living were worth investing energy and that when unhappy experiences were imposed on someone like a caregiver, they will willingly take up the challenge and be determined to work towards seeking meaning in the presenting situation. Pallant and Lae (2002 in Johnson (2004) conclude that a part of SOC appears to refer to an active and dynamic disposition which encourages adaptive coping. In caring for patients, most times the caregiver gets involved in care function because of the meaning the caring brings to the life of the patient and that of the caregiver.

Reading other literature and based on the works of Antonovsky, Cattan and Tilford (2006) observe that Salutogenesis theory promotes the critical need of looking at factors

that make some people continue living well despite being high on risk factors. Hence it asks questions such as: What is different about them? How do they cope? What helps the person to cope?, and why do some people cope better than others? (Cattan and Tilford, 2006)
For example, Cattan and Tilford (2006) earlier observed that an individual's wellbeing in relation to mental health vis-a vis supportive environment was a key factor in determining the resilience which enable us to enjoy life, and to survive disappointment and sadness.

Therefore, with the salutogenic model, Antonovsky redefines the environment and likens it to a flow of a river, as long as one has a breath of life, an individual will be floating in the stream of life. The stream with different risk factors, as the individual walks along the shore, there are experiences of many challenges and where safety was not always guaranteed. Mainly because the nature of one's river and the ability to swim and remain afloat are but the many factors that need to be considered whenever we are reviewing individual's abilities to meet challenges in life.

The SOC, although not a coping style, did facilitate the appropriate selection of the mode of coping. Therefore SOC will provide opportunity for the individual to cope with situations, and that ability to do so will depend on the internal and external environment and how the individual reacts to it (Forsberg-Warleby et al., 2002; Bengtsson and Bengtsson 2005; Klepp et al., 2007) based on how the situation is appraised. GRR and SOC can be positively related and compared to the interpretive approach in Symbolic Interactionism that provides an avenue for individuals to understand their internal and external environment and structure their lives in dealing with the environment more appropriately. However, it is also important to note that, the ability of the individual to identify and understand the elements in GRR should be viewed as key to the coping process. It is further believed that if individuals have these resources within their environment and within reach, there are chances that they will deal with life challenges better. SOC therefore provides the opportunity to use the GRR (Antonovsky, 1979). The degree or levels of SOC in an individual will facilitate the development of different perception of how to appraise a situation. Some will appraise the same situation as a threat whilst others will appraise it as an opportunity that is negative or positive and this is also dependent of the nature of the stress (Antonovsky, 1987).

**Table: 4.1. Dynamic Interrelatedness of the SOC Components**

| | **Component** | | | |
|---|---|---|---|---|
| **Type** | **Comprehensibility** | **Manageability** | **Meaningfulness** | **Prediction** |
| 1 | High | High | High | Stable |
| 2 | Low | High | High | Rare |
| 3 | High | Low | High | Pressure to move up |
| 4 | Low | Low | High | Pressure to move up |
| 5 | High | High | Low | Pressure to move down |
| 6 | High | Low | Low | Pressure to move down |
| 7 | Low | High | Low | Rare |
| 8 | Low | Low | Low | Stable |

Source: Antonovsky, A. (1987 p. 20)

Table 4.1 above provided the study with the guide to understand the components of SOC, whilst explaining how the components of SOC are interrelated. Antonovsky (1987) observed that types 1 and 8 as high on SOC, hence do not pose any problems as they will view the world as high on coherence (type 1) and low on coherence(type 8). Whilst types 3 and 6 are inherently unstable in that there will always have the desire to move up (type 3) and move down (type 6). Further, type 4 is viewed as the most interesting as the person who is low on both comprehensibility and manageability tend to show the spirit of wanting to be engaged in the search for understanding and seek resources for addressing the challenge at hand. Although there is no guarantee that there will be some success but, the effort will have been made towards that type of result (Antonovsky, 1987). These three components in the framework were important during the analysis of data in trying to understand and answer the question relating to the “WHAT” was going on in the daily lives of caregivers and “HOW” caregivers were coping and dealing with the different circumstances related to care work.

### Coping and Stress properties

People manage life events in different ways. Some manage life events better than others, whilst others continue to struggle and the process to struggle differ in different individuals despite being so “high on risk factors”. The GRR as observed earlier, are an individual’s attributes that could be associated with life skills training that help determine how one will survive the encounter with a stressful situation and have the ability to cope.Researchers have over the years conducted investigations into the psychosomatic domain finding out the construct of coping and Oxland et al., (2004) argued that there are many definitions of coping that have been proposed. However, recognition of coping definition as researchers have observed is based on the one propounded by Lazarus and Folkman (1984).

Coping therefore means responding to those demands in a way that reduces the threat and its effects; it includes what a person does, feels, thinks in order to master, tolerate, or decrease the negative effects of a stressful situation (Baron and Bryne, 2006). The understanding of coping means that there is need to be aware of the process that an individual goes through in an effort to respond appropriately to the situation, which is a major factor in understanding coping mechanisms. In coping an individual makes deliberate effort to consciously address or deal with a stressful situation. An individual will adopt different coping strategies in trying to overcome the stressor or may adopt other methods to avoid the stressor (Love, Zahir, and Marinos, 2001).

Stress is described by some experts as “an event that produces tension or worry”, while others recognise stress as a person’s physiological or psychological response to such an event” (Kasschau, 1995 p. 317). While stress is said to mean any physical or psychological event that is perceived as a potential threat to physical or emotional wellbeing of an individual (Baron and Bryne, 1995). The research on stress reveals that individuals vary in the way they react to stress, as an event that stresses one may not stress the other (Kasschau, 1995; Baron, and Byrne, 2006). There are internal factors in an individual that are responsible for the ultimate reaction to that particular event. These reactions according to Kasschau (1995) may be perceptual, cognitive, or emotional to what is stressing the individual, (also Baron and Bryne, 2006).

The above observations can be viewed to mean that stress is a normal daily process in one’s life. As one faces the daily challenges, the individual will work hard to overcome the presenting challenges with the goal to register greater achievements (Kasschau, 1995). It is argued and observed that coping with those challenging situations, makes life very interesting, as “complete freedom from stress is death” (Selye, 1974 in Kasschau 1995).

However, Folkman (1984); Folkman, Lazarus, Gruen and DeLongis (1986 in Eaton and Bradley, 2008) earlier observed that contemporary cognitive approaches conceptualizes stress in relational terms as a function of a mismatch between perception of environmental demands and personal resources. These two internal processes according to their argument are thought to play a mediation role between exposure to potential stressor and the health related outcome. This perception of the stressor results in a subjective process of appraising the stressor. Eaton and Bradley (2008) further argued that during the stage of cognitive appraisal the individual will go through the process of interpreting the event and determine the stress impact hence shaping the outcome.

Folkman and Moskovits (2000) recognise that adjustment leads to psychological well-being, hence the important need for a positive psychological state in any individual as they face a stressor. The process of appraisal involves making a mental assessment of the stressful situation, which Clark and Stone (2007) observe, is done to ascertain the importance or significance of the stressor to that individual. The individual will conduct a primary appraisal by carrying out cognitive and physical identification of the stressor and continue to evaluate or make judgment (secondary appraisal) of whether there are internal and external resources available to deal or not deal with the situation (Lazarus and Launier, 1978; Schneider, 2008; Eaton and Bradley, 2008), subsequently one will feel confident or feel fearful to deal with the situation.

Individuals have different perspectives on different presenting issues; the manner in which the individual perceives the significance of the event will therefore be a factor in determining the outcome of the appraisal. As the appraisal is in process, the individual internalizes the threat and as he makes a decision, this will in most cases be based on past experience, age, gender, and beliefs (Clark and Stone, 2007). This may also be true of the FC who, having conceived the challenging situation, will appraise the situation and behave in accordance with her choice of action.

Making choices in coping has been argued to be dependent on past experiences and more especially those choices that had worked well. People have been known to withstand difficult pressure and have dealt with stress with strength and resistance. Researchers have also identified factors like resilience as some attributes that have made some people cope better and continue with good health (Antonovsky, 1979, 1987; Cattan and Tilford, 2006).

Family environment has been known to enable coping techniques, for example, parental supportiveness and the level of structure and organisation within the home (Hardy, et al., 1993 in Martin et al., 2004 p. 284) are some of the factors to support coping. Others include, relationships between parent and child and there is evidence to support the assertion suggesting that patterns of coping differ according to the family composition (one-parent versus two-parent homes) (Brazil and Krueger, 2002 in Martin et al., 2004) and the same could be assumed to relate to family relationships.

In the advent of AIDS and its chronic nature, many providing care are not professional carers or health workers, but volunteers, family or friends. Increasingly, care providers in households may be trying to cope with stress in attempting to meet different needs of patients, their own needs resulting from lack of resources, support and training needed to provide the care (Manchester and Barnes, 2000; Homan et al., 2005). The underlying factors in coping may have the following elements: Firstly the individual becomes aware of the threat, mental recognition of the threat, evaluation of the threat, determining whether the threat is benign or an impending danger. Secondly, there is an appraisal of the individual's ability to deal with the threat in whatever format it may present itself. In determining resources to deal with the threat, the individual further analyses the effects of the threat to self or others, whether there has been past experiences and how resources were galvanized. This process usually takes short times as decision for example to Flee or fight will need to be arrived at. The arguments put forward by Lazarus and Folkman (1984) are that in coping, there are process that constantly are changing, are specific, and requires some form of effort to be made to address, manage them either positively or negatively. These are factors that are being managed in each individual's daily life.

Individuals with low resilience skill and those who are disadvantaged may have more difficulties. Schoon, (2006) has expounded on the concept of resilience as an attribute in an individual that result into positive outcome in behaviour despite experience of adversity. Further, Schoon (2006) argues that an individual will exhibit continued positive or effective functioning in adverse circumstances or recovery even after significant trauma (Masten et al., 1999 in Schoon, 2006). The central and underlying assumption in the study of resilience is why and how others continue to do well even when exposed to similar adverse risk factors, while others do not. (Schoon, 2006; Schmolke, 2005)

The ability of an individual to cope will also be dependent on mental and physical health status, and that may also be an attribute in counteracting the effects of stressors (Bengtsson and Bengtsson, 2005; Cattan and Tilford 2006; Dixey, 2013). Bengtsson and Bengtsson (2005) further argue that social support is valuable for a healthy life as it helps people avoid getting into stressful situations and events. For example, the ability to deal with or not deal with a stressful situation may depend on one's resilience (the concept of resilience will be discussed in detail later). An individual's skill to recognise, find meaning and adjust to social support can be factors in the ability to cope with stressful situations (Klepp et al., 2007). However, the ability to recognise that some form of support exists within the community is one step caregivers can take to manage a stressful situation and be able to cope.

### Coping strategies

People face different challenging and/or stressful situations differently. Eaton and Bradley (2008) argue that when individuals are faced with identical stressors, they will differ in the way they appraise the stressor, the way they react and the choice of coping strategies. Coping strategies according Lazarus and Folkman (1984) refer to a person's behavioural and psychological efforts to manage stressful events.

Monat and Lazarus (1991) describe coping as the way individuals physically or mentally deal with or adapt to a threat (also Lazarus, 1993). To avoid the unpleasantness of arousal evoked by strong emotions (especially negative e.g. fear, anger or anguish) people often seek cognitive or emotional ways either to fight or flee when encountering these affects (Johnson, 2004). It is natural that individuals will adopt ways that had previously worked best for them (Endler and Parker, 1990). Schneider (2008) further argues that if the significance of an event is elusive, it will be more difficult to evaluate its relevance to one's beliefs, values, goals and the extent to which one begins to evoke any type of appropriate coping strategies.

Studies on coping strategies, styles, and mechanisms have examined the common framework based on the works of Richard Lazarus and Susan Folkman (1984), Martin et al., (2004). These researchers claimed the different coping styles which are either active or passive. Active coping style is problem-focused and occurs when an individual views a stressful situation as amenable to change and include techniques such as generating solutions and learning new skills to deal with the challenge, hence efforts are made to take action and alleviate the stressful circumstances. In accordance with Lazarus and Folkman (1984), emotion –focused coping occurs when an individual believes that nothing can be done to change the presenting stressful situation and will include techniques like avoidance. Further it is argued that emotion-focused coping also aims at reducing unpleasant emotions resulting from the stressor by, for example, accepting responsibility, seeking support from others, venting of emotions, and self-blame (Martin et al., 2004; Eaton and Bradley, 2008). In coping with stressful events, individuals carry out cognitive appraisal of the event which is a process of evaluation that reflects the individual's subjective interpretation of the event (Lazarus and Folkman, 1984).

Studies that have compared the effectiveness of passive versus active coping styles have found that among HIV-positive adults, passive or avoidant-coping techniques are associated with higher levels of distress while those active coping techniques are associated with decreased emotional distress (Martin, et al., 2004).

### Resilience a Resource to Coping

Active coping mechanisms, which can be described as resilience, have in the past decade been receiving a lot of attention, and research has been conducted to understand the role of resilience in public health and its effects on families and individuals (Walsh, 2002). A scientific focus on resilience has been mostly aimed at generating understanding as to why individuals or families differ in the manner in which they react to adversities within their environment. For example Windle (2011) conducted a comprehensive review and concept analysis of resilience, from psychoanalytical, ecological and sociological perspectives. In the review it was observed that resilience could be understood or defined to be a process involving effective negotiating, adaptating to or managing significant sources of stress and trauma. From the individual's perspectives, they argue that assets and resources within the individual, their life and environment were key facilitating factors in adaptation and "bouncing back" in the face of adversity. However, they also concluded that there were variations in the experience of resilience across the life course. (Windle, 2011).

Walsh (2002), described resilience as transactional between the individual and his/her environment. For example, traditionally, life skills training were taught in the home but the trend of deliberate teaching of life skills has grown as a response to some levels of diminishing in families. The life skills training as discussed in this study were reported to be individually focused and linked to empowerment and self-efficacy, factors that help an individual achieve some form of control of what was happening in their lives and these accordingly is related to attainment of high self- esteem (also Dixey, 2013)

Resilience means, in general, psychic resistance, despite stressors, adversity, high risk environments, and challenges in different stages of human development (Schmolke, 2005). He further argued that, research on resilience in the 1970s-80s and in several bio-social medical disciplines mostly came from the United States of America (USA) and Great Britain. Resilience is the capacity of people to decrease the impact of events that negatively affect their health, livelihood and human development" said Thierry van Basterlaer, (July 2012 anecdotal evidence).

It is with the above definitions and observations that explanation may be made of why some individuals that are reared in adverse circumstances appear to live a more healthy and productive life than others (Blum, 1969). I have heard such people being referred to (in Zambia) as "survivors" and can be of any age groups. However, research on resilience within the discipline of developmental psychology has mostly focused on children and adolescents (Windle 2011). Having had made this observation, there are still methodological limitations in the way the subject of resilience has been discussed in other studies which according to Windle (2011) was based on concept analysis, which is a process used routinely to understand concepts by clarifying meaning and develop operational definitions (Walker and Avant (2005) in Windle, 2011). However, it is argued that despite these analyses, the aims of the analyses were not clear, search strategies were not provided and so was the extent of coverage and other observations that could have made possible to omit other attributes of resilience. For example, Windle (2011) argues in his review that some studies conducted by Gillespie et al., (2007) state that self-efficacy, hope and coping were the defining attributes, and whereas Dyer and McGuiness (1996) stated that a sense of self determination and pro-social attitude were other defining attributes. His reviews have common elements that describe or even define resilience- ability or capacity to “bouncing back, to thrive, maintain equilibrium, not to be adversely affected by stressor, personal strength” (Windle 2011, p 152).

Resilience therefore can be defined differently depending on the context and the perspective of use and its application.  In the context of this study, resilience is being used in relation to how FCs continue to “function” presumably well under currently adverse conditions (stress-resistance/coping) (Windle, 2011 p.156), for resilience to take effect, there should be other factors that promote its actualization in an individual. These according to Windle, (2011) are the protective factors that constitute the basics for interplay to achieving resilience. The protective factors are said to be at three levels Vis: individual (psychological, neurobiological) social (family cohesion, parental support); and community/societal (support system.).

### Resilience in Families: A Resource for Coping

As stated above research on resilience has been receiving much attention as more and more scientists are trying to understand the differences between individuals, where when exposed to same adversity, there were marked differences in the outcomes. Resilience was viewed as an “in-born” attribute or was acquired through own effort, and overtime from experiences of life time events. However, there were other observations that viewed resilience as a factor during the interplay of risk and protectiveness overtime, involving individuals, family and larger sociocultural influences (Walsh, 2002).

In discussing family resilience, Walsh (2002) describes the process as one that is premised on strengthening family capacities to address situations that they are faced with. She further observes that the capacities being strengthened are those that enable one to master adversities, while recognizing the fact that when stressful crises occur, in most situations they affect the whole family. The family responds through a process of mediating the recovery and resilience of the vulnerable family members (Walsh, 2002).This process, as noted in the earlier section of this chapter, allows for the family to understand the nature of the adversity through the appraising process. The process therefore facilitates the building of family strength to address the problem or challenges and subsequently reducing its effect especially on the levels of vulnerability.

It is further argued that family distress, may in most cases result from failure to successfully address an adversity or challenge that may be appraised to be overwhelming, thus appraising and viewing themselves as not having the potential to do anything (Walsh, 2002). The presence of HIV/AIDS in a family for example, can be termed as such life event/crises that can cause persistent stresses which can eventually result in derailment in the functioning of a family way of living. As noted earlier, HIV/AIDS in families contributes to disturbances in most family structures, for example, men and sometimes in the productive age groups have been severely affected with the pandemic, leaving women or the elderly to take care of those remaining in the households (Williams et al., 2010). This situation therefore is a factor that may expose them to different forms of adversity at different times in the life span.  However, despite these crises, some families have emerged and have dealt with the challenge positively.

Research has shown that a family-resilience approach to practice stems from the conviction that families have the potential to recover and grow from adversity (Walsh 2002). For example an old saying in Zambia with similar connotation is “Tukaba bwino kuntanshi” meaning that “we may struggle to-day, but things will be better in the future”. This belief gave some individuals the impetus and the zeal to work harder with the hope of attaining a better future.

The family resilience framework developed by Walsh (2002) was aimed at guiding clinical practice, as it was informed by  a number of research studies, that sought to contribute towards the understanding  of resilience at the individual level and that related to a well- functioning families(Walsh 2002). She draws on these studies in order to conceptualise the concept of resilience and how determination of functionality of individuals within the family and the family as a social unit.

The framework essentially, has benefits in that it does offer a conceptual map facilitating the identification of target key family processes that are known to reduce the risks of dysfunction, buffer stress and encourage healing and growth from a crisis. Thus the framework does help identify the three domains of family functionality; including family belief system, organisations and communication process (Walsh, 1998b). Through the processes of the family belief systems,  families can be helped to gain a sense of coherence Antonovsky and Sourani, (1988) by looking at a crisis as a shared challenge that is comprehensible, manageable and meaningful (also referred to as GRR  by Antonovsky, 1979, 1987) to address. Therefore the “can- do-it” spirit is subsequently enhanced making the individual or family members to go on and address the challenge.

In another related argument Windle, (2011) views SOC a theory of Salutogenesis which had been closely linked to resilience as both are trying to understand the attributes from the perspective of how people manage difficult situations and continue to stay well. As noted earlier in Walsh, (2002) both theories incorporate protective factors which have been referred to above as GRR which are resources that either promote a SOC or does not promote it. The sense of coherence according to Aaron Antonovsky is believed to be formed in the first 30 years of an individual's life. Resilience however is not a stable attribute since it is dynamic and depends on different factors related to the adversity. Lindström, Ericksson and Wikstrõm (nd) view resilience as an assets approach to Salutogenesis which is under the umbrella directly connected to Kobasa's theory of hardiness. Some individuals with the ability to bounce back can also be likened to Kobasa's theory of "Hardiness" (Kobasa, 1979), which was introduced to describe a stable personality resource consisting of three main attributes like; commitment, challenge and control during which those committed are said to turn events into more meaningful and important situations. Whilst control is viewed as one's ability to have strong belief that certain situation or events can be overcome or dealt with as long as one puts in an effort.

### Conclusion

In summary this study therefore carefully reviews and discusses the Salutogenic model as it relates to understanding the coping mechanisms of family carers in HBC in Zambia. The concept of Salutogenesis by Aaron Antonovsky is said to bring out some inner attributes of an individual that make one avoid getting into disease status despite being exposed to stressful situations The chapter brings out key concepts and models related to coping and their importance associated with appreciating the concepts in order to have an informed understanding of the care environment in home based care services. Utilising key concepts like caring, coping and related processes, the salutogenic model provides a richness of informed understanding of care environments, both internal and external. Resiliency was introduced as an attribute in the domain of caregiver that according to research has explained the differences in how individuals deal with different care situations and make positive or negative contributions to the well-being of the patient and the household.

# CHAPTER FIVE: Application of the Theoretical Framework to the study process

## Introduction

This chapter will describe the conceptual framework for the research, drawing in the theories presented so far. It will show how the salutogenic model can be built into a conceptual framework that will guide the study.

In the appraisal of the different theories that provided the guide to the writing of the thesis, I make careful selection of key words and concepts that appropriately inform the reader with the relationships of the components to coping by adopting the salutogenic model as the main guiding theory that will assist in understanding coping mechanisms at household level. The chapter relates to coping theories and how these contribute to the different levels and types of coping, to symbolic interactionism as an approach to understand behaviour. The chapter further gives an explanation to questions "why", "what" and "how" of how words, actions and language are used in caring and subsequently finding factors that influence coping mechanisms adopted by caregivers. The framework uses the key concepts of Family carer, Salutogenic model: SOC and GRR Comprehensiveness, Manageability, and Meaningfulness and/ Emotional Closeness), coping, and other related concepts providing meaning to coping at the household level, which were discussed in the last chapter.

## Symbolic Interactionism

The purpose of the study is to explore how those providing home based care services cope with the burden and dictates of caring functions. The key components of this study are presented and discussed, their key relationships are described. This chapter therefore, sets the parameters for discussing and presenting the study process and its results. In order to achieve this, an Interpretivist approach, located within the limits of Symbolic Interactionism Theoretical Framework was adopted. Blumer (1969) observed that SI came into use as a "label for relative distinctive approach to the study of human group life and human conduct" p.1. A key assumption of this framework, according to Berg, (2004) is that symbolic interactionism (SI) in qualitative research, describes aspects of human behaviour, what they say, do, the results of how they interpret their social world. He (Berg, 2004) further observes that SI provides explanations of how communication takes place and what they learn through symbols. Social Scientists and Researchers take on roles to capture the meaning of this human interactions and capturing the essence of the interaction process thereby interpreting or attaching meaning to what was being said using language as a symbol of communication (Berg. 2004). Blackie (2000) argued that the construction of social reality is a symbolic world of meanings and interpretations, which seek to discover what people do and why they do those things, whilst uncovering mutual knowledge, symbolic meanings and motives and rules (Blackie, 2000). For example Serpe (1987 p 44) had observed that SI seeks to understand behaviour highlighting the 'Why' and 'how' individuals select among role performances, a specific way of doing things whilst selecting from different possibilities: "why one person chooses to work over the weekend and while the other chooses to spend time with his/her child". This person is signaling what is important or otherwise. Berg, (2004), alludes to SI as central to qualitative methodology. SI is viewed as an umbrella concept within which a variety of theoretical orientation can be placed and is a concept that furthers the focus of SI on the subjective understanding, perceptions, about people, the symbols and other objects used in their daily interactions. Blumer (1969) argued that people act towards things based on the meaning the thing has for them. This meaning he observed is derived from social interaction with others, and that the meanings are handled or modified through interpretation made by the individual.

The suitability of SI in this study is anchored in the belief and understanding as described by Mikkelsen, (2005) that:

> *People transmit and receive symbolic communications when they socially interact. People create perceptions of each other and social settings. People largely act on their perceptions. How people think about themselves and others is based on their interactions.* (Mikkelsen, 2005: p158)

The descriptions therefore show the basis upon which meaning can be explained in any interaction and behaviour therefore becomes the central part of the discussion on SI. Mutual knowledge is an attribute related to the background of persons in a community, which is constantly being used and modified by the social actors as they continually interact and it consists of beliefs and practices (Blackie, 2000). During the process, individuals take part in the social construction of reality of their world, of which Lakey and Cohen (2000) explain that people will construct theories of their world based on their understanding of their own social context which has a bearing on social support. Accordingly, in a symbolic interactionist perspective, the social environment is believed to promote health and well-being by providing people with a way of making sense of the world around them especially through the use of language and symbols (Lakey and Cohen, 2000)

The study therefore focuses on ways caregivers as a group in the society interact with care situations and manage their patients within the HBC context and interpret the care reality. Arising from this attention, different cases of FC's views about coping is presented in the findings and compared in order to arrive at theory/theories/models of coping. Theory/model of coping development in this study is grounded in the behaviour, words and actions of FCs during their daily encounter with caring roles and responsibilities.

Building on SI, theorists observe that "individuals engage in a world which requires reflexive interactions linking to the environmental response" (Goulding 1999, p 5). These responses are purposive and hence individuals act or react to environmental situation according to the meaning that is held for them. The meaning comes from societal interactions where the interpretation is attached to different forms of communication such as language, gestures and the significance of objects. It is the behaviour of the FC as they socially interact with patients that give the interaction meaning and the environment of care that justifies this framework in this study. The study further constructed what the caregivers see as their social reality and how objects or experiences contribute to the construction of this reality, and provide the basis upon which SOC can be explained at the household level. Meaning as conceptualised does not depend on people, objects nor situation but according to Berg (2004, p 9) "meaning is conferred on these element through and by human interactions". Individuals will confer meaning to their everyday life and how they interact with situations, and objects.

By adopting Antonovsky's theory of Salutogenesis, (which was explored fully in chapter four), this study sought to understand the mental process of how FCs interact with internal and external environment in coping with care functions. Further, Dixey, (2013)(ed) observe that healthy communities are salutogenic and that positive health outcomes in an individual are also dependent on the way they viewed their life. Therefore, living in a community that facilitates individuals to build their SOC was salutogenic, and these can be linked to communities with different levels of social capital and network support (Dixey, 2013). There are other key protective factors like "being able to get the needed support”, “Focus on religion” with their effects on the individual were observed to have a bearing on the development of resilience and contribute towards wellbeing (Billings and Hashem 2010; Langeland et al., 2007; Lindström and Ericksson, 2006).

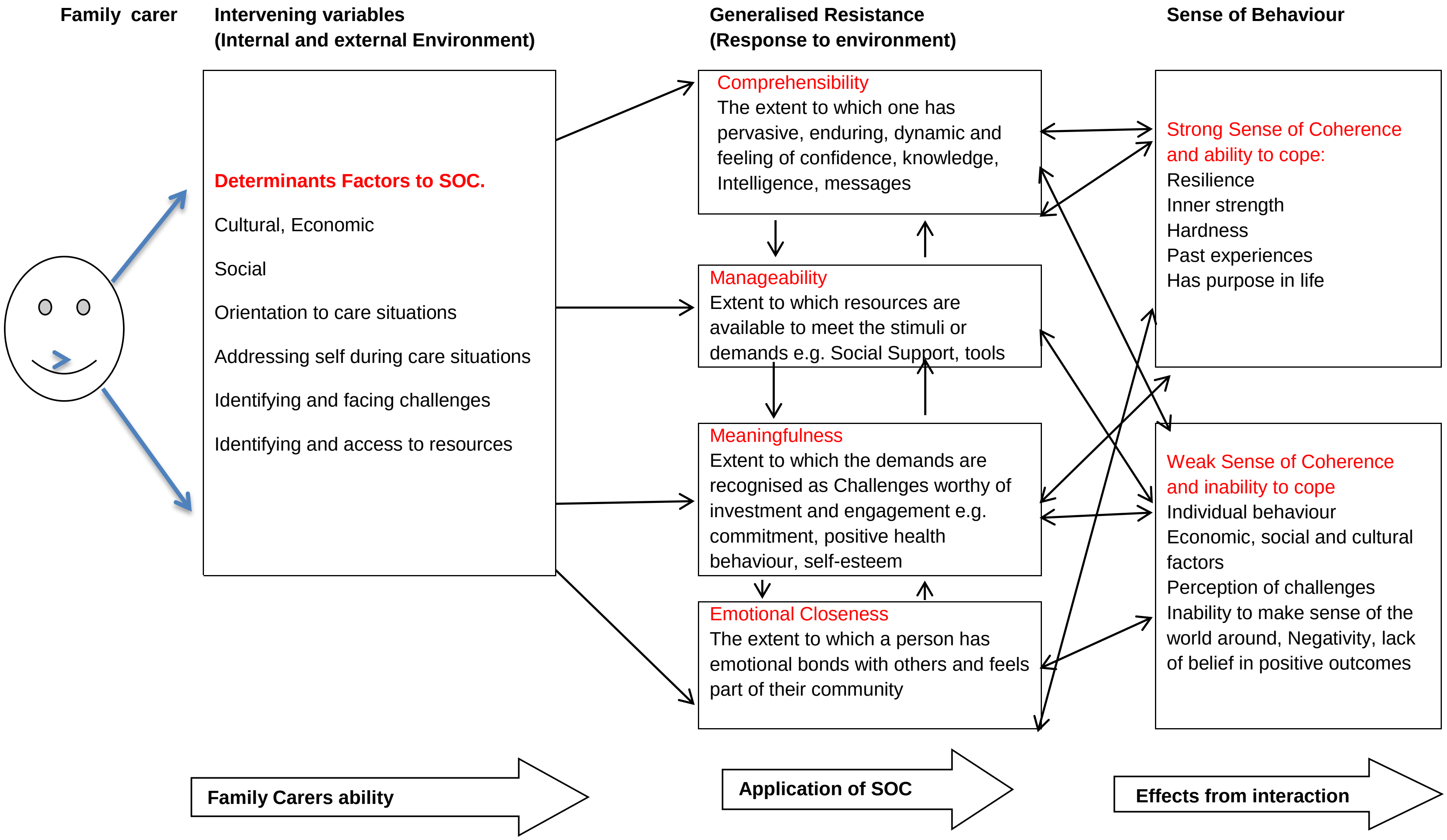
The framework is built around the way people/individuals use words, actions to communicate as they interact with their internal and external environment. However, the responses to stimuli that may be seen to bring about observed behaviour lies in a number of factors which develop throughout the course of life and further determined by life experiences. These are some of the factors in sense of coherence (Goulding et al. 2010; Cattan and Tilford 2006; Cowley and Billings 1997; Langeland et al. 2007; Lindström and Ericksson 2006). However, SOC is made real when an individual has the ability to identify key structures within the internal (self) and external (outside self) environment. Meaning that, the individual will be expected to use his or her capacities and resources to address those factors that may be found to be exerting pressure or challenges. Thereafter, will structure their lives in care environment and subsequently work towards identifying of resources within or outside that are or maybe important in addressing the challenges being faced. Antonovsky called such factors as “Salutary” as they did help individuals cope better despite the effects of the stressor (Antonovsky, 1990, 1979, 1987). The GRR according to Lindström and Ericksson (2006) are important ingredients (resources) to SOC. It is further believed that if individuals have such resources available to them or have in their immediate surroundings, there are possible chances they will deal with challenges of life better (Antonovsky, 1979, 1987; Lindström and Ericksson, 2006; Johnson, 2004).

## Theoretical Framework

The theoretical framework Table 5.1 below shows how different factors affect behaviour and the intervening variables that could be responsible for behaviour in coping with stressful situation as FCs provide care to chronically ill patients.

The meaning or explanation of SOC is described by Antonovsky, (1979, p 123) as “ a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one’s internal and external environment were predictable and that there is a high probability that things will work out as well as can reasonably be expected” A strong or weak SOC plays a major part in determining whether an individual chooses to remain or change one’s structural situation.

**Figure 5.1: Conceptual Framework of Sense of Coherence: Adapted from works of Antonovsky, 1979, 1987**



The framework in Figure 5.1 above provides the basis for understanding the work of FCs in HBC setting whilst being mindful of the fact that FCs operate in an environment where the support structure is understood to be not well defined. In line with Antonovsky, (1987) in Johnson (2004), SOC as adopted in this framework in figure 5.1 explains that:

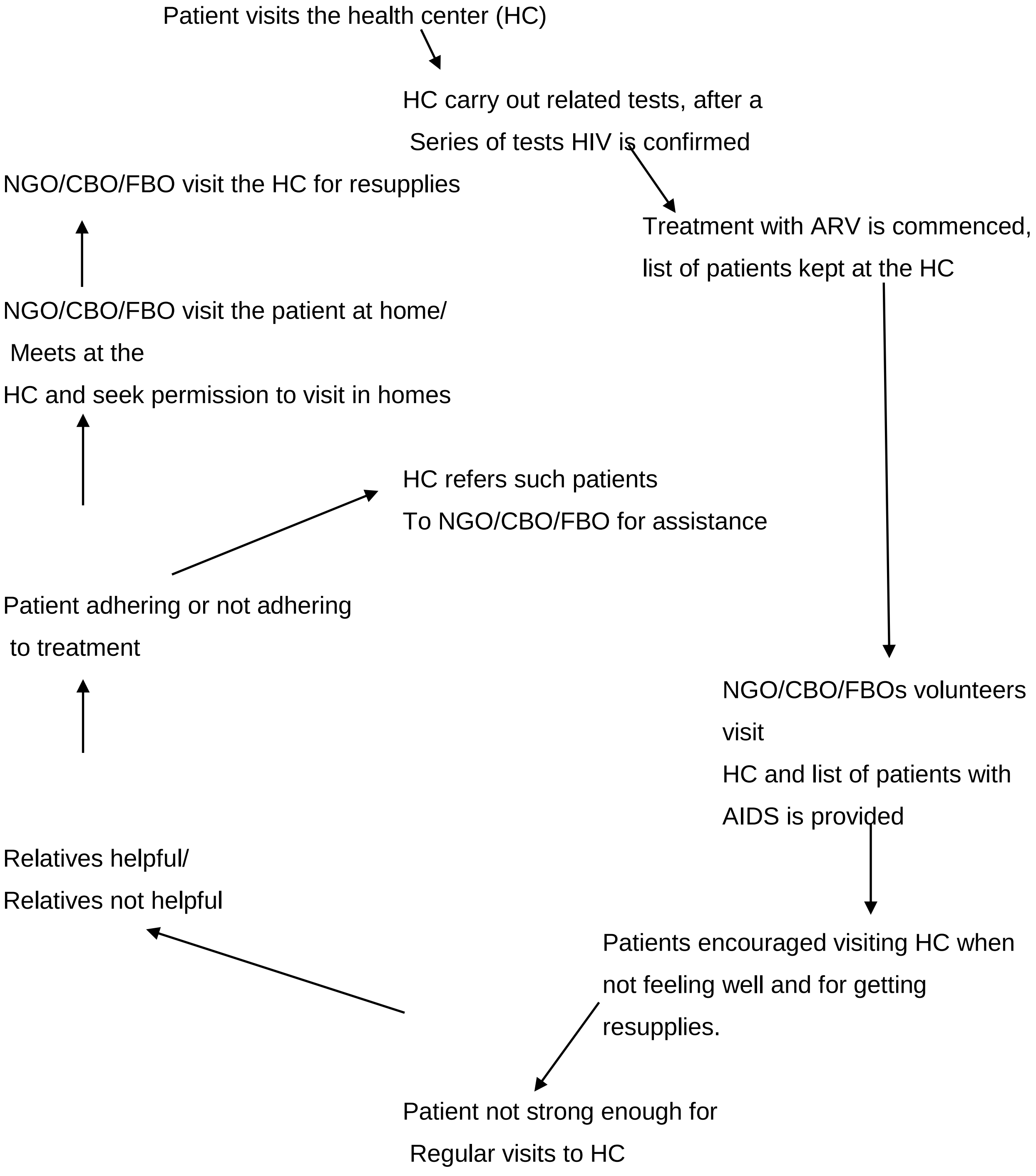
Coping mechanisms are actualised by individuals, with the central base in the development of knowledge and skills through life long experiences and other genetic, psychological and sociological factors as key determinants in the resultant behaviour of the individual. SOC therefore provides capability to use the GRR alongside ability to manage the many stresses an individual encounters in life (Benzl et al., 2014).

The framework includes the concepts and thoughts that are important to this research and I have tried to give a presentation of the key relationships between these concepts. The FC being at the centre of the framework is the individual charged with the responsibilities of providing care to chronically ill patients. However, according to the internal and external environment within which care is being given, there are expectations by the community, of the FC in ensuring that patients were well cared for and provided with basic needs necessary to improving health. Therefore in addressing the effects of care demands and situations, the FC will be required to possess certain positive physical, psychological, and social attributes that will enhance the process to positive results in the care but more specifically how the FC cope with challenges in the interactions with the care environment.

Within the environment both internal (in the individual) and external (outside the individual), exists the determinants of care provision that will either enhance ability to provide care and have less untoward effects of care. The determinant factors for SOC to be high or low are the way the caregiver responds to cultural, economic, social demands. Further, it is important to note how the caregivers orientation to care, how they address themselves in the “fit” of care scenarios including the preparedness to face related challenges.

The framework therefore describes the determinant factors as those that are within the social cultural context described by Antonovsky (1979; 1987). The framework further demonstrates that interactions were seen to be dependent of broader picture of HIV/AIDS response structure in the community (see Figure 5.2).

**Figure 5.2: Identification of patients needing support from and by the Care Environment in the community**



Current structure to support PLWHA and offer continuum of care

These are the facets and the understanding of Salutogenesis/SOC that were used in understanding the behaviour of FCs for chronically ill AIDS patients in HBC in Zambia.

Antonovsky, (1979, p 108) viewed GRR the central concept to ego- identity when discussing emotions of an individual. He further postulated that knowledge –intelligence was central decisive GRR in coping with stressors and the framework points to possible existence of these abilities in the caregiver and how they contribute to management of care of chronically ill patients. He (Antonovsky 1979) went on to observe that a strong ego-identity was taken to be the equivalent of mental health and subsequently physical well-being. In this framework and going by Antonovsky's (1979), postulation, views the central component of GRR to coping strategy as those that promote rationality (an objective assessment of extent of the stressor as whether a threat or not); flexibility (availability of contingency plans or tactics and of the willingness to consider those plans either by constant reviews of the plans or strategy as dynamic in nature) and foresightedness. In this context, we are looking at how the caregiver will be rational and flexible in dealing with care roles and be able to take actions based on the elements of GRR. However, the framework above provides a guide on how the different components in this study describe the world within which caregivers provide care and attempt to recreate the care environment thereby giving a clear frame in which to research this environment.

Salutogenesis which can be linked to the strategy of primary health care and health promotion will facilitate the "unpacking" or putting care work in household into context and appropriate compartments that make caring comprehensive. The model will provide a lens through which the lived experiences of FCs can be understood. The three components of GRR whilst being central to ego-identity, when discussing behaviour and emotion of and individual, they form a key part in understanding and explaining the roles played by FCs during care work. In my opinion, the salutogenic model offers a unique opportunity for exploring and describing the work of FCs. The work of FCs at household level fits very well within the description of GRR as they relate to the different roles and segments of caring in the household. FCs are expected to provide care to their patients or family members however, through the GRR lens, we begin to see that caring may not only be about what we see in everyday life. It is about how someone has been prepared to assume the caring role, what messages and how consistent the messages had been during the period of preparation. The GRR components as a framework in this research facilitated bringing to the fore the ways that FCs are prepared to provide continuum of care in the households. Preparation spans to the first 30 years of life (during which according to Antonovsky, 1979, 1987, SOC is developed) when socialisation of an individual mostly takes place. The salutogenic approach will facilitate the initiation of identifying individual GRR for caregivers (Wennerberg et al 2012). In my view, I find the salutogenic model more favourable to enhance understanding the tools that were made available to facilitate an enabling environment for FC to manage related care work in households. It is the enabling environment in each family that is important to building up of capacities to care, and ensure that an individual lives up to the values and norms of care in the family. The values and norms will mostly depend on the culture of the family and how they perceive the different roles each family member will play.

The roles that culture place on people provides for understanding of those roles and subsequent behaviour associated with the roles. I support this model as the norms and values are anchored in every culture of a tribe or family. In describing FCs in this study and by using the salutogenic model, I believe, there will be more revelation of different factor associated with care work and how FC fit into their prescribed role to care family members and bring to life the lived experiences and how coping or not was taking place.

Salutogenesis therefore, will facilitate our understanding of how FCs make sense of the world around them, how they will conceptualise resources needed to live, how to use the resources and provide meaning to their actions. Benzl et al., (2014) argue that comprehensibility comes from a stable culture, where an individual will receive messages that are consistent, manageability is associate with the tools made available to an individual in order to live a life which responds to the values and norms and meaningfulness was related to how we value roles of people through what culture has placed on the roles.

### Intervening variables

Culture gives individuals place in the community and society and the world they live in and according to Antonovsky (1979) is also a health promoting factor. The understanding of culture according to Cattan and Tilford (2006) is important to explanations related to the way individuals adopt coping mechanisms, which is further related to the need to recognise the parameter of the environment in which an individual was raised, for the adoption of coping skills.

Johnson et al., (2004) observes that striving for self-esteem may contribute to a sense of meaning, engagement, and purpose in one’s life, and they are factors that may facilitate the development of some sense of competence and self-pride in an individual, explaining the reasons why some individuals, despite not having undergone any orientation to care, have been known to provide what may be termed adequate care to their chronically ill patients. There are acknowledged variations in culture, norms, and values in different ethnic groups. The way individuals react to situations may in most instances depend on the structure of orientation process in that family, tribe or community (Cattan and Tilford, 2006), a factor that may also affect the way FCs react to their care situation.

There are general factors that influence the biological and physical behaviour of any individual, for example Cattan and Tilford (2006) refer to some of these cognitive and emotional factors related to behaviour as knowledge, intelligence, which will give insight and actualisation of actions, whilst self- identity was viewed as a crucial coping resource. Behaviour of an individual caring for a patient with HIV/AIDS will be further guided by their perception of the disease, the patient, the self in the midst of care, the care situation, resources available or not, family and friends associated with the patient (Airhihenbuwa and Webster, 2004).

### Operational Definition of terms and concepts

It is important to provide some specific meanings to the key concepts and terms used in this study, in order to provide the contextual use. Although these concepts have been introduced above, here I state precisely what I mean by these concepts.

*Coping:* In the context of this study, coping is defined as constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person (Lazarus and Folkman, 1984, p. 141). Whereas Antonovsky (1979 p.112) defines coping as a strategy of an overall plan of action for overcoming stressors. The two definitions take cognizance of the behaviour based action to address an encounter confronting an individual.

*Coping mechanism*: Method(s) adopted by an individual to deal with a challenging/difficult situation or a threat.

*The concept of caring:* is understood to mean the acts of meeting, social and psychological needs of someone or a patient. Caring has been known to have a number of definitions or the way it has been described most especially in relation to the contextual application. Whilst Mitchel and Oakley(1986) attempted to describe caring by identifying experiences like emotions, actions taken, to meet the needs of the one being cared for. Caring means the interrelationship between the caregiver and the cared for (Sargent 2011; Hogan, 2013. In the context of this study, caring will be confined to describing acts of behaviour directed at meeting the needs of an individual with HIV/AIDS and being cared for in the household.

*Appraisal:* are evaluations of situations that have implications for people's beliefs, values and/or goals (Lazarus and Folkman, 1984, p. 151 in Schneider, 2008).When one is faced with an encounter, they make quick cognitive analysis of the nature of the encounter in order to make decision on the actions to be taken to. This appraisal can be positive or negative depending on the understanding of the encounter in terms of its value, or whether it was a danger or threat (Lazarus and Folkman, 1984).

*Family Carers:* are family members or friends who take on the responsibilities to provide immediate care to chronically ill family members within households. They are untrained and were also referred to as caregivers or can be referred to as primary caregiver.

*Chronically ill:* can be described as the state of an individual suffering from a persistent disease condition that is difficult to treat/manage and has lasted for three months, or will last for a long time

*Home Based Care*: A system of providing physical, psychosocial, prevention, care and support services to the chronically sick in their homes beyond the clinic walls to meet the overall needs of people suffering from prolonged/chronic illness (WHO, 2002). It can also be defined as the Care given to people living with HIV/AIDS and other chronic illness in their homes, families and communities (MoH/CBOH, 2005).

*Caregiver:* Someone providing either one or all of financial, instrumental, psychosocial, or nursing care to a person with a chronic illness, (Chepngeno-Langat, et al., 2009; )

*Resilience:* Walsh (2002) has described resilience as the ability of an individual to withstand adversity, or pressures and being able to bounce back. It is a psychic resistance to stressors, adversity, and high-risk environment (Schmolke 2005). This concept in this study is being used to understand the attributes of FCs that enable them to manage or not manage care situations for chronically ill patients with HIV/AIDS.

*Sense of coherence:* According to Antonovsky, (1979; 1987) was a global orientation that expresses the extent to which one has the pervasive, enduring though dynamic feeling of confidence that:

- the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable
- the resources are available to one to meet the demands posed by these stimuli

- these demands are challenges, worthy of investment and engagement. (Antonovsky, 1987 p. 19).

  *Another explanation of the understanding of SOC which aligns and further explains my position is.*
- that it is a resource that enables people to manage tension, to reflect about their external and internal resources to identify and mobilise them, to promote effective coping by finding solutions and resolve tension in a health promoting manner (Eriksson and Lindström  2006).

## Conclusion

In this chapter I provided the framework for examining the coping mechanism of family carers, whilst also highlighting the benefits and limits of symbolic interactionism as a theoretical framework, to make presentation of how family carers socially constructed their care environment. Further, I provided theoretical understanding of key concepts in the salutogenic model that provides the basis for constructing the processes to understand how FCs cope with care responsibilities. I have further provided some operational definitions of key concepts and terms used in this study.

# CHAPTER SIX: Methodology and Study Development Process

## Introduction

In this chapter I describe the processes that were followed before and during data generation. I also give the strategy that was devised and used during data generation and subsequent steps taken to arrive at final research data. The strategy included identification of key informants who at the time were considered suitable to provide information related to HBC activities. I also discuss key data sources which included key informants comprising of nurses, clinical officers, HBC Center facilitators, nutritionist, TB supporters, church leaders, elder men in communities, HIV/AIDS Counselors, as informed by the staff at the health centres. With facilitation by key informants, I was able to identify FCs from different communities within Chazanga catchment, which will be described later in the chapter. The Key informants who were well informed and qualified to speak about HBC in their communities provided me with information on the location of different CBOs, NGOs and FBOs involved in HBC activities. Such an inclusive approach to generating data which included research participants beyond the FCs themselves was important to provide the opportunity to understand the nature of the environment within which chronically ill AIDS patients were being cared for by the family members. I therefore sought more information mostly on the extent of support to HBC activities by community based organisations. These were organisations that were also quite active in supporting volunteer caregivers who provided information on HBC activities by sharing with me available records of their activities.

Finally the chapter provides a concise description of FCs, how they were selected to participate in the research, and processes followed to collect data. Discussion with key informants to obtain background information on HBC activities in the target community is also provided.

## Methodology

This was an exploratory, descriptive phenomelogical study concerned with the understanding the holistic issues of behaviour involved during the caring encounters that were being managed by FCs and the form of actions taken, expressed emotions, perceptions, and attitude of FCs as they were engaged in the provision of care to the chronically ill. The study methodology was based on FCs' experiences during care giving episodes. The exploratory and descriptive approach to the study was anchored in the understanding that, the researcher's ability to build theories of coping and to predict events in the care situation was to be enhanced. This study provides an interpretive explanation of distinctive ways that FCs dealt with care concerns. The differences in reasons for adopting coping mechanisms were explored, including the different reasons why FCs assumed caring roles.

I will discuss later the different techniques used to generate data and provides reason behind the adoption of the research techniques. The main focus for the study were the FCs who were the primary source of information, and key informants were a secondary focus as they lived in environment within which the patient were being cared for. Caregivers participated in both In-depth interviews (IDIs) and focus group discussions (FGDs). However, similar questions were also asked of the key informants during focus group discussions to validate the information given by FCs. Particular attention was paid to age of FCs hence participants for FGDs were grouped according to the age groups for homogeneity in the group to facilitate equal contributions and free discussions (Masadeh, 2012).

The study was conducted in Chazanga catchment area of Lusaka district in Lusaka province of Zambia. Chazanga is a residential compound in Lusaka district where I had paid many visits especially during my role as a Programme officer and Community Mobiliser for HIV/AIDS responses. The HIV/AIDS pandemic had added another key community experience in my work, as most of my community based activities focused on mitigating the effects of HIV/AIDS at the household and community levels. At national level, I interacted with programme managers, policy makers, managers at provincial and district levels. Whilst in the community I interacted with Community AIDS Task Force (CATF) and different CBOs, NGOs, FBOs who were active in mitigating the effects of HIV/AIDS in communities. Chazanga community will be discussed later in this chapter.

### Study design

The study used a qualitative approach to data generation with demographic data collected to facilitate the understanding of the environment within which HBC services were being provided and provide the researcher with characteristics of those involved in caring, and that of the patients being cared for. Socio-demographic information was collected of the environment where the caregiver was engaged in providing care to the chronically ill patient. The quantitative data that was collected was especially related to characteristics of households, the environment within which chronically ill patients of HIV/AIDS were being cared for. Data were collected on the characteristics of FC and the patient vis: age, gender, marital status, normal place of residence, economic status of the family carer and that of the patient before falling ill. This information was important as it provided a general picture of the care environment, the support structure that existed within the locality and data on who was involved in providing this care.

In view of the subjective nature of the study and especially the information that was to be generated, a qualitative research approach was fundamental in understanding how coping mechanisms were devised and employed by caregivers when managing chronically ill AIDS patients.

This was an exploratory study aimed at providing meaning and description concerned with the understanding of the holistic issues of behaviour based on actions taken, meaning derived from the care situations, emotions, perceptions, daily experiences and attitude of caregiverss as they provided care (McNabb 2009; Kombo and Tromp, 2006; Silverman, 2005) The methodology adopted was most appropriate as it enabled the generation of data that captured the personal and unique experiences of FCs in home based care settings. In tandem with Lindsey et al. (2003), the exploratory and descriptive study approach was most suitable as it did explore and described the psychosocial issues affecting the carers in HBC, and helped provide insight into the current situation on what was happening in HBC care environment in part of Lusaka district.

As argued by Miles and Huberman, (1994), when qualitative research is conducted, there always is prolonged contact with the subject being studied, whilst gaining a holistic overview of the context under study, explicating the way people in particular setting understand, account for action taken and manage their daily lives. Further, Patton, (2001/2 p 39 in Golafshani, 2003) observes that qualitative research is used as a naturalistic approach when trying to understand the phenomena in the context-specific setting in a real world (see also Stake in Chapt.4 in Denzin and Lincoln, 2008 Eds.) without the researcher manipulating the phenomenon of interest. In this context the elements of SI and social constructionism and through use of language and actions by caregivers during interviews, I was able to contribute the reduction of my subjectivity. Attride-Stirling (2001) viewed qualitative research as growing in popularity amongst social scientists, a move deemed as a positive step towards a deeper understanding of social phenomena and their dynamics.

### Rationale to study process

The study rationale was based on proven assumptions that research work was about finding out and having understanding of what lies between discussions and controversies that have over years been seen to surround research philosophies (Denscombe, 2010). Researchers have ventured into research work to discover what has yet to be explained, and answer questions of what has not been explained before (Denscombe, 2002, 2010; Blackie, 2010,). However, understanding the social world has been argued to involve discussions related to terms like ontology which refers to the nature of social phenomena and the beliefs that researchers hold about the nature of social reality and epistemology which refers to the ways that humans create their knowledge about the social world and claim to have such knowledge (Denscombe, 2010). Further, he observed that whilst social researchers acknowledge the importance of ontology and epistemology as the foundation of their research practice, affecting even the very subject they study, they have strongly focused on tools that allowed them to get the best results from the research and further recognizing that, methodologies within different disciplines had specific strength and weaknesses.

## Interpretivist and Constructionism

In this study therefore, a qualitative research approach was linked with interpretist paradigms. Interpretivism in this study was an epistemological position that required that the researcher grasps and interprets the subjective meaning of social action in the care environment and as such was closely linked to phenomenology (what is to be studied) which is particularly interested in how social life is constructed by those who participate in it (Bryman, 2001 in Mikkelsen, 2005 p. 135; McNabb, 2009). Interpretivism believes that creative people have the ability to interpret events, and through their actions and interpretations they are 'agents' who actively create an order to their existence (Silverman, 2000; Denscombe, 2002, 2010; Mikkelsen, 2005; Blaikie, 2010). This was assumed to be the case with family carers who due to the nature of their engagement with their patients are on the daily basis in the process of interpreting the world around them and linking it up to the care functions. Silverman (2000) did allude to the fact that social construction allowed the researchers to get closer to the actor's (the respondent's) perspective through detailed interviewing and observation. During this process, the interviewer becomes part of the environment of the respondents; the interviewer becomes part of the world being described by the participant by following closely the construction of the reality which the participants are trying to describe. With detailed interviewing, the researcher will initiate the process of gathering or generating data that will reveal emerging theory by categorising responses. This was argued by Denzin and Lincoln (2011) that everyday realities are actively constructed through different forms of social actions as in symbolic interaction. The two researchers (Denzin and Lincoln, 2011) further observed that constructionist perspectives represent qualitative inquiry, which could also be viewed as an intellectual and empirical research perspective that surpasses other disciplines.

To further argue the justification for adopting Interpretivist paradigms in this study, Constructionists might challenge the Interpretivist approach taken and argue that it focuses on prioritising interaction over meaning and as such is subject to human error as sets of answers given by respondents for example, may be interpreted by the researcher as inventions of the human mind (Mikkelsen, 2005). They would prefer to look at what people do without any necessary reference to what they are thinking or feeling and as such focus on behaviour without reference to the mental state (Silverman, 2000). This approach however would not be able to give an insight into why caregivers behave the way they do and as such would not bring in a new body of knowledge that will begin to help create an atmosphere and a better understanding of the coping mechanism of HB carers. In the writings of Kasschau (1995) on psychologism in shaping the behaviour of individuals, he observes that individuals behaved in an organised manner and that behaviour was based on personal plans, biases, errors, mistakes and that the primary feature of ideas about the world as constructed by individuals was governed by how he/she anticipates or predicts the world.

In addition, Baron and Byrne (2006) argue the role and effects of social influence on individual behaviour. Individuals in different societies and groups have been seen to exhibit behavioural tendencies that have been known or even believed to be acceptable or appropriate. In accordance with the purpose of the study, whilst adopting the social constructionist approach, it is the behaviour of family carers that the study sought to explore, more especially that different family carers were out in the communities and households providing care to chronically ill AIDS patients. The understanding of how they dealt with the care situation was therefore critical to the study.

An Interpretivist approach in this study focused on the way FCs made sense of the world and how they constructed their social world through their actions and interpretations of the world in their set environment. The research was able to address theoretical issues relating to coping mechanisms by family carers in HBC and other variables determining the outcome of interventions in caring for chronically ill patients. To enrich this study and derive from it results that give explanation of the caring world at the household level, both interpretivism and constructionism are considered. For example, McNabb, (2009 p. 28) argues that constructionist believe that humans “will construct all social phenomena and that no single construction is better than any other”. Some researchers have viewed constructionism as one that can also fall under the interpretivism label. The Interpretivist will focus on processes, process changes and understanding, and data is generated with the view of results that may lead to possible interventions in the situation being studied (Mikkelsen, 2005).

Humans interact with their social world and in the process of such interaction they find meaning to their daily existence. And since reality is mostly subjective, the way the interpretation of daily encounters or the construction of their daily life will vary among individuals, however, they share some common elements (Denscombe, 2002, Denscombe, 2010; McNabb, 2009). And in qualitative research, the subjects being studied may provide answers to the interviews based on the self -belief that the researcher may be interested in certain responses, and hence their answers may be mainly to please the researcher.

Silverman, (2000) supports such an approach when he argues that qualitative researchers believe that qualitative methods can provide a “deeper” understanding of social occurrences than would be obtained from purely quantitative data. The reality is that FCs lived in homes where different phenomena resulting from disease and socio-economic factors played a major role in shaping the general response of families to the environment. Denzin and Lincoln, (2000) argued that, qualitative research stresses the socially constructed nature of reality, how relationships between the researcher, what is to be studied, and the situational constraints that shape the inquiry. With this approach, the research provided answers to questions that stress how social experience is created and given meaning.

These according to Silverman (2006) are guided by particular theoretical focus on people’s knowledge and skills. In this study, I was trying to understand and interpret the world within which family carers provided care and make deliberate effort to infuse this HBC world with meaning, and capture the acts of interpretation of the care reality (Gibbs, 2002).

The Interpretivist and social constructionist approach is therefore justified for this study. Mikkelsen (2005) puts the Interpretivist practitioner in a more advantageous situation with regard to applying research results.

### Reflexivity

It is important to acknowledge that in social research, the position of the researcher should be constructed in a manner that the researcher and persons being researched together share meanings and methodologies that enable the outcome of the research (England 1994). As a researcher, I was therefore mindful of the advantageous position of FCs who, I believed were more knowledgeable in providing appropriate answers to questions which I was not competent to answer. I had lived experiences of coping at a different level as “Me” in the “care world”, but I did not have the perspective and lived experiences of others who may not have been as privileged (as I was a nurse, financially empowered with good family support networks) as I was. Reflexivity provides an opportunity for researchers as observed by Mauthner and Doucette (2003) to reflect on or think about how lived experiences of other peoples’ accounts can be analysed objectively. Research situations in the form of field work is viewed as a dialogical process during which the researcher and the person being research become part of the process of construction of what is being researched (England, 1994). For example, Mauthner and Doucet (2003 p 415) have noted that reflexivity had been “widely debated in relation to theory construction and epistemology and the data collection stages of qualitative research”. However, they (Mauthner and Doucet 2003) further argue that despite this wide recognition of reflexivity in social research, in practice very few researchers have not given reflexive accounts of data analysis, nor have they given any suggestion on how to operationalize reflexivity.

The importance of researchers to consider the structure of their social relations and how such relations are accountable for them and how they are further perpetuated is one key factor to be considered (England, 1994) during social research.

As reported by Young (2008) researchers need to acknowledge their personal opinions, which could have overt or sometimes hidden implications as these opinions may have some control on how “I” as the researcher, perceive the social world within which FCs exist. I therefore needed to work towards providing the thesis with information that was to provide an “interesting true meaning to what was being researched and place value to its sociological importance of the research” Gilbert, (2008 in Young, 2008 p 512).

I will at this point outline that background, to make it entirely transparent. I was trained as a nurse practitioner and a nurse educator, and therefore I had within my professional standing, authority to guide the moulding of nurses as they were being trained and subsequently during their professional life. I understood what was required of them when patients were admitted in hospital or whenever patients sought professional help from a health provider or facility. I also had extensive experience working in communities, more especially with families, community structures and communities in general. I therefore was careful by reflecting on how my own characteristics and experience would influence the interpretation of data generated as I analysed and drafted my thesis.

At the time I was trying to devote most of my writing of my thesis chapters, I was involved in nursing and taking care of my chronically but acutely ill member of my own family. Then I received the devastating information about my own health status which therefore led to the suspension of my generated steam to write my thesis, as I strongly felt the need urgently to address the health issues before commencing on serious writing activities.

Being sick and receiving treatment, with most care at the household level, (as I had spent only four days in hospital after surgery), added a different dimension to the writing of this thesis. It meant that I had to have understanding of what it meant to graduate to home care. The experience of being cared for in the household added a different perspective to my understanding of what caregivers and their patients experience in meeting the demands of the care situation. I now became the “cared for” as opposed to the “nurse” and caregiver that I was when I started working on my thesis. The roles changed a factor that could have added to my acknowledgement of the FC’s situation in caring for their patients.

It is of importance to note that, my roles during the process of my research were dynamic and changed depending on the persons being interviewed and the levels of interaction with study participants. During these interactions, I became aware of the many needs of beneficiaries of our HBC services. However, my subjective position to carry out the research (Watt, 2007) was further influenced by my past involvement in caring for two of my very close relatives with PLWA. One was diagnosed at the time when treatment for ARVs was not accessible to many, so we had to purchase drugs, whilst the other patient benefitted from ART services. In one situation I was the one directly responsible for providing care especially at night as I worked during the day. Whilst in the other situation, I could not manage to provide care and pay full attention to my relative. I made a bold decision (my feeling at the time) without much consultation of my relatives to move the patient, to my other house where I was assured of social support from other family members and other community members would have access to the patient and give more spiritual and psychological encouragement and support than I could. The new environment for the other patient I believed would facilitate respite for me, spiritual healing and more encouragement and support from those around the patient, family members and other neighbours. However, I continued providing material and medical related support.

I also wish to mention that during my experiences nursing a patient in hospital, I observed very poor, limited interactions between health providers (nurses in particular) and family members at the bed side (mostly referred to as Bed-siders by hospital workers) This experience added a different understanding of the emotions associated with caring for loved ones. It was in most cases “trial and error” approach to nursing on the part of the family members but wanting to do the best for the patient.

As I continued with my research work, I was re-entering the community to gain better insight on how FCs in households constructed their lives against the background of inadequate preparation to caring roles. I had actually felt this inadequacy, especially when my patient was discharged and none of the nurses took time to prepare me for what I was to be doing in the home situation, let alone what do when faced with health challenges.

My past experiences in caring for my relatives with HIV/AIDS and working in the area of supporting HIV/AIDS related activities, kept on “sneaking “ in my thoughts of how they (family carers) would have been feeling as they provided care to their patients. Did I go through the same experiences? Yes to some extent, but not really as I was privileged with knowledge and skills in care work, was a counselor, and was financially empowered to provide support to my patients. But as I continued generating data and talking with caregivers, I was from time to time being reminded of the times I too was in similar situations. I experienced empathy and respect for my research subjects, but in social research it was important that I was to consistently consider the “structure of our social relations, and how we are accountable to them, and how our actions perpetuate those relations” (England, 1994, p 241).

My being a woman, elderly, mother and African will have led to me having a particular ‘lens’ with which to observe the phenomena I was studying and to the responses to the research questions during the field work (Hastrup 1992 in England, 1994). As field work is confrontational (England, 1994) it may have disrupted the daily lived life of FCs, which may also have influenced the kind of responses. In order to address such anticipated reactions, my entrance in the community was therefore carefully guided by consultations with community leadership on the most appropriate times to visit household - which mostly were in afternoons after they had more or less completed most of the household chores, and sometimes Saturdays when they felt more relaxed to accommodate my presence. The dress code, appropriate language and issues of respectability were some of the key elements that needed to be observed and paid attention to as I continually interacted with my research participants.

I made every effort each time I entered the community to be aware of my social location and the subsequent personal emotions that may be invoked as I conducted my field work (their narration of experiences of “suffering” in care work kept reminding me of my own experiences though at different level). This stand allows the researcher to accordingly be able to examine the respondent's words, or how that would influence the writing about the particular respondent (Mauthner and Doucet, 2003). I did apply my understanding of the power relations in the field in order to ensure that the ethical issues and participatory research was adhered to (Sultana, 2007). I did identify myself with the community members by the way I always dressed, parked my car far and walk long distances where I was to find households with patients. Sultana (2007) rightly observes about feminist methodologies that emphasize no-hierarchical interactions, understanding during which the researcher has to pay particular attention to how questions were being asked and the methods of data generation, especially that by being the researcher I was in an unequal power relation with the researched.

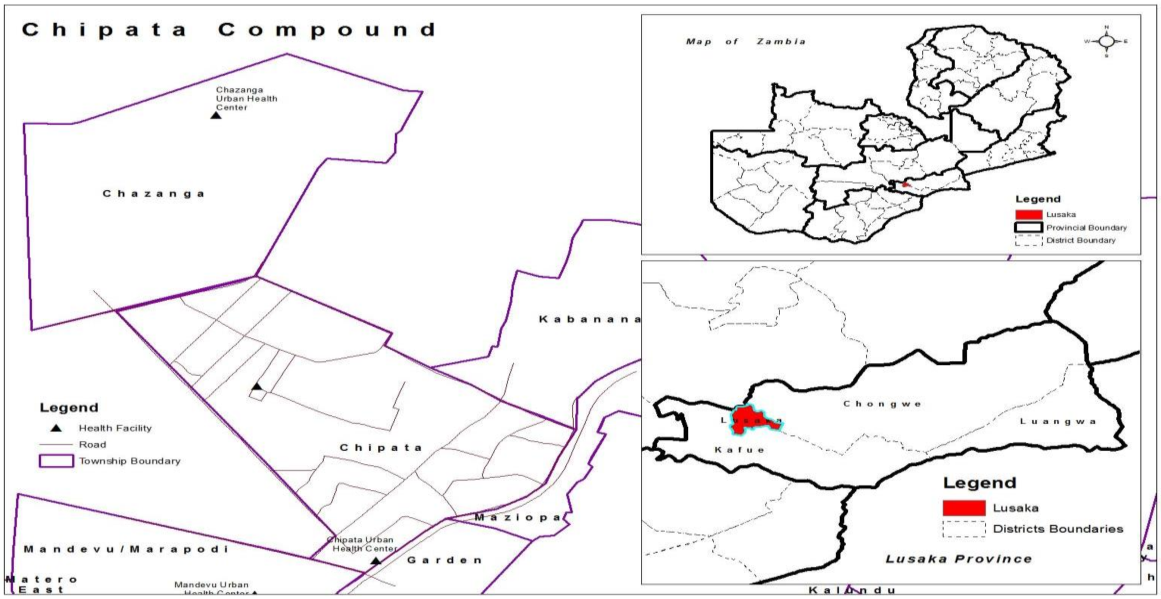
I always felt part of the community although I may have come from a different community and maybe social class. But my thoughts kept coming back and always became aware of my own situation caring for my own relatives. "I had been there I always thought". There were times for example when FCs narrated and talked about experiences, when their patients made many demands that were changed at will. These changes they explained caused frustrations, because sometimes it involved purchasing of preferred food stuffs and when such food was prepared and offered to the patient, the patient refused to take it. This resulted in FCs' feeling of inadequacy because of such changes in demands. I too had similar experiences and these were trying moments whenever they happened. However, these social construction of their lives as they responded to my questions during the interactions, provided me with the opportunity to develop my objectivity in the research process, as they, firstly, were sharing what I too had experienced, and secondly, they revealed to me that more households may be having similar challenges, and thirdly, since I was earning a salary every month, and had adequate resources to meet most needs of the (my own) patients, it actually strengthened my questions related to how FCs were coping with care work, and process of interpreting the reality of caring for the chronically ill then started emerging and recreated.

As I wrote and continued to shape up my thesis, reflection on FCs experiences in caring for their loved ones kept resurfacing and became very vivid and making me an integral part of the living caring experiences of the FCs. I also became part of the research process and contributed to the construction of meaning Gilbert, (2008 in Young, (2008) and we were sharing experiences I concluded.

## Study Site

### Chazanga community: key characteristics

**Map 6.1: Map of Zambia and Lusaka district showing the locations of Chazanga compound and the linked residential compounds in the area.**



Source: Courtessy of Mr. Bwalya Chuba, 2014.

The study was carried out in Chazanga community situated in Chipata compound catchment area in Lusaka district in Lusaka province. Chazanga compound is linked to Kabanana, Chipata, Mandevu/Marapodi, Maziopa, Garden compounds. Chazanga residential area was purposely selected as according to MOH information it houses the largest HBC programme in Lusaka. The compound lies in the northern area of Lusaka district of Kabwe road. The Health information system (HMIS) at Lusaka District Health office(DHO)show that Chazanga community has a population of 17,794 and is within Chipata compound catchment area whose population is 105,582(record review of 2008 data DHMT February 11, 2009). According to the Central statistical Office (CSO) report, Chazanga compound is both urban and peri–urban community. It is comprised (a phenomenon that is common in other high density Lusaka communities CSO, 2004) of a population that has different types of economic activities from trading, production, provision of services and those employed as professionals. The population is a composite of those that are employed with majority being self -employed and a proportion of unpaid family workers (CSO, 2004) Chazanga area has one Government health centres that became operational in 2003, despite the center having poor staffing levels, it provides a range of basic health care and preventive health services. There is poor road infrastructure especially during the wet season. Patients with complicated conditions can be treated at Chipata clinic or referred to the University Teaching Hospital (UTH), the largest referral hospital in the country for specialized care. The UTH is about 10 kilometers away from Chazanga, with cost implications on transport on the patients and family.

### Selection of study community

Chazanga site was purposely selected because it is one of the communities housing a number of CBOs, FBOs providing HBC, and has one of the major HBC program called Bwafwano HBC Centre that is community based.

The selection of this community provided opportunity to explore how FCs cope in view of the fact that the support from the HBC programmes is provided during specific times of the day and week. Further, the selection was also based on the past experiences working and interacting with different segments of the Chazanga and Chipata communities during national HIV/AIDS activities.

### Understanding the Bwafwano HBC programme in Chazanga community

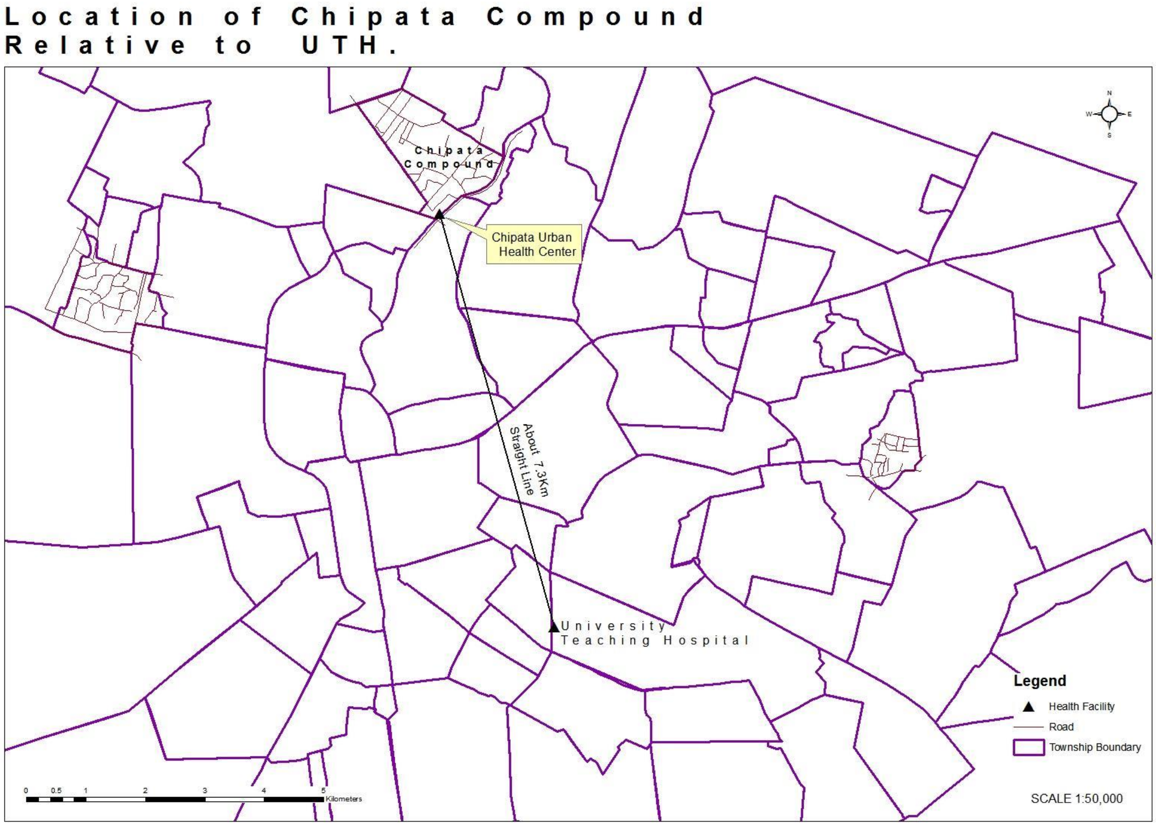
I had earlier experiences working with the communities associated with Bwafwano Home Based care project. As a nurse, who had such caring experiences, and my work in the community it became very clear that, there were more needs in the households for one to adequately provide for the patient. Programmes I was associated with had external funding for support to the few households and such support was never sustainable.  Some of the support was designed to happen during special events like National VCT day or World AIDS Day. Households visited during those times were only those who were labeled as “vulnerable” especially those with chronically ill patients and needing some form of support.

Bwafwano HBC center situated in Chazanga community was established in December 1996 with the main purpose of helping those affected and infected by HIV/AIDS. In their endeavor to help others, Bwafwano HBC centre established and started to provide a number of services targeting HIV/AIDS positive and TB patients. The centre runs a community school and feeding facilities for orphans and vulnerable children mostly from homes being provided with HBC services.  Other services provided include voluntary counseling and testing (VCT), sexual and reproductive health, antiretrotherapy, income generating activities (IGA), integrated survival skills training, feeding services, laboratory services.  Children graduating from the centre are sent to government schools for further education. In addition to the two health centres in Chazanga and Chipata compound, Bwafwano also runs a health care centre. The centre refers clients with complicated conditions to Chipata and Chingwere health centres. This referral network between the health facilities works very well and has support from community leadership. Bwafwano facilitates transportation of clients being referred to other health care facilities.

The integrated services being offered at Bwafwano HBC benefits over six high population density areas of Lusaka district (Chazanga, Chipata, Soweto, Mazyopa, Kabanana, Kabangwe). The centre trains caregivers who provide the link to other services as they work with community leaders. Patients requiring assistance are identified through community leaders. Bwafwano HBC centre has facilitated community work. Bwafwano which stands for “Let us help each other” has trained care givers who provide HBC services three times a week at household level, with one Caregiver providing HBC services to 30-50 clients (10 clients is ideal). Caregivers are also trained in palliative care, HIV/AIDS, ART, DOTS, ARV adherence support, and in integrated management of Childhood diseases (IMCI). In the absence of caregivers at household level, family members are expected to provide care to their patients (Personal communication with a programme manager, 11-09-2008).

Family members who are always with the patients when caregivers are not present were the main focus of this study. A number of other HBC activities in Chazanga area are also provided and managed by a number of CBOs and NGOs existing in the community.

**Map 6.2: Map showing location of Chipata compound relative to UTH and Chipata Urban Health Centre**



Source: Courtessy of Mr. Bwalya Chuba, 2014.

## Sampling Procedures and sample size

### In the community

I obtained prior written approval from the Director of health at the DHO in Lusaka to conduct the study in Chazanga catchment area. I held formal and Informal discussions with senior officer, responsible for HBC services at the District Health Office. The meetings at the DHO were held to give a general government perspective of HBC programme in Zambia and more specifically the HBC programme in the selected study site.

The District HBC focal person linked me up with Chipata HC manager who organised a meeting with the health provider coordinating HBC activities in Chipata Clinic Catchment. During the initial meetings I provided information on the purpose of my study, and who I expected to be my study participants. I met again with the health provider and she introduced me to Community

Volunteers(CVs) who were also referred to as community health workers (CHWs) working in Chazanga community addressing among others HBC activities, and held a similar meeting with the group of CHW. I met again with two of the CHWs and had meetings with HBC gatekeepers in Chazanga compound and those attached to Bwafwano HBC centre and responsible for community health activities. During the meeting, I introduced the study, the purpose, whom I had planned to be my study participants and how I planned to collect data (explained the IDIs and FGDs). During this meeting, the community had input and advised me on the most appropriate days and time to visit households. They further agreed on how gatekeepers were to help me identify households with chronically ill patients with HIV/AIDS. They further agreed to assist with mobilizing caregivers for FGDs and exchanged mobile numbers through the Project Manager at Bwafwano HBC centre on how I was to be contacted whenever FGDs were organised. The whole process of my interactions with different community groups facilitated my acceptance as a researcher and initiated the creation of rapport with those to be involved in the field work.

### Sampling

I used a purposive sample in this study as participants were considered well informed about the phenomenon under study. They were the major source of information on what was prevailing in the care of patients at household level. The selection of the study sample was further based on the assumption that, the participants, who worked within the community, were community members and was recognised by the community.

A purposive sample helped setting boundaries on who was to be included in the study. I needed participants who also had connection to my research questions and those with lived care experiences in the households with the chronically ill with HIV (Miles and Huberman, 1994; Creswell, 2013). FCs are a specific group of persons carrying out a specified function in households, hence their suitability to participate in the study (Lincoln and Guba 1985: Creswell, 2013). This sample was ideal for my study as I was trying to reach participants who had some insights to and experienced what was going on in the area in the context of HBC in order to allow a common understanding (Creswell, 2013).

The selection of KI was based on those individuals in the community involved in, and with particular insight into HBC activities in the community and those with opinion on how HBC caregivers work in households. KI were health care providers, CBO, FBO project officers, HBC Coordinators, Nutritionist, Pastors, HBC Focal persons. The Project Officer at Bwafwano HBC centre was important in linking me up with KI and organised for the FGDs. Further, I could not use participants at higher level of health care system as there was limited information on key HBC activities as evidenced from my earlier discussions. However, they were able to provide me with information on government policy on HBC programme and services.

**Table 6.1: Selection Criteria for Study Participants**

| Category of participants | Age group in years | Sex | Period as HBC administrator/officer | Period in years as family carer | Data collection technique |
|---|---|---|---|---|---|
| Family Carer | 15-60 | Males and females | | 1-5 | In-depth interview |
| | 15-34 | Males and females | | 1-5 | Focus Group Discussion |
| | 35-60 | Males and females | | | |
| Key Informants | | Males and females | 1-5 | | Focus Group Discussion |

Study participants were those individuals who had been caring for someone for not less than 6 months. The justification for this selection was based on the type of possible experience to be shared during data generation as those with less time may not have had experienced both levels of initial care experience and subsequent periods during which learning to care would have taken place.

**Sample size**

A sample of 16(15 women and 1 man) participants who were providing care in households with chronically ill patients were selected for in-depth interviews (IDI) and 10 focus group (FGD) aged 15-34(3 groups), and 35-60(4 groups). Further three FGD with Key informants(Stakeholders) were conducted with participants involved in HBC activities either as managers, facilitators, those responsible for referrals, and those involved in resupply of ARVs and other drugs for patients. Records from 5 CBO/FBO/NGO were reviewed to gather data that depicts the extent of the work that caregivers were engaged in. This was a phenomelogical study conducted in order to describe the lived experiences FCs of chronically ill patients with HIV (Cresswell, 2013).

**Table 6.2 Methodology, Participants and Time Frame**

| Type of Participant | Data collection method | Number conducted | Total Number of participants | Time Frame |
|---|---|---|---|---|
| Key Informants/Stakeholder | Focus Group Discussion | 3 | 19( 10F, 9M) | April to October, 2010 |
| Family Carers | Focus Group Discussion | 7 | 47(35F, 12M) | March to October, 2010 |
| Family Carers | In-depth Interviews | 16 | 16(15F, 1M) | March to October, 2010 |
| **TOTAL** | | **26** | **82** | |

Key: F: Female, M: Male

**Data collection methods and procedures**

Data collection was done over a period of seven months – March to October as reflected in Table 6.2. Data generation was an active engagement with FCs during which construction of meaning of the care environment was being sought as FCs were describing part of their world (Silverman, 2001). I worked with two research assistants (RA). The RA had experience in managing FGDs and IDIs recording of interviews and providing support during data collection. The RA helped ensure that the audio recorder was functioning, noises and other interruptions during interviews were minimized. All interviews were conducted in vernacular (Bemba, Tonga and Nyanja) and translated into English.

I was introduced to the household by the gatekeeper at the entry into each household for IDIs. Before each face to face interview, I introduced myself and gave a brief description of the study and the purpose. After each introductory brief, participants were asked whether they understood the activity and were willing to participate in the study or not. Consent was explained and their right to withdraw at any stage was explained. Explanation was given that the whole interview was to be recorded, to allow the researcher collect all information shared. Informed consent was given by signing or thumb-printing the consent form. All IDIs were done in households and the FC facilitated for the most suitable area to conduct the interviews and they were done inside or outside the house with only the participant attending the interviews.

Each interview process was facilitated by first developing rapport with participants and all those who participated in the research process. A relaxed atmosphere was created at the beginning of each interview. Interview guides provided for participants to describe their lived experiences as FCs of patients who were chronically ill with HIV/AIDS. Each IDI interview took on average of 45 to 60 minutes, whilst each FGD took about 60 to 90 minutes.

The process of data collection was aimed at generating data that was credible and was explaining the situation that caregivers were found in. The texts therefore provided according to Holstein and Gubrium 1997 in Silverman (2001) rich, naturally occurring, accessible data which have real effects on the world. Data generation for IDIs and FGDs continued until no new data, insights, emerged from the analysis or at a point when new concepts were fully explored (Goulding, 2005; Mikkelsen, 2005; Coffey and Atkinson, 1996; Giske and Artinian, 2007).

An open atmosphere during interviews was encouraged to allow for participants to freely discuss their situation and develop trust in the researcher. During this time participants were able to share their thoughts, feelings, experiences. Hence the quality of judgment and sensitivity during the interviews was important. Emotions, gestures, silence, facial expressions, and other expressed feeling were observed and noted, and dealt with by making enquiry with the participant on the observation made.

All data from IDIs and FGDs were tape recorded. Notes were taken during the interview of key issues raised and of non-verbal cues and communication by the FCs and later typed.

Data generated from these sources facilitated in-depth understanding of the environment within which caregivers manage their clients. As a qualitative study data generated through these methods provided different perspectives of the qualitative understanding of lived care experiences and an insight into coping mechanisms of FC. The information sources further explained the interpretive process involved in the experiences of caregivers and the meaning given to caring hence being able to cope (Liamputtong and Ezzy, 2005). There were no repeat interviews with FCs, however, there were follow up discussions with project officers on numbers of males participating as primary caregivers and the displayed faith in religion and Christianity.

Records of HBC activities from 2 CBOs, 1. NGO and 2 FBOs were reviewed. Patient registers, demographic information of patients, those on ART and the type of support given to households.

**Table 6.3: Data collection methods, techniques and tools**

| | Method | Technique | Tool |
|---|---|---|---|
| 1. | Interview | In-depth Interview | Interview schedule/guide |
| 2. | Focus Group discussion | Focus group Discussion | Focus Group Discussion guide |
| 3. | Record review | Review of records | Checklist |

### Focus group discussions (FGD)

Ten FGDs were conducted with mixed groups of males and females FCs and KIs. 7 with males and females FCs (aged 15 – 34{4 males, 16 females} and FCs aged 35 -60 {8 males, 19 females). Three FGD with key informants (9 males, 10 females) comprising of community leaders and participants from organisations providing HBC services including the DHO staff from the health centres(Refer to Table 6.2 for details). The set criteria for selecting study participants was based on age of the carers (15 – 60) length of period participating HBC care functions (6 months to 5 years, Refer to Table:6.1). (Varkevisser et al., 1991; Mikkelsen, 2005).

FGDs as a qualitative research tool has emerged as one of the popular techniques to generate data from different small groups of people more especially in social sciences, health research ( Myfanwy et al., 2002; Blackburn and Stokes, 2000; Belle, 2005; Masadeh, 2012). Social scientists according to Blackburn and Stoke (2000), observed that focus groups lay in sociology, however, market researchers have seen its extensive development (also Myfanwy et al., 2002), many definitions have emerged to describe focus groups in qualitative research. For example, Blackburn and Stokes (2000) had earlier reviewed definitions of focus groups as provided by other researchers and used the definition by Berg (1998) and described it as “ an interview style designed for small groups”(Berg, 1998, p 100). Whereas Krueger and Casey, (2000) defined focus groups as “carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, nonthreatening environment”. However, Morgan, (1988, p 12 in Blackburn and Stokes (2002 p 4) observed that “the hallmark of focus groups is the explicit use of the group interaction to produce data and insight that would be less accessible without the interaction found in a group”.

Focus groups were therefore important in this study as they provided individual, and group interactive opinion, attitude, beliefs, feelings and emotional reactions and finally it provided an opportunity for the researcher to objectively observe the flow of discussions and perspectives on coping mechanisms and how the group describes the situation of HBC for chronically AIDS patients (Mikkelsen, 2005; McNabb, 2009; Belle, 2005; Bloor et al., 2001). The discussions allowed groups members to spontaneously talk about HBC, care functions and coping at the household level qualitatively. It has been argued by Lindelow and Serneels (2006) that FGDs permit the researcher to elicit different views from different participants within one discussion (McNabb, 2009; Bloor, et al., 2001). It provides opportunity for more people involved in an event to have a say in the realities of their immediate environment. Further, FGD obtain in-depth information on concepts, perceptions and ideas of the group (Varkevisser et al., 1991, Mikkelsen, 2005, Blackburn and Stoke, 2000 ) especially that this group of individuals were those who were directly linked to and taking charge of HBC activities in the study area.

In another related observation about focus groups, for example, Gibbs (1997 in Blackburn and Stokes 2000), stated that gaining insight into people's shared understanding of everyday life was one such benefit and eliciting of in-depth information from groups on a particular issue (Belle, 2005). The interactions between the group members was further cited as of benefit as it does provide a sense of a feeling of security and therefore spontaneously generated their interactions with other group members (Stewart and Shandasami, 1990 in Blackburn and Stokes 2000 p 5). Much as focus groups as a technique has its own merit mostly due to group dynamics, social scientists and researchers have also observed their limitations or disadvantages that any research work adopting the technique for data generation needed to be observe.

The importance of skills in facilitating focus groups has to be given priority during data generation. For example Merton et al., (1956 in Blackburn and Stokes (2000) described the three problems that any moderator for focus group required to counteracts follows: possible domination of the group by one person, or a small coalition of participants; the reluctance of some individuals to speak to at all during the discussions and the need to ensure that that the entire group has had the opportunity to express their views on the topic for discussion without necessarily being restricted by whatever agenda. In this study all participants were given opportunity and prompted to talk freely about and share their care experiences on each area under discussion. FGD provided an avenue for participants to share information, and experiences, ideas on the interpreting of the care environment, and was learning experience for those who did not have some understanding on how to deal with key and challenging care giving situations.

The aim of the FGDs in this study therefore, was to provide opportunity for the researcher to obtain primary information related to care reality from the perspective of those who were actively involved in the interactions within care functions. Further, FGDs were an attractive medium for generating qualitative information from the public and required very minimal technical skills from the participants (Bloor, et al., 2001). This attraction to use FGD in this study was further compounded by the fact that FGDs were an appropriate source of information especially that the key participants in the study were FCs involved in the care of chronically ill patients with HIV/AIDS. However, it was also important to take cognizance of the challenges when using FGDs in situations where information on behaviour and/or attitudes of some members of the public on some sensitive issues was the focus of the study. In this regard in-depth interviews then would have been be most appropriate as individuals/participants would be provided with some privacy in responding to such sensitive questions more objectively (Bloor, et al., 2001), this situation did not arise.

However, bringing people together and agreeing on venue was a challenge. However, prior arrangements and agreement were made with the gate keepers from the NGO/CBOs and those with lists of patients being cared for in the households, and that such FGD be held in central places. FGDs were conducted at the health center, Bwafwano center, community school and church buildings.

Only those identified by the gatekeepers formed part of the focus groups and they were known participants who had been involved in the care of chronically ill with HIV/AIDS in the community. Working with gatekeepers according to Green and South (2006) and Silverman (2006) can be a valuable strategy for evaluation for hard-to-reach groups as was the case with FCs who, some of them were not known by health facilities.

They may have been other households in the community that the study missed, especially those not linked to HC, CBO, FBO and those who had fear of being stigmatised if they disclosed presence of patients with HIV.

It was prudent that the research followed approved ethical processes before engaging participants in this study. Codes of ethics relating to obtaining informed consent are enshrined in legal documents and maybe be found to vary in different countries and within different professions Homan (1991 in Denscombe, 2010). In keeping with the ethical requirements related to research, I obtained authority from participants in the FGD by ensuring they fully understood the research purpose and what was expected of them during the interview.

### In-depth interviews

Sixteen IDIs using semi-structured interview guides were conducted with FCs in their households. IDIs allowed the FCs give accounts of their life experiences in care functions. Gatekeepers facilitated the identification of households with chronically ill AIDS patients.

An interview guide was developed to ensure that the interview dealt with key issues on coping mechanisms. The guide was modified during some of the interviews to allow for more information based on participants' responses. This modification was mostly in terms of order of questioning for some participants.

In-depth interviews dictate that only a small group of participants are interviewed. The interview process encouraged clarifications of responses, rephrasing of questions, the interviewer does not have to stick to the guide, and can probe for information on new themes and issues as they emerge (Varkevisser, et al., 1991; Mikkelsen, 2005; Chopra and Coveney, 2006; McNabb, 2009). During these interviews the main areas of focus were on characteristics of the care environment, the patient being cared for, resources to facilitate care and the way the caregiver fits and manages the caregiving roles and responsibilities.

The identified caregivers were approached for their willingness to participate in the study. The study process was flexible and accommodated the needs of the interviewee, especially when more time was required. Sometimes, FCs could request that the interview move to another space especially during the times when perceived sensitive questions were being asked. This proved to be difficult as most households did not offer other alternatives to facilitate privacy during interviews. However, FCs did find and offered some form of privacy (space) to conduct interviews.

### HBC Record review

Records of patients' registers, reports of related activities taking place in the communities, were reviewed from MoH, DHMT, NGO, FBO, and CBO in the study sites. A checklist was developed to help the study determine who FCs were, more especially those managed by community organisations. Age group, gender, their background, where they were found, the kind of care activities being carried out, whether paid or not, the type of support, if any that caregiver received.

The records further showed whether clients being cared in HBC set up were HIV positive or had other chronic diseases. Records/reports from the period of the past 5 years when there had been a perceived concentration of HBC activities in Zambia were reviewed. It was envisaged that information collected will inform the research on the status of HBC and how the different players work to support FCs. Review of records was further meant to give guidance to the study on the prevailing status of HBC activities in the study area. The checklist developed was shared with officials in the selected institutions, who provided information being asked during record review sessions.

### Data Reliability and Validity

Issues of quality in any research are important factors underpinning the way other readers would view the outcome of any study. Quality therefore means that the researcher needs to observe a number of parameters that would constitute the labeling of that research as explained by Silverman (2005) that doing qualitative research demands for theoretical sophistication and rigour. The importance of showing to the reader procedures and evidence leading to a particular conclusions as described by Silverman, (2005) was therefore cardinal in any qualitative research as it will provide the reader with the opportunity to view and conclude the reliability of the methods used and the validity of the conclusions made (Silverman, 2005; Belle, 2005). It therefore means that during the conduct of any research that deserves to be contributing to the body of new knowledge, the researcher should take cognizance of the quality in research and thus ensure that the issues of reliability and validity were being adhered to especially during the design of a study (Patton, 2001).

Definitions related to these terms for example Belle, (2005) describes reliability as the extent to which or a procedure produces similar results under constant conditions on all occasions. Whereas consistency over time and accuracy in representation of data to the general population also becomes one of the facets that defines reliability Joppe (2000 in Golafshani, 2003 ;)

### Ensuring Validity in this research

Validity has been viewed by researchers as some form of qualifying check or measure for their research (Golafshani, 2003). A number of arguments on issues relating to the concept of validity in qualitative research have emerged over the years. For example Stenbacka (2001) in

Golafshani, (2003), argues that the notion of validity in research needed to be redefined so as to ensure and claim that a study is a part of proper research. Whereas Silverman, (2005) views validity by explaining that the concept as one that means "the truth" in qualitative research. Validity allows the researcher to be convinced that the research findings were genuinely based on critical investigations on their data  which will be deemed accurate, real and not based on a few examples ( Silverman, 2005; Denscombe, 2010)

By observing reliability and validity in this study, the construct of the study instrument was based on the fact that it had to measure and gather accurate data which was to represent the reality of the care environment. How FCs manage that care environment to the extent that they “went on-and –on” caring for their patients (Silverman, 2005; Denscombe, 2010).

The design of the study instrument took into consideration the different experiences of family carer in caring for chronically ill patients. The FGD guide was similar to the IDI interview guide but collecting information from different groups, carrying out similar functions.

The use of more than one method in data collection through interview schedules IDIs, and FGDs for FCs, and interview schedule for KIs provided for validation of data collected. This approach therefore which in essence was a form of triangulation also did contribute to the verification and substantiating of the assessment in the study. Triangulation according to Mikkelsen (2005) did provide an opportunity for the researcher to look at things from different point of view.  Hence in this research I used different data sources like IDIs, FGDs. By conducting interview with FCs and KIs as main data sources helped in the validation and cross checking of information as provided, and did limit biases in this study (Mikkelsen, 2005; Varkevisser et al., 1991).  KIs that included professionals in health and HBC services were another confirmatory source of information that enriched and enhanced a deeper understanding of some inherent issues that the study sought to investigate on HBC services being provided in communities.

### Pre-testing (piloting) of the Study Tools

The study instruments were piloted with participants from similar background and position. The DHO HBC focal person through health centres facilitated the process of selecting sites for piloting of study instruments, these were done in Bauleni and Chawama compounds. The piloting of instruments helped identify potential difficulties with the methodology and the techniques to be used. Key concepts were translated into language appropriate to the situation. The experience with the pilot assisted showing minor need to revise the methodology and techniques. The pilot work also revealed that conducting interviews in the morning was not appropriate as most carers were engaged in household chores. As a result, data collection was mostly conducted in the afternoon with a few exceptions; Saturday was most preferred day for morning interviews.  Although questioning was taking long, participants did not show anxiety of wanting to end the interaction.  The pre-test also provided me with opportunity to make changes and revise questions that were eliciting similar responses or being repeated. The initial (Bauleni compound) area selected for pre-testing was unfortunately flooded and reaching selected homes was impossible, so a second area (Chawama Compound) had to be identified.

The pre-test further provided guidance on how much time would be required for each encounter during data generation. Careful phrasing of questions especially those prompting for feeling was revealed. The process further informed the research process to take time in probing for more answers and specific explanations.

### Data management

Data was managed from the time of the development of the data collecting tool.  A carefully developed and pre tested tool was developed to contribute to quality data generation, and accuracy of information collected. Selection of sample through input from NGOs, CBOs, FBOs and DHO also contributed to the quality data.

Qualitative data was generated during IDIs and FGDs of FCs, and key informants, during which similar questions were asked with the view of eliciting information from the different groups and provide the researcher with validation of responses from the groups. All interviews in this study were audio taped, transcribed verbatim and translated into English by two research assistants that had previously been trained. Before the transcribing process, the researcher met with the research assistants to agree on meaning of terms, words as used by respondents. All transcripts were managed and analysed together.

Data was stored in lockable cabinet and protected to avoid loss, ensure privacy, confidentiality, security and easy retrieval of information. Backup systems at different locations like using the external back-up disk, and e-mail to protect data and minimize loss.

After each FGD, I took time to listen to the tapes over and over to assist me in adding more detail to the field notes and facilitate transcribing of information

Notable with this study was that most questions were open-ended to allow further probing and for a subjective discourse with the respondent. By using this method, information related to experience and behaviour, opinions and values, feelings, needs, knowledge were elicited from the respondents (Varkevisser et al., 1991; Mikkelsen 2005; Miles and Huberman, 1994).

All transcripts were checked for accuracy in spelling and meanings of responses, consistency.. Data was constantly examined to check for any new data, the process was repeated with every 5 to 10 transcripts. Field notes were also typed to support data generated and compared with data generated in the audio taped transcripts. At the end of each data collection day, the research team held brief discussions to identify those questions during which participants had difficulty to comprehend and give appropriate responses. All responses as per recordings were listened to and checked to ensure that responses to questions were complete and that the responses were all valid and appropriate and agree on how to deal with and interpret the ambiguous responses. (Kombo and Tromp, 2006; McNabb, 2009, Vaismoradi et al., 2013).

### Data Analysis

The process for data analysis by Thematic analysis was decided during the phase of study design. During this phase a decision was made on the analysis process, and also made decisions on the type of information to be obtained from the study and what new knowledge was to be added to the existing body of knowledge. However, a rigorous approach to analysis was undertaken by the researcher and this involved a process of identifying, analysing and reporting what emerged from the data (Braun and Clarke, 2006, Miles and Huberman, 1994). Vaismoradi et al., (2013) observes that thematic analysis facilitated answering of the research questions and provided a rich and complex detailed account of data (also Braun and Clarke, 2006). And further thematic analysis is been experienced to apply minimal description of data sets, thereby facilitating interpretation of various aspects of the research topic (Braun and Clarke, 2006) hence its suitability for this study.

After the transcription of data, I took time to read and re-read the scripts to get the sense of the “noise” coming from the data. Thereafter initial codes were assigned to data. Thematic analysis follows specific steps that ensure that the data generated was answering the research question and contributing to the achievement of the set research objectives. According to Braun and Clarke (2006), through an inductive process, data is coded without trying to fit into a pre-existing coding frame, or the researcher’s analytical preconceptions. Miles and Huberman (1994) describe this interactive model in Figure 6.1. Coding was carried out to identify common themes and examine them in relation to the context, meaning and circumstances of care giving and what the study was aiming at achieving. Interviews were coded by conceptualising underlying patterns in the data (Braun and Clarke, 2006). As part of the analysis, similarities and differences about the compiled coded were clustered together to create categories.

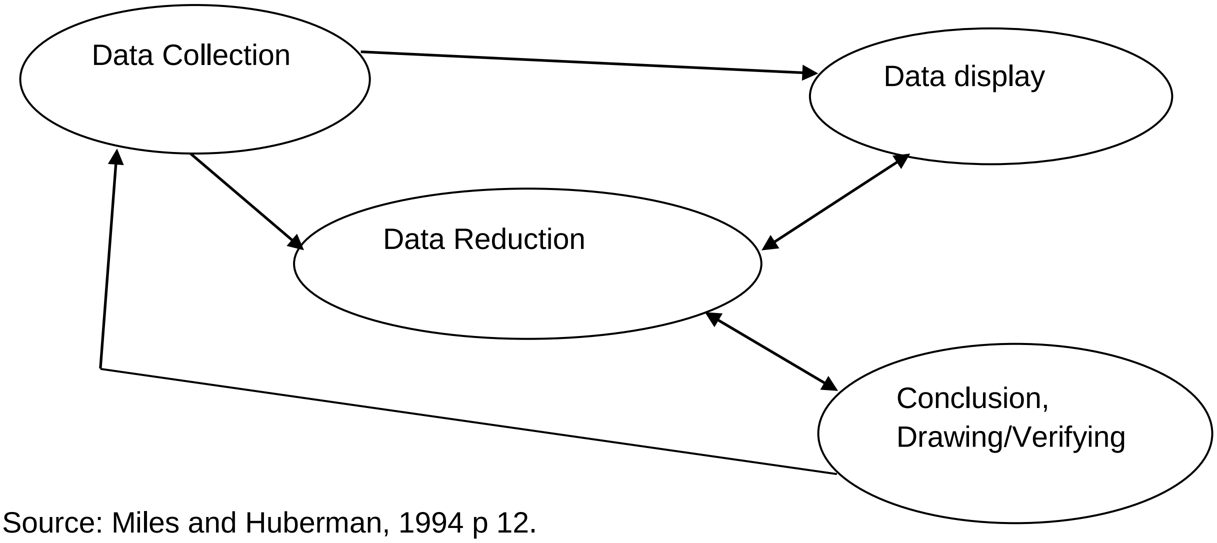
Units of meaning relevant to the research questions were identified and coded into what was considered as early themes. The process included generating, defining and naming codes (Vaismoradi et al., 2013), patterns of the themes were then consolidated.

The major themes were thus recorded to begin the process of the analysis. Accordingly, the process of data analysis for qualitative research is deeply rooted, according to Braun and Clarke (2006 pp. 87) in the six –steps: Familiarisation with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report. The data in the study was analysed manually as well as using the NVIVO software which facilitated creating of models of coping mechanism.

All transcripts were imported into NVIVO software and data continued to be reviewed with the use of NVivo software. More codes were generated and themes refined adding on to the list of other themes. The software facilitated the coding of all data, and then systematically analysed these codes to verify or prove a given proposition. In the second process, the data was examined for properties of categories. The process allowed the researcher to constantly code new data and compare with the old already developed codes to generate new concepts and themes. The process of constant review of the data continued, during data collection, the researcher was looking out for new themes and when no new themes or categories emerged saturation of data was considered reached (Miles and Huberman 1994; Braun and Clarke, 2006).

Through the use of thematic analysis, key relationships shaping caring for the chronically ill AIDS patients at the household, formed the frame upon which the study was to describe the care situations as presented in the main study results.

**Figure 6.1: Component of Data Analysis: Interactive Model**



Source: Miles and Huberman, 1994 p 12.

Figure 6.1 provides the process that thematic analysis follows from the start of data generation up to the stage when the report is ready for final writing. The process described shows that the researcher moves from one stage to the other and back for verifying data and refining or

This was an interactive process during which I tried to understand how the participants were describing their care environment and bringing into focus the reality of what was happening. During this process the importance of documenting well the information, behaviour, emotions (Braun and Clarke, 2006; Vaismoradi et al., 2013) thus generated was paramount to the analysis process, as this facilitated the understanding of the data and identification of the key themes (Miles and Huberman, 1994).

Lindsey, et al., (2003), used thematic analysis when conducting a study in Botswana to learn the experiences of older women and young girls in caring of patients in home based care programmes. By using thematic analysis they were able to describe the realities associated with caring in HBC scenarios whilst also identifying key themes that underpin the caring activities. By using thematic analysis, I was hoping to elicit information from FCs that was to facilitate the process and explain the “What”, “Why” and “How” FCs cope with the tasks of looking after chronically ill AIDS patients.

The application of thematic analysis in data generation and analysis generates themes, ideas and theories (on how people interpret and find meaning in the different interaction processes). In this study I used thematic analysis in order to facilitate the application of Symbolic Interactionism Theoretical Framework and the Salutogenic models which were deemed most appropriate base for the research to explain what was happening in the HBC environment. The key area of this study is to understand how FCs were coping (behaviour based) and in which thematic analysis process did facilitate the exploration of how participants interact, find meaning, take action and resolve issues as they cope with care concerns.

Data analysis in qualitative research manages words, language, and the meanings. Qualitative data analysis consequently has the capacity to create rich descriptions and understandings of social life (Miles and Huberman, 1994) which arguably tries to bring meaning to the data collected. However, the challenge was in working with large amounts of empirical data and texts that had multiple meaning, as was the case in the data generated from FCs at both the individual and social levels.

The software was used to help make analytical process easier as the data was organised in a manner that it facilitated the sorting stage. NVIVO software as argued by Coffey and Atkinson (1996) is one that can build relationships of the data amongst and within the code categories and hence referred to as “Theory- building function” and is claimed to support generation of theories grounded in the data (Coffey and Atkinson, 1996 p. 177-178). The use of NVIVO software permitted attachment of analytic materials or other memoranda to specific points in the text.

The process of coding, in thematic analysis, was more appropriate as it brought out different responses from FCs related to categories of coping when caring for chronically ill patients. It was anticipated that in view of different situations caregiver found themselves in, the way they interact with internal and external environment may differ significantly., As noted earlier, the Interpretive and constructive approach of qualitative nature of care work at the household, in dealing with different HBC situations provided insight into how FCs reacted to and dealt with external and internal stimuli, how resources available are recognised and harnessed appropriately in an effort to find and attach meaning to care work as observed in the different pathways The pathways developed from analysed data helped visualise care from the perspective of the FCs’ thinking, description, feelings and resultant behaviour. Key concepts of major themes formed the initial development of pathways as reflected in Figures: 9.4, 9.5, 9.6.9.7 and 9.8 and the follow on of movement of events in the pathways were also from the FCs’ interpretive and constructive description of care events.

Models were created through the use of NVIVO software to visualize relationships in coping mechanism of caregivers in HBC. By using the queries, relationships were isolated from the coded data. These relationships showed which sources contained particular relationships from the coded data. The sources indicated the individuals who mentioned that relationships as a central idea. Through this process I was able to visualize the data and see factors surrounding comprehensibility, manageability and meaningfulness of HBC. To create theory from the data, models were created by adding project items to a central explanatory concept. The common central concepts were around “coping mechanism” (Figure 9.1), “motivation skills”( Figure 9.2), “Care attributes” (Figure 9.9) and “emotional closeness”(Figure 9.10). The queries helped in identifying project items linked to the central concepts. These queries were derived from the researcher’s inquisitiveness on the “what”, “why”, “how” and “where” questions from the data. These project items were the nodes and sources around the central concepts/items. The sources were organized in sets of FGDs for FCs, KIs and IDIs for FCs, and subdivided into these categories. This helped in creating models based on these categories. Some of the nodes (themes) project items in the models were developed from asking the data questions through queries.

Miles and Huberman (1994) argue that, data display was a key element of the analytical process. The authors further observe that “displays help us to understand what is happening and do something – either analyse further or take action p.11”. In my view the visual display in form of pathways, was reconstructing and describing the reality of care environment presented by FCs of their lived care experience. Common occurring themes and categories from the analysed data provided description of FCs’ experiences and different actions taken to address presenting situations.

Pathways developed from analysed data helped look at care from the perspective of the FCs’ appraisal process hence illuminating the thinking, description, feelings and resultant behaviour. Key concepts of major themes formed the initial development of pathways as reflected in Figures: 9.4, 9.5, 9.6.9.7 and 9.8 and the follow on of movement of events in the pathways were also from the FCs’ description of events.

## Research Challenges and Ethical Considerations

### Methodological challenges*.*

Translating vernacular into the English language and vice versa was quite challenging and the research team had to constantly review the transcribed scripts to ensure that the original meaning of what the respondents said was not distorted. It took longer than planned to review the scripts due to large amount of data generated in English, Nyanja, Bemba and Tonga. We took time to translate the scripts and have common understanding of responses from the interviews. However, with the research assistant we had agreed from the outset on the language/words that were appropriate to use and the translations of some of the key concepts and words so that the information generated was appropriate to answer the research questions.

### Ethical Considerations

Ethical clearance and approval was sought and obtained from the University of Zambia Biomedical Research and Ethics Committee. Further approvals to conduct the research were obtained from the Ministry of Health (MOH) Research Committee. Approval was also obtained from Lusaka District Health Office (DHO) who officially wrote to the Nurse- in-charge of the main health center in the research catchment area. With the approval from the DHO, further suggestion was given to conduct the pilot in the Researcher's area of choice. Before obtaining approvals, initial discussions were held with Executive Director and Director of Programmes of the Main HBC- Bwafwano HBC center in the study site who were happy and approved to have the study conducted in their area. .

Participants in the study were informed by providing them with detailed information related to the study and why the study was being undertaken. The possible benefits to be derived from the study, known risks were discussed and how results of the study were to contribute to the practice of HBC in Zambia and discussed possible sharing of results with participants.

I was particular about giving respect to views expressed by participants and assurance was given for confidentiality of and anonymity of information provided and that names of participants will not be divulged in the research. I was also cognizant of the fact that some questions would elicit emotional response(s) and could be uncomfortable for the interview process. Special considerations for such events were addressed appropriately by allowing time for the respondents to recompose, or moved away from the patient's hearing range. With my knowledge and skill in interviewing, I was able to provide comprehensive explanation of the expectations during the interviews.

I was mindful of daily activities in the households and did not disrupt any normal interactions. Interviews were conducted at convenient times to the family carers as prior arrangements on the appropriate times to visit had earlier been made by the Gatekeeper from the HBC center. All Gatekeepers were met at Bwafwano HBC center. During the initial meeting with each gatekeeper, further explanations on the structure of the interviews were provided and emphasis was made on the importance of privacy between the Research team and the family carer and that the Gate keeper was not to be part of the interviews.

During the course of interviews and more especially during in-depth interviews, I was very particular with being observant of and mindful of uncomfortable situations during which the respondents failed to answer a question or was uncomfortable to answer some questions, more especially when answering questions related to “feelings about care work” and when asked about “how they found themselves to be the ones caring for the patient”. Most FCs had difficulties answering the above question as they displayed some form of discomfort to provide a ready answer. However, with prompts this was realized. In two interviews, the FCs made a non-verbal sign that the question that had been asked was not appropriate to be answered in the presence of the mother-in-law as she (the patient) was within earshot. While in the other circumstance, the FC requested that we move and sit outside the house away from the patient. In such situations the researcher respected the request of the FC needs. (Note: in one household, the interview was conducted on the veranda and with floods almost touching the entrance to the house, sometimes we agreed to conduct the interview on another appropriate day). This shift in position to conduct the interview in privacy also allowed the respondent to provide answers without the feeling of being intimidated by others in the household.

### Conclusion

In this chapter, I was able to describe and provide key information to relate to the methodology and the design of the study. I further did provide the reader with the opportunity to ‘participate’ in the understanding of the process of interpreting the world within which caring for chronically ill patients with HIV/AIDS. In addition, this ‘participation’ sets the pace for the reader to construct the real caring world for FCs and understanding the analysis process used in the study. In the next chapter I will present the findings from the analysis of data on demographic characteristics and the environment of care to facilitate the construction and interpreting the care world for HBC services.

# CHAPTER SEVEN: Demographic characteristics of general environment, profile of study participants and their patients

## Introduction

The following chapter present findings of the study on coping mechanisms devised by FCs in the context of changing family roles in home based care activities in Chazanga residential areas in Zambia. I have provided findings of information on how the data was generated and analysed. I have further discussed the characteristics of individuals who participated in the study (the profile FC, and their patients). Analysis of demographic characteristics of the FC (n=16) and the patients (n=17) relates to data from individual interviews. I have gone on to describe the environment as they relate to the socioeconomic status of the FCs in households with chronically ill patients and that of the patients before falling ill. Data on organisations offering and supporting HBC activities in the locality was collected by reviewing programme records, the details of which are discussed in the methodology chapter.

Themes were derived from data and based on key social areas of care work. The chapter is divided into the following sections:

a. The introduction which sets the frame of what is contained in the chapter and the sequencing of the sections and main themes.
b. Social demographic characteristics of family carers and their patients, including gender, age, marital status, economic activities and circumstances leading to care work
c. Other demographic characteristics of the patients to include diagnosis and the length of illness.
d. Social demographic data which analyses the environment within which the study was undertaken and more specifically the care environment detailing the actual scenarios existing that had some relationships and possible influence on the outcome of care efforts and interactions of family carers in households.
e. FC's revealed knowledge and understanding of care work
f. FC's stated orientation to care functions
g. Types of challenges described by caregivers in caring for chronically ill patients
h. Type of resources available and needed to facilitate care work.

Specifically these formed the major themes that guided the analysis of the data as the study was trying to understand the meaning of constructed knowledge or the reality of the care situations in the households.

## Socio-Demographic characteristics of Family carers and their patient

### The Family Carer

The FC in this study is also referred to as the primary caregiver. When asked who the FCs were in the respective communities, the respondents for example in the focus group discussion (FGD: 09 of key informants in Kabanana, reported that there were different groups of caregivers, ranging from "*young girls of tender age caring for elderly people*" with ages ranging from 12 to 15 up to beyond the age of 60. It was reported that sometimes FC are the elderly, an example was given of one FC aged 75 who was providing care to grandchildren (in this instance, there was no patient in the household) as parents to the children being supported (daughter and son) had died. Caregivers were also described as the elderly people/women mostly, "*who can't even afford to find food for the patients. They just go out to ask for food. Some are looked after by their children who don't even have the means of earning an income, as result, they get into prostitution so that they can buy food for their parent. Their relatives abandon them."* (FGD: 05: R2) caregivers, they further said, included men, women, mothers, fathers, wives and husbands who were caring for their spouses. Most caregivers are women as reported by all FGDs, of key informants and that in most cases were members of the households. The results also showed more mothers caring for their children and wives providing care to their husbands

**Table 7.1: Demographic characteristics of Family Carers (N. 16)**

| Variable | Frequency |
|---|---|
| **Gender** | |
| Female | 15 |
| Males | 1 |
| **Age** | |
| Below 25-34 | 2 |
| 35-44 | 7 |
| 45-54 | 4 |
| 55-64 | 3 |
| **Marital Status** | |
| Married | 7 |
| Divorced/separated | 1 |
| Widowed | 4 |
| Single | 2 |
| Not stated | 2 |
| **Relation to patient** | |
| Wife | 4 |
| Parent | 5 |
| Other relative (e.g. sister, Brother) | 4 |
| **Number of Children** | |
| 0-1 | 2 |
| 2-3 | 5 |
| 4-5 | 5 |
| 6-7 | 2 |
| 8 | 2 |

Source: Field data 2010

### Demographic characteristics of Patients being cared for

This study generated information from the caregivers related to the sex, age, marital status, economic status of the patients before falling ill, length of illness, and the number of living children, to provide and reconstruct the possible magnitude of challenges that the family could be facing, more especially where the family was large and the patient was the bread winner. This information was important as it was to provide further explanations on those being cared for and provide the basis for understanding the probable effects of the illness on the household. The Table 7.2 provides a description of patients and the immediate care environment..

**Table 7.2: Demographic characteristics of study patients (N.17)**

| Variable | Frequency |
|---|---|
| **Gender** | |
| Male | 12 |
| Female | 5 |
| **Age** | |
| 1-5 | 2 |
| 06-15 | 1 |
| 16-24 | 0 |
| 25-34 | 3 |
| 35-44 | 4 |
| 45-54 | 1 |
| 55-64 | 1 |
| Adult (age not specified) | 5 |
| **Marital status** | |
| Married | 6 |
| Single | 1 |
| Separated/Divorced | 3 |
| Widowed | 4 |
| Children | 3 |
| **Diagnosis** | |
| HIV/AIDS | 10 |
| TB | 6(HIV related) |
| Cancer | 1 |
| **Economic activity before falling ill** | |
| Self-Employed (knitting, chicken rearing, hair plaiting) | 5 |
| Piece works (painting houses) | 1 |
| Not employed | 7 |
| Child | 1 |
| Doing nothing /no mention | 3 |

Source: Field Data 2010

## Gender of family carers and their patients

### Gender of Family Carers

There were more females participating in the study as the Gate keepers who were both men and women led the research team to those houses that had been known (to management of HBC organisations) to have chronically ill patients with HIV/AIDS and were being taken care of by family members. They were in the age range 15-60 years, actively involved in the care of chronically ill patients and of not less than 6 months duration of being sick. Noting from the findings, women were in the majority in these communities providing care in the households. There could have been other probably unnoticed men who could have been providing care as family carer givers to chronically ill relatives, however, only one man was sampled by the gate keepers. The study further revealed that most men providing HBC services were those attached to FBOs, CBOs and the type of care provided was on voluntary basis. This meant that church members, who volunteered to go out and assist with HBC activities, visited a number of households to check on the patients and provide whatever kind of assistance within their ability (Personal communication with a Pastor from Madaliso HBC 3-12-2011).

However, when men participated, they mostly took care of patients outside their households. Men mostly followed-up those patients who may have been referred by health centres to CBOs and FBOs and especially to those caregivers that were active in taking care of chronically ill patients. Hence most of the men who were active in HBC, were those who cared for referred patients from the health centre. Findings also show that when an illness occurred in the family or household affecting a spouse, a man will seek assistance from other family members, normally women, or call on CBOs, where they existed to assist with caring for the patient. However, where men were actively involved in care, they were mostly involved in taking up tasks like obtaining drugs and resupplies from the health center, looking for transport, looking for money for the purchase of household needs for the patient. (Personal communication with Programme Coordinator Madaliso HBC). It was observed that women more often than men take up the caring role in families, largely because they have no choice. The care giving role adds on to the strain on the women who are already loaded with multiple competing roles in the family. The gender-biased nature of care giving responsibilities in the households has further disempowered the already overburdened women as observed by other researchers that during the long term care giving, women experienced untold physical exhaustion, mental strain, economic hardship, emotional and social deprivation (and Esu-William et al., 2006; Ogden, et al., 2004; SWAAZ, 2007). However, only one man in Chazanga was identified and singled out as caring for his brother and there were no other members of the family core resident in that household.

### Gender of patients in the study

Table 7.2 shows the sex of the patients. Of the total number of chronically ill/patients under study, 12 were males while 5 were females. From the table above, the results may mean that there are few female patients who are cared for in the households in the six study compounds in Lusaka District. The sample size was not large and hence, chances were that female patients in the households may be very few in the sampled areas to be captured within this sample size. Generally, the survey results show that majority of the respondents were male patients.

### Age of family carers

The study was also guided by the pre determination during the design of the methodology that FCs to participate in the study were to be aged between 15 and 60 years. This determination was guided by literature reviews showing that most carers at the household level were aged between 15 as the lower limit and up to 60 years as the upper limit. The age range of caregivers were between the age of 35-44 (7), followed by those aged 55 to 60 (3) the other 6 did not state their age. This sample was predetermined with the selection and exclusion of some age groups was mainly meant to allow the researcher generate special information from those with specific attributes in representing the group of caregivers (Blackie, 2000). Further, the sample was selected based on the assumption that no population list existed that described who was providing care, hence it was imperative that the list of research participants have a reasonable lower and upper age limits, thus 15 to 60 years were selected.

Table 7.1 shows the age range of the respondents. Age is an important factor in the care of the chronically ill/patients. The results show that 7 of the respondents were aged between 35 and 44; 4 were between the age of 45 and 54; 3 aged 55-60 and 2 were aged between 25 and 34 years. Significant also from the survey results is that the majority of the family carers are 35 years and above.

### Age of patients in the study

Table 7. 2 also show the age range of the patients under care. Age is an important factor in the care of the chronically ill/patients. The age of the patient may be one of the key determining factors of the way the FC interacts with the patient. The age of the patient may further be an element in deciding the kind of care appropriate for the patient, the anticipated kind of demands from the patient, time taken to adequately provide care, and the kind of help that maybe needed to support care needs. The results as noted in Table 7.2 show that the age groups of the majority of the patients are aged between 25 and 44 years, demonstrating that there may be more such patients from the productive age group those require urgent attention specially in providing for health care services. The need to address their greater concern of availability of ART and to offer opportunity for such groups to participate in viable economic activities can never be over emphasized; the findings did therefore demonstrate this urgent observation*.*

### Marital Status, roles and number of children of family carers

The sample shows that six caregivers were married, four were widowed (with husbands having died from HIV/AIDS), three were separated (one was deserted by her husband, when she tested HIV positive) and two were single.

Marital status as reflected in Table 7.1 is an important factor in understanding those that were taking care of the chronically ill (HIV/AIDS and TB patients). As the presence of the spouse during the period of caring, may provide some form of respite to the caregiver , by the other being able to take on some responsibilities and relieve the caregiver from pressure of work.

Some of the FCs played double roles as they were caring for other patients within the household, as well as themselves needing to be cared for. Such was the case of IDI 08 who was positive and breastfed her son who too became positive. This FC stated that could not conceive of any ideas of stopping breast feeding her child as she did not want the risk of starving her son to death hence she opted to continue breast feeding and take the risk of infecting the baby with the virus. The decision to continue breastfeeding despite her knowledge of possibly infecting her baby was based on the fact that, she was in a situation that her ability to source for resources to offer alternative feeding supplements to facilitate taking care of her child were hard to achieve. Also in another related case, the husband and the FC were both HIV positive and shared roles in taking care of each other (IDI:13) when feeling ill.

Results show that the majority of the FCs were now the heads of the households and nursing their spouses or were the heads of households because they were widowed, separated, divorced or single. The concept of unstable households in any community means that those who are breadwinners were sick and unable to provide for their families. Therefore, women in these households assumed the responsibility of taking care of the patients as well as meeting the other social and economic needs of the patient and the family, despite their inability to do so.

Table 7.1 further shows the number of children of the respondents in each of the household in the study. The table shows that two respondents had eight children living in a household. and that were overcrowded as most respondent indicated poor housing to adequately provide some form of comfort to all members of the family and ensure the patient is also comfortable.

The number of children per household has implications for the provision of adequate care for the chronically ill. Households with many children are more likely to face more challenges in meeting the needs of the family than households with fewer children. The reason for this observation is that usually households with many family members may experience difficulties in providing adequate food and shelter for the entire household. However, research has shown that changes in family structures has resulted in children in some households afflicted with HIV and AIDS, known to abruptly discontinue with education of their children and more especially girls in order to assist with caring for the sick or carrying out chores in the household or assuming roles of selling at markets in order to raise money for household sustenance (Yeh et al., 2008; Lindsey, et al., 2003; Demmer, 2006).

It is further learnt from the findings of this study that patients especially with HIV/AIDS, and TB will require more nutritious food as they take medicines that give them good appetite, while some medications require that food be taken before medication. There was different perception regarding medications and food, as study participants viewed households with fewer children as being able to provide and manage the levels of patient‘s nutrition as compared to those with more children. The demands for daily nutritional needs were perceived to be lower in households with fewer children, where the demand for food and other necessities may not be as high. It is important to note that most study participants did indicate that on average, households were only able to manage one to two meals per day. The meals may not even be of nutritious value to the patient, with some households going without food more especially on days when they were not able to find money to buy food. Frequency of this provision and the quality of food was significantly different between households. Further, the food was also mostly of the same nature vis:  Nshima a staple food made from maize meal and mostly eaten together with vegetables, in majority of households. In view of the fact that the FC had in most households needed to go out to engage in piece work to earn some money to buy food, some patients were made to go for hours without food.

### Marital Status of Patients in the study

Significant also is the presence and number of single, divorced and widowed patients in the study areas. This should be a concern to government and other stakeholders in that majority of the respondent who are single, divorced or widowed are the ones who are facing different socio-economic challenges which may be a significant challenge in care work. The issue of conjugal relationships between wife and husband raised concern with one of the family carer. She was troubled by the fact that the husband frequently used to ask for sexual relationship. The wife, the family carer was much aware of how the virus was spread she (IDI: 10) expressed fear of contracting the virus said about caring for the husband who was HIV positive;

> *“I think I might also get sick since I care for the patient”……*
>
> *“I think to myself that anytime I can also get sick”*
>
> *“I look at myself and know that I won’t be looking well for so long” (IDI: 10)*

Such were some of the real fears expressed by the respondent. She further went on to say about the illness and other circumstances associated to the disease …. *“ I have managed for two years because of training………..I was trained to take care of the patient……they encourage me because this illness keeps going back and forth. ……only God knows, the biggest thing is to take care of yourselves properly…….. Sometimes my husband asks for sex relations and that I cannot do that because that’s one of the things I was told not to do while he is in the situation he is in. It is difficult but what has to be done has to be done. I stick to rules because I want him to be better in future.”(IDI: 10).* These are some of the many experiences and fears that family carers have to constantly face, especially with family carer s nursing husbands/spouses.

### Economic status/activities of family carers

Questions were asked to ascertain the levels of economic status of FCs to meet the needs of their patients. The results show that majority of respondents in the six compounds that participated in the study were not employed and therefore not earning any salary to meet their needs. Of the 16 FCs who participated in the study 15 were not in any formal employment as only one was employed (the caregiver was also HIV positive). Meeting the physical needs of the patients was one of the key areas identified by majority of key informants and family carers, as one aspect of providing adequate services to patients. KIs and as generally stated by nearly all FCs, care being provided by caregivers was lacking key elements of resources to support adequate provision of services to their patients.

The majority of respondents (15) were engaged in running some form of small scale businesses of buying and selling very basic commodities like vegetables, some groceries. While others earned their incomes by being involved in piece work like (washing clothes/laundry and drawing water), others (4) were trading in merchandise at green market, and 1 is engaged in stone crushing. The rewards from such income activities were in most cases very low and could not adequately meet the needs of the households. Selling of some household items were some of the means that 2 FCs were able to sustain household income levels, as there were no other sources of income. One mother who experienced loss of 8 of her 12 children mentioned that she had to stop her engagement in her small business of “buying and selling” in order to take care of her sick son who was part of the household (IDI:FC:03). One IDI:FC:02, who before taking on the responsibility of caring for her mother-in –law, had been in gainful employment which she had to relinquish as her husband’s family brought into their house her Mother-in- law with AIDS to be cared by her.

The significance of the findings on sources of income appear to mean that caregivers needed to be economically empowered to enable them have sustained sources of income to meet the needs of their patients. Meeting the needs of patients was identified by majority of key informants as one aspect of taking care of the patients in households. Meeting the needs of patients and especially those on ART, was one of the major challenges, as health providers advised that patients be given food before taking medications, or that food should be taken soon after taking drugs which according to the findings posed one source of frustration for the family carer in view of the scarcity of such a resource in households.

Money was also another need mentioned as a key necessity to facilitate transporting of patients to the health facilities either to meet their appointments for reviews or when patient’s condition needed medical attention at the health facility. All family carers indicated that sometimes patients did not meet their appointments and hence follow-up to ascertain the health status and progress being made was not met.

### Economic Status of the Patient before falling ill

Determining the economic status of the patient before falling ill was important in order to understand the degree of reliance on others or none at all. If the patient was actively involved in some economic activities, it meant that the family could have lost their regular source of income thus subjecting the family to some form of financial hardships. Six respondents in the six study areas were engaged in piece work (washing clothes and drawing water), 5 were trading in merchandise of buying and selling at the market; 1 was formally employed, while the economic status of 3 of the patients is not known.

The patients in the households had, before falling ill, been economically viable and provided for their households. They were self- employed at most, being engaged in activities like; Bricklaying, running small businesses, vegetable growing and vending, buying and selling fish, poultry keeping, and others.

The need for finances to manage and respond to care needs was mentioned by nearly all respondents in the FGDs and IDIs. The financial constraints were made worse especially when it was the bread winner affected by HIV. The chronic nature of the disease meant that there were prolonged periods when affected families would go without adequate resources to meet the needs of the patients and that of other members of the family. For example, children's education was affected as they had to drop out of school. The wife, the family carer (if the husband is the bread winner) has to take on the responsibility of looking for resources like money by engaging in some form of piece-work within the community. The fact that the wife has to leave home to go out to look for money further worsened the situations as family carers felt that they were neglecting their patients and expressed fears that anything could happen to the patient in the long and many periods of their absence from home.

Respondents referred to the need for availability of money in a household, and this preoccupied most FCs, as most of them reported that lack of money in the household affected the provision of many other needs for both patients and other members of the family. Households were situated far from the health centre\ (clinic), and most patients were immobile, and therefore needed some form of transport to take them to the health centres for the regular reviews and resupply of drugs.

Lack of money further affected the kind of food the household has to buy to benefit the patients and the frequency of meals for the patient. FCs report that they had been informed that ARVs were very strong (potent and was believed to make the patient weak if taken on empty stomach) and as such patients needed to eat before taking drugs. The poverty in most households worsened the conditions in that family as the lack of or inadequate food in the home meant that the number of meals had to be reduced; amount of food had to be stretched out to meet the requirement of the patients. When the patient is not regular in the timing of taking drugs or patient is not taking ARVs as per instructions would result in adherence being compromised. In one instance the family carer resorted to starving herself in order to let the patient eat and be able to take the drugs.

As noted earlier, most households in the study area use communal sources of water which has to be paid for. FC expressed deep concerns in that a situation where there is no money meant that patient's need for proper hygiene, clean water for drinking, bathing, laundry are compromised and generally not adequately addressed.

### Diagnosis of the patients in the study

Since the study was focusing on coping mechanisms of caregivers of family members who were chronically ill from HIV/AIDS, it was important that the study established the family carers' knowledge of the diagnosis of the patients under their care. Such knowledge about the diagnosis would facilitate caregiver's understanding of their roles and responsibilities in providing the much needed care, support and maybe able to manage their patients appropriately.

**Table: 7.3: Description of patients in the study by Diagnosis**

| **Diagnosis** | **No. Patients** | **Comments** |
|---|---|---|
| HIV/AIDS | 10 | Family carers lament that most households do not have understanding of infection prevention, do not have resources to assist in infection prevention, they do not have adequate food to provide good nutrition to patients on ARVs. One family carer /mother was nursed by a 25 year old daughter, has fears that the daughter may contracted the virus from the mother. |
| TB –related to HIV/AIDS | 2 | Infection prevention issues are a major concern of the family carer as there is fear of contracting the infection |
| HIV and TB | 4 | Most family carers have misconception and believe that patients taking ARVs should not combine TB drugs and ARVs. This has created situations where patients are not adhering to ARV or TB drugs and resulting into worsening of patient's condition in most family carers. |
| Cancer (HIV related) | 1 | Costs for providing nursing to cancer patients is enormous as the cost for reviews and medications are beyond the reach of the family carer. |
| Total | 17 | |

Source: Field data 2010

Data in Table 7.3 show the diagnosis of the illness of the patients. All FCs seem to have knowledge of the diagnosis of the patients they were caring for. It was the aim of the study to select households with patient suffering from chronic disease of HIV/AIDS. Three family carers were also HIV positive and receiving ARVs whilst one was an epileptic patient taking care of a patient with HIV/AIDS. They too despite their affliction of chronic nature were also providing care to other chronically ill patients. The table shows that majority of respondents in the six study areas were diagnosed with HIV/AIDS (10), with HIV/AIDS related TB (2); HIV/AIDS and TB (4) while only 1 was diagnosed with cancer ( could not explain the type of cancer).

This finding was similar to what was given by key informants in the study compounds who were of the view that most of the chronically ill patients in the households were suffering from HIV/AIDS and TB. As most patients were suffering from HIV related problems, FCs did not have much knowledge on the presentation of the disease especially understanding symptoms of the different opportunistic infections. Some caregivers were worried about the possible spread of the virus to other members of the family and including the caregivers, as they did not know how to avoid spread of the disease.

### Duration of the illness of the Patient

Five of the patients had tested positive and living diagnosed with HIV/AIDS for two years, 3 for one year, 2 for seven years, and 2 for six years. On the other hand, 2 had been ill for one and half years while only 1 had been ill for four years. Significant also from the study results is that most of the patients have been ill for a long period of time at least more than one year as this was in accordance with the intended study sample. However, the chronic nature of the disease should be taken seriously by the government and other stakeholders. The protracted nature of the disease would significantly affect the length of time it may take to provide assistance to such families. Further when the bread winner is the patient is meant that someone has to make extra effort to provide for the many needs of the family and the patient. The actual costs of such support would put a strain on both the family and the government. Most patients being cared for were already part of the household, and few others came from elsewhere specifically to be cared for in the sampled households.  Another perceived extra burden exerted on the members of the family was that they had to make double effort to ensure that provisions were available for the family.

Some patients were not regular members of the households as they were in most cases imposed on the household or FCs. Various reasons for accepting patients from outside the household were provided which included, having more room in the house for the patient, having better understanding of caring functions, perceived easy access to the health center or clinic, no one else to take care responsibility.

In another related situation, the FC had her mother –in –law brought in to be cared for in the household. The family carer (IDI: 02) was never consulted by the husband who made the decision to bring in his mother who was in a chronic state of illness. The son felt that he needed to bring his mother in his own household, as there were no other family members to help her out if she had to be left in her own household and therefore may not receive the necessary care.

Most of the patients being cared for by FCs suffered from other conditions and/ or opportunistic infections like, diarrhea, generalized body rashes, sores on the body, HIV related TB, swelling of feet, urinary tract infections, prolonged severe headache, vomiting, mouth sores and other symptoms.

### Characteristics of Households

Caregivers were asked to respond to questions related to characteristics of the household units, and other amenities that provided a safe mode for patient care. Good housing provides an environment that could promote healthy living especially for the patient, since proper ventilation and cleanliness could be guaranteed. Housing was therefore a key factor in the provision of care to chronically ill patients. Questions on household units including home ownership were asked as a way of determining what other factors in patient care could have influence and affect the caregivers' ability to provide some level of care in terms of ensuring comprehensibility in the care provided to the patient. There were eight family carers renting houses while 7 lived in their own houses. Some of the rented houses had other tenants within the same household. The study further found that more than 10 people were living in one household, more especially those having large families. Two families in different localities in Chazanga (IDI: 09 and IDI: 08) were living in two rooms each, a bedroom and a living room, where the patient slept in the living room with children, and the FC and husband slept in the bedroom with other children. This situation meant that, there was constant movements in the living room, disturbances and the environment did not provide adequately for rest ( in both cases the patient were women; a sister to the FC and mother-in-law to the FC).

Significant also is that the majority of the FCs live in rented houses of which they have to meets the costs of monthly rentals as well as ensuring that their patients were provided with adequate food, a fact that is complicated by the uncertain economic levels where the household has to meet the rentals and daily social requirements

**Table 7.4: Access of households in the study to social amenities**

| **Variable** | **No of households** | **Comments** |
|---|---|---|
| Toilet/Pit latrine | 16 had pit latrines | All households had some form of a toilet, inform of pit latrines. At the time of data collection, 2 toilets had collapsed. Although toilets were available in some households, the structures were not adequate as the wall were made of plastic paper or grass. |
| Electricity | 2 | Although Electrification has reached this residential area, only a few can access. This also means that household have to use other sources of energy for cooking and lighting. |
| Clean and safe water | 1 | Most housing units use communal water sources and pay a fee to access water |
| No such facilities (toilet, water) available | 5 | This is meant that, the household has to go elsewhere to access these facilities |
| Accessibility of such resources to meet the needs of patients<br>**Yes: 3 No: 13** |  | Accessibility to facility/resources was a major concern for nearly all family carers. They were of the view that availability and access to resources would make care work easy |

Source: Field Data 2010

In terms of facilities that were available for the provision of care, although all respondents had toilets/latrines for use by the household, only 4 said that a toilet was available with easy access by the patient. Another 2 said that they had electricity and 3 indicated that toilets and electricity are available and only 1 said that clean and safe drinking water was available, while 5 said that no such facilities were available and had to use facilities in the neighbourhood. One FC resorted to the use of plastic as a receptor for excreta for the patient who had diarrhea instead of subjecting the patient to a state of a toilet which was partially collapsed. It was easier for her to use the plastic bag and dispose of the plastic and its content into the pit latrine.

Significant too is that the majority of the caregivers said that facilities for the provision of care were not available, which made it difficult for the caregivers to meet the social, health and physical needs of their patients. For example, water was fetched from far away (from households) places and at times this had to be paid for. Clean water and sanitation were essential for daily hygiene like bathing the patient, laundry, cooking, drinking and disposal of human waste. Where pit latrines existed, they were shallow and poorly kept posing health hazards to members of the household. Water as reflected earlier is fetched from communal sources, where sometimes it is paid for or in other cases as reported the households contribute some money for maintenance of the well. Others pay a small fee to access water. This situation therefore, is meant that the FCs who in the majority of cases were also expected to generate funds to purchase care resources, will be required to make extra time away from the patient in order to source for money.

The perception of distances was very different from each FC and also for the KIs. Distances was conceptualized as mostly “far or near” for most respondents. However, when asked to state the distance in numerical value, they mostly estimated the number of kilometers from the household to the health centre. Estimations of distances were also based on the accessibility of the households to the main commuter routes where access to transport could be found (Map 6.1) Of the total number of respondents, seven said the nearest health center was far (about 10 km), six said that the health center was very far (about 15 km), while three said that the health center was not far from their residential areas. The available health centres in the study site include, Bwafwano HBC (the kind of services offered were discussed in Chapter 4), other health facilities mentioned were: Chingwere Clinic, Chazanga Health Center, Chipata Clinic and University Teaching Hospital the largest referral hospital in Lusaka and in Zambia. Thirteen family carers indicated that the nearest health center was not easily accessible since they were located far from the residential areas. Therefore, in the event that the patient will require to go for reviews or when the conditions of the patients requires some interventions by the health provider, transporting the patients for such care was a challenge and very difficult for the families. The inability for the FC to take the patient to the health center could exacerbate the anxiety situation especially when the patient’s condition requires urgent attention by health personnel.

### Conclusion

In this chapter, I was able to set the scene of the environment within which care for chronically ill patients with HIV/AIDS was provided. In the next chapter I will present findings related to the variables that relate to social determinant factors that have influence on caring for such. The presentation will be based on the GRR that have bearing on how individual’s SOC is realized.

# CHAPTER EIGHT: Findings on lived experiences of FCs to care work

## Introduction

This chapter presents findings of information pertaining to care work, general preparedness of family carers for care functions, and their feelings about care work or functions are discussed. FC's stand in the midst of the effects and impact of HIV/AIDS in households, the type of challenges faced during care work, the perceived source of challenges and how they cope with those challenges. The chapter also describe the attributes the FCs possess that make it easy or difficulty to provide care to patients and how such attributes contribute to coping mechanisms. Finally provides information on the kind of needed resources, perceived source or resources and also gives a short brief on organisations involved in HBC in the study area.

Based on the conceptual framework in Chapter 5, I was able to adapt the Salutogenic Model of SOC and GRR, the works of Aaron Antonovsky and SI to facilitate the understanding of what was happening in the care environment. The framework provided the parameters to describe and assist constructing of the lived care environment and understand how the behaviour of family carers was categorized. However, in this chapter I have provided the opportunity to learn how the daily lives of the caregivers who participated in the study can be examined and explored by ascribing how sense is made out of the daily interactions with care functions, how conceptualization of actions taken by caregivers and how they manage or don't manage to cope when faced with challenging situations.

## Why and how they became FCs for chronically ill patients.

Generally, the findings indicated that in some circumstances, FCs did not necessarily have to be related to the patients, but could be living in the same locality (this was common among CBO or FBOs who provided some form of support of chronically ill patients). However, the majority of respondents indicated that FCs were members of the household. In one FGD of FC aged 35-60 in Chazanga community reported that they provided care to patients who were husbands. Whilst one was taking care of her brother, one respondent in a FGD 06: R2 said being a carer *"…. for me, I didn't even have to be chosen because he is my husband".* While the other in the same FGD said "*The time my brother's wife died, I took him in and started taking care of him".*

Some FCs had not been residents of those households under study, but were asked to travel to the household where the patient lived and be part of the care team. It was evident from the interviews that the reasons for asking these caregivers to move from their usual residences to the household with patients were that a) they had no other big responsibilities in their own homes, b) they had lost a husband and did not have much to do despite having own children to care for, c) and that those in the household with patients were not strong enough to provide care to chronically ill patient (in one case, the mother to the patient was elderly and was not able to manage with care functions).

Different circumstances resulted in some individuals participating in care work, with some called from outside the home to come and help out. Others made a personal decision to take on the responsibility and in some the patient was forced on them.

> *"My mother came and told me that I should come to Lusaka and take care of my sister as there was no one to look after her as she has no strength to do things on her own. My mother stays in Ndola; she is the one that told me to come here."(IDI: 12)*

Some family carers took on the responsibility to care mainly because there was no one else within the family to do so. In one case, the FC was a tenant and had to take care of the landlord as he had no one around to take care of him. In other situations for example, family carers IDIs; 03, 04, 05, 06, 07, 08, 09 indicated that care work was a responsibility that is, in most times assumed by someone in the family based on the relationship with the patient, or there could be no one else in the family to do so.

> "*I take care of the patients because the patients are my children and if I do not take care of them, there is no one who can provide them with necessities" IDI:6*

> But IDI 08 in Chazanga commented about taking on care work as follows: "*Despite my HIV status which is positive, I have been taking care of my son who is also positive as there is no one who can take care of him. Nowadays, there is no one who wants to take care of the patient not even relatives in most instances. No one can look after someone who is HIV positive very well the same as your mother can. This is because it is not easy to take care of someone who is HIV positive, so it is better to stay on your own and what is important is just to look for food and stay alone"*

This was one important finding as it brought to light the differing development on changing ideas of the application and/ or observance of filial obligation in families. They (FCs) felt the sick were "their patients". Notable about the behaviour of the caregivers was that, as soon as the fact was established on the relationship of the caregiver to the patient, any subsequent related responses most times referred "to the patient" and not the relationship status. Like my son, daughter, they used terms when referring to the patient like "bo dwala" in Nyanja or "abalwele" in Bemba or “balwazi” in Tonga.  The only situation when the patient was being referred to as “my son” for example was when the 30 year old was being cared for by his mother (IDI:03) . And mostly she was emotionally touched by providing the kind of sensitive care to her son.

### Orientation of Family Carers to care work and functions

*Providing care to chronically ill AIDS patients*

Caring for any patient requires knowledge and skills that caregivers need to display during the caring interactions.  The skills range from counseling, providing food that is balanced to meet the nutritional needs of the patients, proper hygiene that promote healthy living. Knowledge related to care of patients was mostly obtained from past experiences when FCs participated in nursing relatives who were spouses, children, siblings or other, may obtain through structured training or the non-structured ones. One FC in (FGD: 5: R1) explained that she obtained knowledge of caring from reading books, watching videos, she said;

> “……….*I have a series of books that I have been studying which talk about how  to care for the sick in the community from Mt. Makulu Research Information  Center like people with TB and HIV and other information in form of video tapes…….. I watch other people are being cared for and steps to take and also sensitisation through the Ministry of Health”.*

All caregivers could not conceive of anyone else who would be charged with the responsibility to care for the patients other than themselves. Other caregivers within the community believe that patients do not have to be relatives, hence they were obliged to provide care to any patient living within their catchment areas. Caregivers were of the view that caring was meant for them and no one else could provide such care to the relatives in the family circles. They did express the fact that they were indispensable especially when it came to caring for their sick relatives the “I” in the context of providing care as they accepted and felt were the best suited to do the work. There was recognition that a strong and a coordinated family structure was cardinal in patient care at household level. Help from other members of the family appears to have dwindled especially with pandemic of HIV/AIDS, where it is observed that everybody was busy nursing other members from within the household. Hence, expecting help was a far-fetched reality as the sources of help were no longer in existence. Each family was now expected to look after its own patients. Hence, respondents from one FGD: 07 of FCs aged between 35 and 65 observed that families now cared mostly for their biological children.

When elderly people in the family died, "….. *Things would be bad. Because there wouldn't be anyone to take care of my children*…." The FC was convinced that the situation would really worsen if they died as there would be no one to care for their patients. They believed that only them (as relatives) would be most suitable to provide care. One of the FC in a FGD, who was epileptic, was also taking care of her adult son and they expected the community to help her. When in state of epileptic attacks (in the caregiver), there was no one to take care of her patient until she (FC) got relief of the attacks (FGD7 of R2 caregivers aged 35-60).

### Knowledge in caring for chronically ill patients and types of care functions

Family carers were concerned with the disease due to their inability to understand the mode of transmission of the virus. For example, in one FGD of KIs, they were concerned with the lack of understanding of the disease as one of the challenges faced by FCs *"they are ignorant on how these other diseases are transmitted, they don't even know what TB is, how it is transmitted and how to look after a patient who has TB, it's a big challenge" (FGD: KI: 02.* Compounded with lack of understanding of care work requirements, FCs expressed fear of being infected, as most of them bathed their patients without protective clothing like gloves. This was also supported by all FGDs with key informants, who were concerned with the situations of caring services in households. They did express fears that caregivers in households did not have adequate knowledge and resources to support the continuum of care for chronically ill patients with HIV/AIDS. Key informants also tried to implement some orientations activities within households but due to the limited number of visits the frequency of such supportive visits to households and poor support structures and further compounded with the large number of households needing the support, their efforts were very minimal. Some were afraid of being stigmatized felt alone, and isolated, hence they kept the silence about the patient and thereby denying the patient of any support that could have come their way. The FC lacked knowledge on how care work was to be managed, but with time, some reported caring becoming clearer.

> *One FC in IDI: 11 said "the challenges were that I didn't know what was needed to be done, I didn't know what type of food to give the patient, the time when the patient should be given food. I also didn't know when to give the medicines and the clinic from which to obtain medicines. This made the patient to be complaining that if she had strength she would do things on her own"*

### Family carer’s understanding of care functions and responsibilities

This study was undertaken in an era when the face of HIV/AIDS had dramatically changed, with more and more people living with HIV/AIDS (PLWHA living longer due to availability of ART. The introduction of ART has improved the lives of HIV positive individuals and with proper care and management, such individual were living longer, with some going back into productive life. ART services in Lusaka were being provided for in a number of health clinics and can be accessed by those with the means to get to the health center and those who have gone through counseling and testing. Patients who test HIV positive now have choices available as to whether they can receive treatment or not, and there exists a very effective community sensitisation activities about HIV/AIDS at community level through the Community AIDS Task Force (CATF) a structure at community level that we talked about earlier in Chapter 2 in this thesis.

Despite the introduction of ART in the health care system for HIV/AIDS, the long term effects of the disease continue to be on the patients and their families. The care demands on the patient and the family were of different nature and the results in this study showed different experiences by FC that emerged during care interactions. The understanding of care functions and responsibilities were either patient based or FC based. These experiences as described by FCs were those that were related to what the patient needed to be provided with on daily basis. These physical needs like bathing, feeding, dressing, washing clothes and linen, keeping the patient’s surroundings hygienically clean, giving medications at the right time, dose and frequency, assisting to go the toilet, walking, turning the patient, changing bed linen when soiled or just keeping them clean. However, there were also the FC’s based responsibilities and functions that needed to be provided for, most FCs talked about the social support in care work, psychological and emotional support and or psycho-social support for the patients as well as the FC. All study respondents were very clear of these responsibilities and expected functions to support the patients as well as themselves. Although the levels of understanding did vary considerably between FCs, as some had been nursing their patients for longer periods (2 to 5 years) of time whilst others had been nursing for about 6 months to 2 years. These variations in lived experiences, therefore was a major factor in the description of their understanding of care responsibilities and functions.  The emotional needs for some patients was further compounded by the knowledge that  the progression of the disease was chronic in nature and  that cure was farfetched and hence will continue to nurse be patients till death.

### Family carers addressing care responsibilities

We analysed information from FCs and KI on the description of the kind of work they were involved in or expected to perform. Caregivers were able to provide the category of different care responsibilities as much as they were able to recall from their daily experiences. These responsibilities ranged from monitoring of the patient day and night, to providing basic nursing care, physical, emotional support, psychological, rehabilitative, spiritual support and care. Generally, though most care responsibilities in some FCs are very overt, the ability of the caregiver to execute them was said and known to be difficult. Nearly all FCs reported not to have received any form of orientation on caring hence especially at the time that they were assuming the care responsibilities. There was for example a mother (IDI,03) nursing her 30 year old son, and expected to manage care needs surrounding a catheter; she did not understand anything about what was needed to be done to maintain an expected standard of care and management of the catheter. She further felt concerned with the feeling of the son especially as she was dealing with the most private and sensitive part of the son's body.

Another FC who did not have any understanding of the stages of the condition of the patients especially symptoms said;

> "There *was a day, in the night, I was sleeping. I woke up and I thought he was not breathing, I screamed and the neighbours came, but he was breathing I just didn't see properly, I really screamed and started crying ("IDI: 11)*

Those were some of the real fears that caregivers have to cope with especially when caring for patients who are bed ridden and needing more attention than what the caregiver can possibly provide. However, another caregiver (IDI: 04) positively described her ability to provide care to be on "know-a lot" about caring basis. She had a number of siblings who had been infected with HIV and subsequently died. Hence, she proudly talked about the wider family recognition of her abilities to care for patients with similar symptoms, to the extent that whenever there was a sick patient in the family she was the one requested to care for them.

### Family carers Emotional feelings about care work

Providing care to chronically ill patients regardless of the diagnosis emits different feelings in each individual that find themselves in caring situations. Some FCs have considered themselves with special skills and will welcome those who are ill into their households. However, there were those who found providing care a big challenge that may require special individual resources to manage the care processes. Most FCs indicated not to have had any choice in deciding whether to take on caring role or not to. When a patient is sick in that household, someone spontaneously assumes the caring role, and directs further actions that maybe required for addressing needs of that patient. Mostly these are women. One male FC (IDI: 05) who had been living alone in a bigger house (2 rooms), had his relatives conclude that the house was big enough to accommodate the patient and moved the patient from another town to this FC's house to be cared for by the young brother in a rented house. The family carer was not in any employment but was able to sustain himself through engaging in odd jobs. Therefore, due to the nature of his activities, he was required to leave home and go out in search of odd jobs that would give him some form of income to enable him meet the different obligations of a person taking care of a patient.

When FCs were asked about their feelings and thoughts about care work, nearly all caregivers had varied responses in terms of emotional feelings. They described feelings that had positive and negative connotations.

Some negative shared experiences included expressions like:

*IDI: 11 said "I work too much, am suffering, sometimes I don't sleep, I have to be up by 04:30 Hours"*

*IDI: 04:* who is also employed as a counselor says*: I get upset sometimes when the person that is caring for the patient hears from the community that TB and HIV drugs when combined together kill and they tell the patient to stop taking the drugs, when you ask the patient why he is not taking both drugs they will tell you that they have been told that if they take both drugs they can die, I feel discouraged and I also get upset*

IDI: 03: *I become very worried about the sources of help. I always wonder where I would get help. I thus become unhappy about care functions.*

*IDI: 05: I did not understand the reason why my relatives did not help me in taking care of the patient. I felt neglected and thought of taking the patient back to them so that they could also feel how it is to take care of the patient. I almost gave up.*

FGD KI: 02, R 3***:** People are ignorant about how these other diseases are transmitted. Some also follow myths and traditional ways of looking at the disease such as thinking that patients are bewitched. As a result, they go to the prophet or the witch doctor*

These were some positive expressed feelings related to caregivers':

*IDI: 09: Said I feel happy when my patient eats and asks me for food she feels like eating. Sometimes when I am washing the dishes outside, she asks me to stop and go in the house to sing songs with her. That makes me happy. I like it when she talks to me about nice things.*

*IDI: 05: I have the passions for my brother. I have the love to look after my brother. I have the love and experience of taking care of my relatives. But because of frustration, you can be anoid because you have failed to find money for food. My concern is to use soft words with the patient so that he cannot be emotionally affected by the bad words*

Such feelings had different meanings whereas for some caregivers were satisfying and made the caregivers go on with care work. Other negative feelings made family carers view caring as stressful and required one to be alert for 24 hours each day for example IDI: 03, 05, 08, . Further, they recognise the fact that at the beginning of care work most FCs were not well versed with and had less knowledge and skills to facilitate proper care. However, with time some carers were satisfied with the contributions they were making to the lives of the patients and to their own life. They claim that there was outside recognition and commendation from neighbours about their efforts. They are filled with satisfaction when there is observed improvement in the patient's condition, when there is food and especially when the patient eats that food (IDI: 04, IDI: 09, DI: 11)

*"God tells me that everyone gets to have problems and I should be strong. Then I get strong. God will make him better (IDI: 10)*

*"God is the one who created us and he is the only one who can make this illness go away. God also gives the nurses at the hospital knowledge on what medications to prescribe for patients", IDI: 08* "*I feel happy. Even when he gets upset at times, I take care of him, when someone is sick they have short temper so I don't have to mind what he does, even when he doesn't want to eat , I have to force him to" IDI:13*

### Family Carer's feelings and their perceptions about care work

The study demonstrates variations in responses in how caregivers' experiences in terms of feelings about care work. It recognised the differences in the situations and conditions in terms of social-economic status, which could have a bearing on the way they interpreted their situations as caregivers. These feelings, according to the study results were varied and were a reflection of how caring affected their daily living. There were those expressed feelings that evoked positivity in their lived experiences. Most caregivers, viewed caring work as providing a sense of attachment to the patients, as in nearly all households, patients under care were relations, either as children, parent, spouses, or related through marriage. Therefore caregivers felt obliged to provide the care. When they assumed the caring roles, they felt satisfied as they were the ones providing some form of relief in terms of contributing to a better health condition of the patient, especially when the patient felt better with some symptoms having been dealt with. Further, they went beyond the households in trying to describe their feelings about care work, as they also listened to what the neighbours "said about" their roles in caring. They listened and when the comments were positive, it made them feel appreciated and recognised by those observing from the outside and that made them feel encouraged to go on.

Similarly, in responding to feelings about care work, caregivers were also open about the negatives about what they went through caring for their patients. For example, they were of the view that caring was difficult and one needed to be on her feet for 24 hours, as during the day one is busy trying to find means to provide for the patient and meet the many needs and demands. Whereas, caring in the evening and night time, the caregiver is preoccupied with staying awake at night taking constant checks and observations on the condition of the patients more especially in patients with worse off condition. Furthermore, they were of the view that care work did not have a start and end point, it was a difficult, demanding and they were always tired. Some caregivers were experiencing constant fears of contracting the disease, and that caring was lonely as caring required more than one person to provide for the patient.

### Family Carers' expressed fears associated with care work

It was further noted from FCs that despite their feeling that they were the "chosen" ones to provide care to their relatives, some did have some understanding of the nature of the disease more especially of the potentiality to spread to others. They had different lamentations on the chances of them being sick either already having had contracted the virus or time was yet to come and they too would be sick. Others feared that they may already be sick and that time may not be "ripe" before showing any symptoms.

IDI: 02*"…….. Its good but I always think that I can end up getting sick as well"*

They will put in their best to provide for their patients, with expressed feelings of what they were going through as caregivers:

*“I work extra hard as I strive to provide food for the family, despite the fact that the situation has been hard for me to cope. I also have love for my husband that makes me work hard to take care of him….” (IDI: 15).* Whilst another said:

*(IDI:10)“From the time my husband became very sick, I have been struggling to cope with hard moments but cannot manage to fend for the whole family and I will always remember the suffering that I am going through”.*

Family carers did recognise that they lived in communities and did appreciate the existence of others within the communities. They expressed negatively that those around them, whom they had expected to be part of the “care team” were not there for them, one said:

*“The care workers are not welcome by all people not even my relatives, they don’t even come to visit; even our relatives have shunned us” (IDI: 16)*

Family carers talked of total commitment to care work and that required most of your mental equity to provide for the patient. They felt their lived experience of having to do more than what is visible in caring as seen by people outside the household. One participant in FGD: 09 : R1 had this to say:

*“Because you can’t be chosen, if you don’t have the will to work for people that are sick. Because with the sick you have to give your all. Sometimes you find that they have soiled the beddings and if you don’t have a caring heart you can’t clean such a person who is not even your relative. Some people even fail to clean their relatives so you can’t be chosen to work”.*

These were some of the lived experiences that caregivers continued to face daily as they became part of the world that is expected to provide for the sick relatives in the different households. Such are some of the examples of the many expressed situations that most caregivers find themselves having to deal with. One caregiver IDI: 10 talked about fears of contracting the infection more than 4 times in the recording. This was a great concern for her health and needed help. The lack of control and even choice by caregivers in matters related to care was quite common and kept being mentioned by all study participants. There was a lack of consultation prior to being given to play the role of a caregiver.

Caregivers started to care for their patient not as a planned event but in most cases were dictated to by the family situation. The caregivers were found in situations where they had to take care of patients as there were no other members of the family to do so or because of their past care knowledge, they were parents, sister, wife in most cases, and in most cases however, caregivers felt it was their responsibility to do so. They could not conceive of any suitable person to take on the role of providing the required care. For example, two caregivers, IDI: 04:09 decided to move their patients from their usual places of residence into their own households for the purpose of providing them with care. Whereas, one IDI: 05, 06 were asked to move into the households with patients. In nearly all situations of households with chronically ill patients and as presented by caregivers, there was an observed phenomenon of the FC not having any say in the matter and sometimes could not question the reasoning behind their being in the position of caring for the relatives.

Despite caregivers having to take on the care roles, others were managing while others were not managing, and were struggling to understand the patient’s needs, the disease care and disease requirements.

> For example one caregiver, IDI: 10 had this to say about care work: “*It came unexpectedly, I didn’t prepare myself. I am not fit as well. I have BP. I cannot strain myself. I do it because I have love for the patient. It was not my wish.”*

When asked to describe circumstances that led them be the ones providing care. One respondent in IDI interview stated that “

> “*The patient was just brought to me. I had no choice. I was alone and moreover the house is big. No one can look after him apart from me” IDI: 05. (the only man actively involved in caring)*

There was a general feeling amongst all caregivers that taking care of patients in the household was considered their responsibility especially when the patient was a close relative. However, in the same voice, they also expressed some form of disappointment with their other members of the family and relatives who did not render any form of support to the patient. More especially members of close family, who were not seen making effort to provide respite to the care situations. All caregivers were convinced that care work was difficult and only the strong ones or those with some form of support would manage adequately. Caring, they said, was a full time undertaking with very little time to take care of their selves. At times, depending on the condition of their patients, caregivers lacked enough sleep as they spent nights caring and observing the patients.

### Family carers' attributes fostering management of care functions

During IDI and Key Informants interviews, questions on how family carer was perceived in terms of special attributes to manage care functions were asked. Information on their perceived and felt attributes included being: dedicated to work, desire to see an improvement in the patient's condition. Caregivers expressed desire to understand what was going on the care environment and do something for their patient. There was an element of self – encouragement and hope that all will be well with the patient. Caregivers had faith in God, and hence the thought of helping the patient gave them the impetus and made decision to work and pay more attention to the patient. Despite the difficulties that were being faced, caregivers had strong belief that they could source for help from others and be able to meet the needs of the patient. What is interesting about the findings were that all caregivers were able to appraise themselves in the care environment and gauge their strengths and weaknesses in caring for their sick relatives.

> For example IDI:12 said *" I had self-confidence that I will know what needs to be done", and further said, "the love that I have, happiness and hard work". IDI: 13 said "God is the one that directs me at all times, he has given me strength, compassion and I don't get angry at the patient".*

Most caregivers had recognition of their own special relationship with God, liking what they did in care work, as they had felt pity for the patient and hence the desire to help others was paramount in their daily lives, despite caring being viewed as difficult and time consuming. They had the ability to recognise a problem when it arises and try to find a means of dealing with it. They were dedicated to what they were doing, a strong sense of confidence to help, and further a sense of responsibility over others were some of the strengths caregivers had in their daily interactions with the patients. As IDI: 16 said *" I dedicate myself to care work as I am the only one who can do this work, I have confidence in myself or motivate myself to do my best to provide for my daughter,…..*"

Family carers were in constant interactions with their "self" and with the immediate care environment. Resulting from these interactions, they always appraised or defined every situation they faced relating to caring for the patient. Each time they were in constant determination of their ability to do something for the patient. They weighed their potentials in the different circumstances and also why they felt they will be able to perform, what strength they possessed, what special inherent skills, what made them go on providing that care.

### Challenges facing family carers in households

Challenges are some of key elements that have formed part of care work, and the study tried to establish and further provide a description on whether family carers were actually aware that there were such challenges, their source and how they dealt with the identified those challenge that directly affected them. This information was obtained from FGD of key informants and family carers and from in-depth interviews of family carers.

Both FGDs and IDI revealed that the environment within which FCs care for chronically ill patients with HIV/AIDS were filled with challenges. These challenges affected family carers differently as they all experienced not only one but many challenges. The challenges were mostly related to medical, nursing care, understanding the medical condition, meeting the social, psychological and physical needs of the patient, However, all respondents expressed concern on the common lack of key resources required to meet the many needs of the their patients and family as a whole. These challenges according to study participants negatively affected the caregivers' effort to create an appropriate environment for provision of basic care to the patients.

### Patient based Challenges

Family Carers further expressed challenging situations emanating from the patient, including desires and demand for special food that was difficult to obtain as the need for money to purchase the needed type of food could not be met. At times the patient would keep demanding and sometimes requesting different types of food, but when such food was provided, the patient would refuse and instead ask for something different; such situations, which happened quite often did create some form of confusion and feeling of frustration in the family carers who would be subjected to situations of doubts whenever a demand for certain food stuff was mentioned. Money was not adequate to constantly buy the needed food and this sometimes resulted into some family carers opting to starve and provide the little food to the patient.

IDI: 13, talking about the early days of care work said

> "*The situation was bad at first. I didn't even have a plan, the patient would sometimes sleep without eating anything, he would cry for porridge but I couldn't provide that for him, I would also start crying. But God always gives some plans of what to do".*

Later on she said that "*when there was no work (piece work) to do, then there was no money and no food*" they would then sleep without food.

There was also a general observation by caregiver and key informants that their patients had temperament that was difficult to deal with. One caregiver said

> “*The problems are there, when a person gets sick, sometimes they have bad temper and the patient would be moved from one home to another, that’s why some patients die of depression because they feel that they are not being looked after well. If some find people that can take care of them, they would be refusing to be looked after by other people” (FGD 06: R5).*

Despite all efforts caregivers put into caring for their patient, one caregiver (IDI: 10) mentioned that care work was very challenging and recounted one day in her care work as follows:

> *“The problems that I have encountered that I will never forget, some problem come into a manner that you don’t know how they come. Such that you feel you are going to go mad. Like how I am caring for my husband, it will take long for me to forget because I have gone through a lot of problems. Caring for him and struggling to survive. I feel like I have become like those people who go out asking for money to borrow. I find myself asking for help most of the time. I explain that I am suffering and merciful people give me things like maize meal. I will never forget this illness because it has put me through a lot………..”*

When asked further on why she will not forget, the same caregiver above said,

> *“The reason I will never forget is because I have never cared for a patient before like I have right now, in all years. I have never experienced problems like I am at the moment; it’s something I have never seen before”.*

During FGDs and IDIs, participants were asked of other challenges that they faced in caring for patients and especially in the early days of providing care. Caregivers talked about lack of knowledge in care work, especially when the patient was bed ridden and had to be turned, lifted, taken to the toilet or soiled beddings and bathing the body as bigger challenges in care work. They faced different other challenges resulting from the lack of knowledge in dealing with medical symptoms like diarrhoea, swelling of feet, body rashes, sores, when patients refused to eat anything. In one IDI: 04(The FC was HIV positive and on ARVs and was also providing care outside her home), discovered that one of her patients was not taking the prescribed ARV as he was also taking TB drugs and that he had been advised to stop the ARVs till after the TB was treated. Most caregivers did not know how to handle such situations as they experienced coping difficulties, and were unable to find solutions to presenting challenges.

> IDI: 16 said this about knowledge of care work "*I fail to understand at times what to do about the problem of care work. I have thoughts of what I should do so that I can take care of the children…… I just pray to God to give me strength to handle these hard tasks'.*

Such were some of the many similar responses from IDIs and FGDs of FCs and supported by KIs.

The inability to provide for themselves with dependence on others for sustenance brought about worry by the Caregiver and patients anxiety that they were not able to meet their own needs. The patient at times made excessive demands that were unrealistic and the demands requiring money to meet them, or special skills to address the need. Frequent situations of such nature would further result in frustrations of the caregivers (FGD: KI: 03, 04; IDI: 06, 08, 10, 12). It was further noted that, there were always anticipations by patients and family carer of certain outcomes from any care interventions. Especially, such expectations included a state of feeling better by the patient and of relief by the caregiver. When these feelings occurred the patient sometimes did appreciate the caregiver's contribution, resulting in the feeling of satisfaction on the part of the caregiver. Sometimes the caregiver was blamed when the patient failed to feel or get better but this was more of self-blame than anyone outright pointing out this overt failure as they(caregivers) felt they were not performing to expectations.. The patient was always aware of his/her incapability to perform as before falling ill, while the caregiver was also aware that any of her/his actions were meant to bring relief or improvement to the patient's condition, when this did not happen- there was a feeling of inadequacy especially by the caregiver. One said.

> In FGD: 07 aged 35-60: "*there is no one paying us, not even any form of help, like I said earlier, if you were to go and see my home, you wouldn't believe that I am the one caring for the patient. I do it to care for the sick children, as old as I am. I crush stones to make money. People who build foundations come and buy the stones. From the money I buy a bit of maize meal, charcoal, and a few bit and pieces. What am I going to do? I also buy relish and when I check on the patient, he says he wants cold water to drink, I bring the water. Sometimes they ask for relish I can't provide and sometimes they even refuse to eat the food I have cooked because they don't like it"*

One IDI: 03, providing care to her 30 year old son, experienced different challenges ranging from inadequate food supplies, understanding how to take care of the catheter, and other medical needs, expressed her challenges as:

> “Food *is a problem, I have to look after the patient and find food, I was told by the clinic staff to be turning the patient after an hour, and I have to look for food, charcoal, I have to buy the urine bag and sometimes I don’t have money. I wrap him in a chitenge so that the urine doesn’t sip onto the beddings.”*

Another participant in a FGD of those aged 15 -34 of caregivers said that:

> *“ I started taking care of my mother because my father passed away, my mum then started getting sick, our first born my sister passed away as well as the second born, am the third, there is not one else that could look after my mother”.*

These families were experiencing many deaths in the families affecting the possible support structures at the household level.

In view of the changing family structures resulting from the effects of HIV/AIDS, one caregiver said: “I *do not have relatives to help me. They all died. I cannot depend on my brother’s children. They also struggle to survive. My husband’s relatives are also too far to help. Caring for patients when relatives are nearby gets easy………..” (IDI:12)*

In another related response, the mother (IDI: 03) with a bedridden son and experiencing difficulties emptying bowels lamented: *“…… I have never experienced this with my husband (who also was chronically ill before he died), sometimes I leave the bedroom and I cry to God for help that I have to look at my naked son, he fails to go the toilet, I have to put my fingers to relieve him” (*at the time of writing the son had already died).

Such situations, where a number of families were not there to take care or help in providing care of relatives was seen to be declining (Aboderin, 2006), families afflicted with HIV/AIDS may have lost family members who could offer help and in most cases the only source of livelihood from productive members of the family had been lost, thus diminishing the source of support. Respondents in FGD: 07 said “there *is no one else*” to help with care work, as one respondent observed that “the *old understanding family is no longer present. Families nowadays only care for their biological children*”. Furthermore, for example, Wangmo (2010) in relation to care for older family members, observed that their own adult children now had their own children and has resulted in uncertainty of what help to provide to others especially elders that may need support. However, with the AIDS pandemic affecting almost all households, that support which existed in our traditional times had since disappeared. This could sometimes, be due to the number of patients in the communities especially in the number of households with patients needing care and support. According to reports and research findings, most households have been affected by the pandemic of the virus (UNDP, 2007)

Focus group discussion of family carers (FGD: 07) 35 -60 Chazanga

> R2*:"I look after my cousin's child. The parents died and I am the mother, I have to look after the patient because if I neglect him she can die. I wasn't chosen but it's because of my compassion*"
>
> R3: *I have a brother who gets sick and when he gets sick, am the one who takes care of him. My sister came from the village so that she could help but he refused. Some relatives wanted to get him but he refused. He says I look after him well, he told that I wash for him and cook for him."*
>
> R4: *I look after everyone when they are sick. It could be my husband, my sister or my child. I have to look after the sick person that I live with. I have to take them to the clinic and hear what the diagnosis will be. If it's TB then I have to help that person*"

### Social Structures enabling the care environment

In any community, family, society there are social structures that govern individual's relationship to one another. According to Bernardi et al., (2011 p162) a structure is referred to "sets of elements that has some measure of coherence and stability". In addition it is how those in communities are expected to be organised or ordered in the way they carry on with their daily existence. I further needed to understand how the different parts of the families and caregivers' existence are interrelated and their effect on caregiving in the household. In the context of this study, I am looking at social structures existing in the study sites that could support caregivers' involvement in care work. For example, I am trying to establish patterns of doing things as they relate to social interactions between different relationships when providing care.

Traditionally, as observed earlier in this thesis, the Ubuntu concept in Zambia prevailed in most communities and families existed with knowledge that help from relatives would be available whenever that need was exposed. The study therefore sought to find out how families shared social structure especially as it related to the wider family structures provided for the patient and the support to the caregiver. Only in two households was help accessible from relatives although that was very minimal. In one of the families where support was available, children (daughters) took turns in helping taking care of their ailing mother. When one went out to look for food the other remained behind to help. In most households, families did not provide any respite or any kind of support to the patient or the caregiver.

IDI: 02 said “am *alone in Lusaka. My whole family is on the Copperbelt. My mother in-laws family… her sister is in Mkushi, the other one is in Chakunte, her 3 married children….. one is in Garden compound, the other one in Chawama and the other in Chilanga but they don’t come to help me, they just come to see her, they don’t even wash her blankets*

HIV/AID has its effects on both the breadwinner as a patient or affects the bread winner in terms of protracted periods of support and the many demands of a chronically ill patient. Households where the bread winner was affected by the disease suffer most as those individuals who may have responsibility for providing for their families were unable to do so.

> “The *challenge is that I am not home all the time because I have to go and look for food and he remains home alone sometimes, that troubles me a lot, if I had money I would have been staying at home and looking after him properly, but we are poor so I leave him alone...” (IDI: 11.)*

The majority of family carers lived with their families in rented households, as observed above resulted in such families being subjected to various demands from the landlord especially when it was evident that the patients were suffering from HIV/AIDS. The landlord were not sympathetic when rental obligations were delayed, and lacked compassion for the patient and sometimes evicted families from households with chronically ill patients. Such households were then subjected to shifting from one house to the other, a situation that made their living arrangements complicated with constant thoughts of, and fear of eviction became a regular preoccupation of the family. In one household in Chazanga compound, for example, the landlord was not happy that the patient had developed diarrhea and was constantly using the shared pit latrine and asked the family to vacate the house ( IDI:05). However with intervention from the neighbourhood the eviction was not executed.

Most caregivers recognised the absence of the formal family structure to assist with care work, especially where the bread winner was the patient or had died leaving other members of the family without a source of income to sustain the whole family. One respondent in FGD of participants aged 35-60 said of the current structure to offer respite;

"…. *The old understanding of family is no longer present. Families of nowadays only care for their own children*." And another stated that "*that is why if an old person like me were to die, things would be bad because, there would not be any one to care for my children that would be bad*."

The advent of HIV/AIDS has resulted in many households being infected or affected by the scourge. The AIDS pandemic had not spared any family especially in SSA. There was an evident disruption in the family structures, where family heads were either sick or had died from the disease. The spouse may also be infected and chronically ill, with children of various age groups that may be left to fend for each other and experience disruption of the only opportunity for education. In other families, children are being made to take care of the sick and thus lose the chance to be educated. The support structure that had existed before seemingly is dying slowly. Nearly all caregivers indicated that support from families had dwindled. Where possible they will only visit the patient to check of the progress being made in the condition, without offering any form of assistance to the patient or the one caring for the patient.

> IDI: 05 said "*No relative comes to visit us and not even one brings any food. My relatives who are in Lusaka are not employed. Therefore, they fear that when they come without anything, they can be blamed for not supporting the patient".*

A situation where children were helped by a Volunteer Carer was highlighted in one FGD: KI: 03 where a household with children taking care of a parent was identified during one of the regular community visitations. Volunteer caregivers took turns to care for the mother and allowed the children to attend school.

### Coping with challenges during provision of care

The study sought to discover the phenomenon of coping mechanisms of family carers as set in an environment where caregivers were taking on care responsibility that befits individuals who were chronically ill with HIV/AIDS. Further, due to many effects of the disease this study also tried to find out how such carers were devising coping mechanism to address the many challenges that faced them. Challenges were those care circumstances or situations that caregivers were not familiar with, situations that required their interventions to produce relief of the patients and the stress that the caregivers mostly experience during care work.

The study also looked at different situations and conditions of caregivers who mostly are not trained or oriented in how to manage patients in their households; most of the family carers were not ready to assume caring responsibilities; patients were being cared for whilst living in environment that appeared to be hostile especially that there was overwhelming evidence from the study findings that most caregivers were living in abject poverty; there was poor resource base in the affected households under study; poor external social facilities to meet the different needs of the patient and; an evident breakdown in family structures resulting from the effect of the HIV/AIDS and the chronic nature of the disease.

Family Carers were asked questions relating to the kind of coping mechanisms devised in order to address the challenges they were faced with in the course of providing care to their patient. The results show different mechanisms amongst caregivers. However, the most commonly mentioned source of the ability to cope and was related to spirituality, and there was strong belief in the power of God. Caregivers also mentioned their own inherent strength and attributes related to the way they were brought up during childhood. They talked about the kind of upbringing which fostered a sense of responsibility and piety to others. They further learnt from adults who were role models in their life during the socialisation process, how to manage life situations in family setup. They felt sensitive to the needs of others, and sometime there are inherent fears of sanctions and as Keller et al., (2005) concluded, the principle of fairness and the principle of care were important aspects of morality of the in close relationships. In addition they mentioned situations where they were made to take care of other patients within the family situations that gave them the opportunity to learn how to care and cope and gain experience in how not to be affected with challenging situations. Some caregivers did not view caring as challenging as they felt obliged to provide the care to their sick family members

> For example IDI: 16 said “*you don’t have to put a lot of thought when it comes to such things. You just have to tell yourself that I accepted this work and dedicated myself because if you are not dedicated you can’t work, you fail to carry out the work. There are many things that we find in these houses so you just have to keep secret the things that you find in some houses*”.
>
> IDI: 10 said “*God, He tells me that everyone gets to have problems and I should be strong. Then I get strong. God will make him better”*
>
> IDI: 13 also said “*I just feel okay because God guides us, without Him there is nothing that we can do, our friends are sick but for me I can’t say I am sick….”*

> “*When my patient came, I had a lot of challenges. I had a lot of thoughts as I did not have food to give the patient. More so, the house has had a lot of leakages during the rainy season. The house is made of mud. I had thoughts that maybe the house would collapse due to the rains………….. I relied heavily on the Home based Care for food, but when it comes to the house, there is nowhere were I can get help, it’s a problem even now, and the house is made of mud and has cracks”* IDI: 16.

The (IDI: 02) said of the attribute that help her cope with challenges was that she was strong and had compassion for others and she said

> “*When things become worse, I ask for God’s guidance and strength. Sometimes I feel like am not supposed to look after her because she is my in-law but then I have other thoughts that she can die*”

Most caregivers described their challenges as difficult to address. Each time they were confronted with a challenging situation. Mostly they did not have the ability to find solutions, and sometimes they did not even understand the challenge facing them.

Most data from KIs showed that caregivers were not coping with challenges related to caring for their patients in the households. Most households they observed sought help from CBOs/FBOs within the community. However, in some of these communities there were households that did not know where to get assistance and did not have knowledge of the existence of CBO within the community, especially those communities with programmes that support HBC activities. There were some households that could not have caregivers from within the household and those who provide care to their patients were in most cases coming from CBOs/FBOs.

This help could also be from an existing community support programme from CBOs/FBOs or NGOs. However, most of those who had the ability to identify such resources had been seen to cope better in terms of meeting the needs of their patients. Others were engaged in some form of entrepreneurship, getting donations from well-wishers from within the community. Whilst others resorted to begging, some did not feel like going out to beg, hence could not find solutions to their problems and were not able to cope*. “Children (men and women) in productive age are now dying (*says FGD:09 of Key Informants in Kabanana*) leaving behind young children to be cared for by elderly people…….these old people don’t have businesses, no money to support these orphans. They need to go to school. These old people can’t manage…..”*

Some caregivers felt that members in the community will scorn or laugh at them when seen going out begging. Other caregivers felt that lack of education was another factor that contributed to not building skills to cope. Findings also show that some participants were of the view that inadequate observed gaps in the socialization process of individuals in families, did not groom children at the time on how to look for resources when faced with a situation that required immediate attention. Past experiences, more especially when faced with challenges of a similar nature were mentioned as some of the elements in positive coping. For example knowledge of taking care of patients was learnt through such experiences. Children learnt and observed their mothers take care of patients and slowly those skills became internalized. Some caregivers further harbored the strong belief that they could do something for the patient. This belief was imbedded in the way caregiver feels about the patients' condition, the presenting situation requiring to be addressed, and the feeling of pity for the patient

There was as feeling that the ability to cope or not to cope was hereditary as caregivers felt that the ability was a value that someone is born with and therefore when confronted with a challenging situation a number of factors came in play, such as: Determination to provide for the patient and, the desire not to fail, the courage to move on and on and help. The religious conviction - this belief makes the caregivers trust that God was the ultimate provider and would guide the caregiver on what to do for the patient or what not to do. And the study further observed that other caregivers manage to cope because they have a special gift from God. This gift, is believed to be inherited, and comes naturally because the caregiver does not want to see others suffering.

Johnson (2004) observes that when individuals are faced with challenges, they have a deliberate determination of the "feeling of confidence" that, in believing that what was current in the patient's presenting situation, the FC will work towards coming up with an interpretation of the situation and find meaning which then is a determinant of the caregivers' social action.

### Perception of resources by FCs needed to support patient care

The questions related to resources were important in this study as it was imperative that it be established whether caregivers did have an understanding of the critical resources in the care environment and further be able to ascertain where such resources could be accessed from and the value of such resources to patient care. In addition, the study sought responses that pointed to the type of resources they would need to facilitate their care work in households.

When family carers and KIs were asked about the availability and accessibility of resources within the environment either immediate or external and, nearly all respondent described the situation as one that needs to be addressed and that they were in desperate situations in terms of accessing resources that were meant to help with care of their patients.. The perceived care environment included: the family immediate and or extended, the neighbourhood, the church, the health facilities, community organisations and the members of the community at large. The caregivers receive very little help from their immediate families, most reasons advanced were that they too were struggling to survive and therefore they could not adequately support others. Family carers also felt that their patients were not regularly visited because of the fear that they may be expected to provide some form of support to the patient

It was important to understand caregiver's perception of type of resources appropriate to deal with care work. The following were those expressed by caregivers;

*Resources to meet the physical needs of the patient which included*: Food (different types) of which they believed would facilitate healing, people to help with exercises for the patient, help with walking, lifting the patient, money to buy basic necessities like food, soap, blankets, water, good linen, some prescribed drugs, to meet the needs of the patient, While some caregivers further recognised internal resources like strength to carry out care functions, and passion to work

*Resources to meet medical needs:* Transport to and from the health clinic for reviews, when patient condition becomes worse and has to go to the clinic for management, funds to purchase drugs, Jik and gloves for infection prevention, urine bags for some.

*Resources to meet spiritual needs:* Prayer for strength, visits from church members, by worshiping, scripture reading, and spiritual counseling.

*Social support:* Formation of support groups, visitations from Volunteer care givers, formation of community groups that share information on health, family issues, income generation, skills development .

*Resources to meet emotional needs:* Being visited by relatives, friends and being offered encouragement, just having people around them was comforting. They further felt that having a caring Government to take the lead in ensuring the caregivers are provided with resources that will enhance their capacity to provide care in households.

When asked what family carer s would like to see put in place to help family carer meet the needs of patient and their own needs, the following were some of the responses:

> One R3 in FGD:05 said "*for us to carry out our duties properly and the affected to enjoy our services, the government should come and in and empower us with resources whereby we are able to generate funds which will enable to run these programmes of care giving because they are a lot of things involved."*
>
> R3 in FGD: 05 went on to say that "our *cry is to see that our job is carried out nicely, as care givers, we aim to see each and every member of the community live to the fullest not a situation where someone is living not according to expectation. Each community member should enjoy just like other people".*

**Finding meaning in care functions by family carers**

Family carers stated that the desire to find meaning in whatever they did for their patient was a priority in the care interventions and therefore they worked towards the realization of that result. They did feel convinced that meaning in care work meant that they contributed to the improvement in the condition of the patient.

IDI: 09 when asked about the care she was providing, responded as follows; "*when I cook food for her (sister) and she is happy to eat the food I feel I am doing the right thing"….."Food helps me care for the patient in a way that with food, the patient gets strength………" "I encourage her to take the medicines, I tell her when you take the medicines, and you'll be fine*."

In this circumstance, the FC appreciates and shows concern for her sister and believes that her (FC) effort in encouraging the sister to eat, take medication is worthy and may bring relief to the patient. Caregivers have considered their effort in caring for the patient brings relief and other worry when the patient's condition does not improve despite all the effort being put into the care situations. One family carer (IDI: 04) was HIV positive, taking ARVs and had previously received training as a caregiver, sympathized for his son and daughter- in-law (both HIV positive) as they were residing out in the farming area. She invited the daughter – in – law to move in and live with her as she (the caregiver) had more knowledge on HIV/AIDS and care functions, and she had easy access to the health clinic for any care or medical management.

### Community Based Organisation in HBC

The study further reviewed key programme records of community groups actively involved in HBC activities. It was the objective of the study to gather information on the extent of participation of such CBO/FBO/NGO in the HBC programme. It was learnt from the literature review, that most HBC activities were conducted by private organisations and not specifically the government. However, the government provides oversight of related activities including the policy framework that governs organisations implementing HBC activities, more especially faith based organisations that followed the Christian principles to support those suffering and needed some form of spiritual, physical and psychological care. Evidently CBO/FBO and NGOs did take the lead and were being urged to do so by the government. However, despite recognition, and the government providing the policy framework for the operation of such HBC programmes, much is yet to be accomplished. Many HIV patients are in the community and not hospitals or other health facilities.

Data collected from local CBOs, FBOs and NGOs on their involvement in HBC activities reveal a number of gaps in terms of provision of support to households with chronically ill patients with HIV/AIDS. There was a number of reporting gaps in the data collected as, data quality accuracy appeared to be problematic. However, the four organisations that were involved in the study were those that were active in in providing support to those with chronic HIV/AIDS conditions. All organisations did not pay the volunteer care givers. (Anecdotal evidence October, 2010). A report from Madaliso HBC indicated that though Volunteer Caregivers do not receive any form of payment, trained voluntary caregivers did receive some incentives like, bicycle, T-Shirts, and medical kits. Other CBO/FBO/NGOs do not do so.

Each organisation had a number of clients/ households that were directly under their supervision. The range of clients in each organisation was 65 up to 265. The record reviews show that clients/patients were visited on regular intervals from a minimum of 2 visits per week or more visits depending on the nature of condition of the patient and/or the condition and situation prevailing at the household. Volunteer Caregivers provided voluntary services and derive their motivation to do more because of positive responses by the patients and the family members. Whereas in some households, volunteers were seen as the ones to provide care to patients and would even refer to the patient as being “theirs” and would express happiness at seeing them visit the household.

The kind of support patients/households received from CBO/FBO/NGO was different in type and depth. Some included medical resupply (ARVs, TB DOTS) especially for patients who are unable to walk to the clinic for reviews, or where the patient could not be left alone by the family carer. Support being provided includes psychosocial counseling, nutritional food supply in a few cases, and spiritual support. Madaliso HBC for example, supports households with AIDS patients with regular visits, health talks, psycho-social care, spiritual support, provision of nutritional food. Other organisations like Bwafwano HBC provides services like Counseling and testing, adherence support, family education how to care for patients, palliative care and pain management.

All caregivers belonging to the community organisations as reported provide voluntary services; their motivation to do more is derived from the positive effects of their interactions with the patient and family. However, there were times when their work was frustrating in terms of family taking on responsibility for the patient. They (family members) referred to the patient as one belonging to the visiting Volunteer Caregivers. Although the visits did cheer the patient, they also frustrated the Volunteer Caregivers who would be expecting the family to take full charge of the patient and not wait for Volunteer Caregiver to take the lead in care work (personal communication with Programme officer Madaliso HBC:2012).

**Figure .8.1: Identification of PLWHA, existing and perceived support structure of care in the community level.**

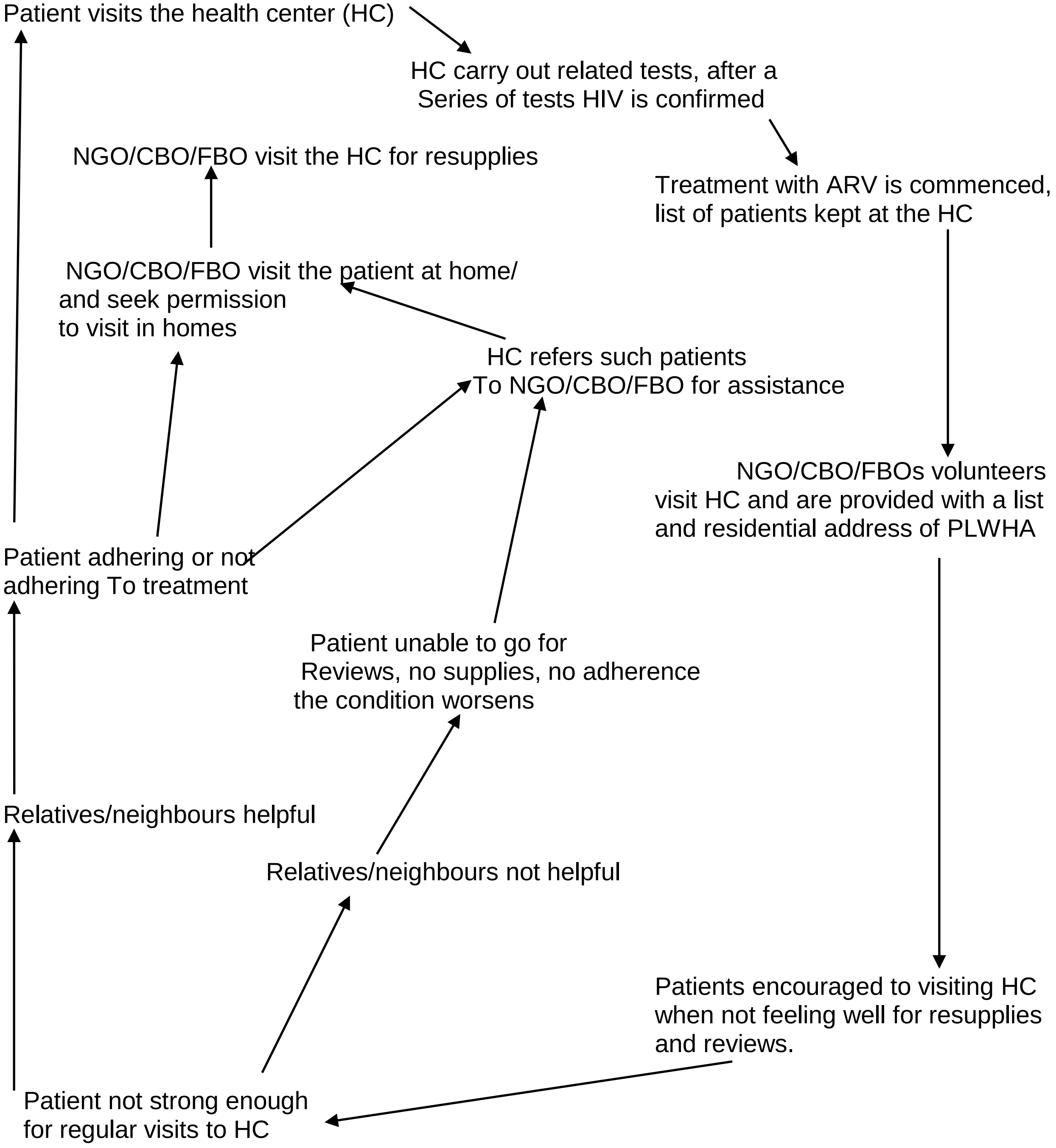


Figure 8.1 above is a demonstration of the process followed to identify patients that may require continuum of care. There are three scenarios in the identification process:

The patient reports to the health clinic with symptoms, is counseled and tested for HIV and is positive

- Other confirmatory tests are done and patient is commenced of ART.
- The health center (HC) keeps a record of all those on ART and plan for supportive home visits is drawn up to check on progress being made and identify other medical needs of the patients
- Due to pressure of work, HC is unable to execute the supportive visits to the patients' homes and the patient's condition does not allow the patient to go back to the health center for reviews and resupply of drugs. But other community organisations have some resources and personnel (Community Volunteers) to do so.
- Personnel from Community organisations with HBC activities are given a list of patients and households where relatives are not ready to take on care responsibilities. Community volunteers visit the health center and are shown the list of patients on ART that will require regular visits support visits. They seek permission from HC to visit.
- At the household they also seek permission to visit the patient regularly. The relatives can be helpful to the patient especially where they have the feeling that they will manage the patient. The Community Volunteer will visit such households only when there is need to do so. Where relatives are not helpful to the patient, they require the Community Volunteer to visit often. From personal communication with the programme officer from Madaliso HBC, it seems that most family members in such households alienate themselves from the patient and minimally provide care to the patient. During such visits, family members would in most cases address the volunteer as the one responsible for the patient in view of the created relationship. They would say for example a greeting would be followed with "welcome, your patient slept well

## Conclusion

The study provides a story of what was happening in the lives of FCs during daily provision of care to chronically ill AIDS patients. What is clearly evident is that most Family Carers were facing challenges. However, the intensity of challenge was also dependent on the orientation of the FC to care work, the kind of support available at the household level, and outside the household. Most FCs did not have the ability to adequately appraise the challenging situation and find ways and means to address and cope with challenge. Further, that ability to appraise may lead to situations where the FC is able to identify internal or external resources that can help in dealing with challenges. However, the results of the study revealed very desperate situations as most FCs were experiencing abject poverty where food, money, social support were generally difficult to access, let alone know where to find such resources.

The study findings generally point to the fact that care work was a serious preoccupation in most households in the study area. Men and women were engaged in care work with ages ranging from as young as 15 to those above 65. These men and women, provide care as primary care givers (mostly women) of volunteer caregivers (mostly men). Phases of care require that certain resources be made accessible to most of those providing care, in order to make caring more meaningful. However, existing care situation has not promoted resources allocation. There is no deliberate structure in communities to support and address those basic needs of the patient and the caregivers, without burdening the household. The phases of care as reflected in the findings are not addressed appropriately. Caregivers face difficulties in understanding what each phase of care entails. Finally when care is provided is not of an organised nature. As observed by Andershed and Ternestedt (2001) most family members were actors in caring and were in need of adequate resources at their disposal. Those with adequate resources were deemed to have a greater chance of gaining insight in care functions. We also need to be cognizant of the fact that, each of the caregiver in this study who are involved in caring are doing so because they had no choice in the matter or they felt obligated to do so.

The need for funds to meet the many needs of the patient, the caregiver and the entire family has overshadowed all other key requisites in caring environment. Although there were differences in how the caregiver experienced care work, it still remains that nearly all caregivers and supported by key informants, have experienced and observed that caring was very difficult and more especially where there was not support on any kind.

# CHAPTER NINE: Applying the Sense of Coherence and Generalised Resistance Resources in caring for HIV and AIDS patients: Explaining the Family Carer's "FIT" into the care environment

## Introduction

This chapter gives details of what research participants stated as their key roles in the provision of care. It provides an analysis of the SOC and GRR component within which the care activities, resource needed to support each GRR component are determined. The chapter further provides an insight into the extent of expectations, actual and perceived, roles and responsibilities related to caring for chronically ill patients within households. The individual's SOC and GRR as referred earlier in the framework of this thesis, provides explanations of how the individual is able to participate in decision making whenever faced with a challenge or stressor. As noted in the framework, life experiences were responsible for shaping an individual's SOC through GRR which are essential for meaningfulness and coherent life experiences (Antonovsky, 1979). These appraisal processes can also be referred to as a process of definition, which in relation to SI are subjective in nature and are responsible for organizing the behaviour of any individual (Stryker, 1987). They can therefore be assumed to be key factors in identification of GRR in the coping process. The FC will use internal resources that are biological (such as energy, knowledge from past experience) in nature in trying to understand the presenting care situation, while also making decisions on the type of the challenge as to whether it is a threat that he/she can't deal with or a challenges that he/she can confront and deal with.

HBC is one health care strategy that has been adopted by countries in the Sub-Saharan region and Zambia in particular to address the chronic need for caring for patients with HIV/AIDS. Literature has shown the different levels and approaches that have been adapted and adopted to effectively implement HBC programmes activities.

This study therefore, sought to find explanations for the coping mechanisms of FCs in households with chronically ill patients with HIV/AIDS. The findings do provide information and opportunity to understand how FCs constructed their care environment and derive from their actions a sense of reality. Further, the results provided guiding links on how unambiguously the FCs galvanized their own physical, social emotional, psychological resources to address prevailing care circumstances.

Caring in Zambia was happening at different levels and with different intensities in terms of the inputs that were available or sourced to make the act of caring more meaningful to both the patient and the caregiver. Many research documents reviewed highlighted the position of FCs or family members that were currently providing most of the care in households with patients with chronic diseases (Mwewa et al., 2013; Singh et al., 2011; Opiyo et al., 2008; Thabethe, 2011; Akintola, 2014, 2013; 2008; Mieh et al., 2013; Ogden, et al., 2004; Lindsey, et al., 2003). Some of the many tasks that FCs were involved in are both technical, in that they may demand some professional knowledge and skills, and non-technical as any member of the household will have the capability to carry them out. Some of the tasks require specific professional skills to accomplish the desired results; some of these tasks as noted are complex and only those individuals with formal training would be in the position to carry them out. For example, we learn from the findings of how IDI: 03 lamented on the expectations of how she as the mother and nursing her 30 year old son, was expected to carry out procedures related to cleaning of a catheter in situ, and remove impacted stools. However, there are other tasks that even people without specific training would be able to carry out, for example feeding, washing linen, and keeping patient's surroundings hygienically clean.

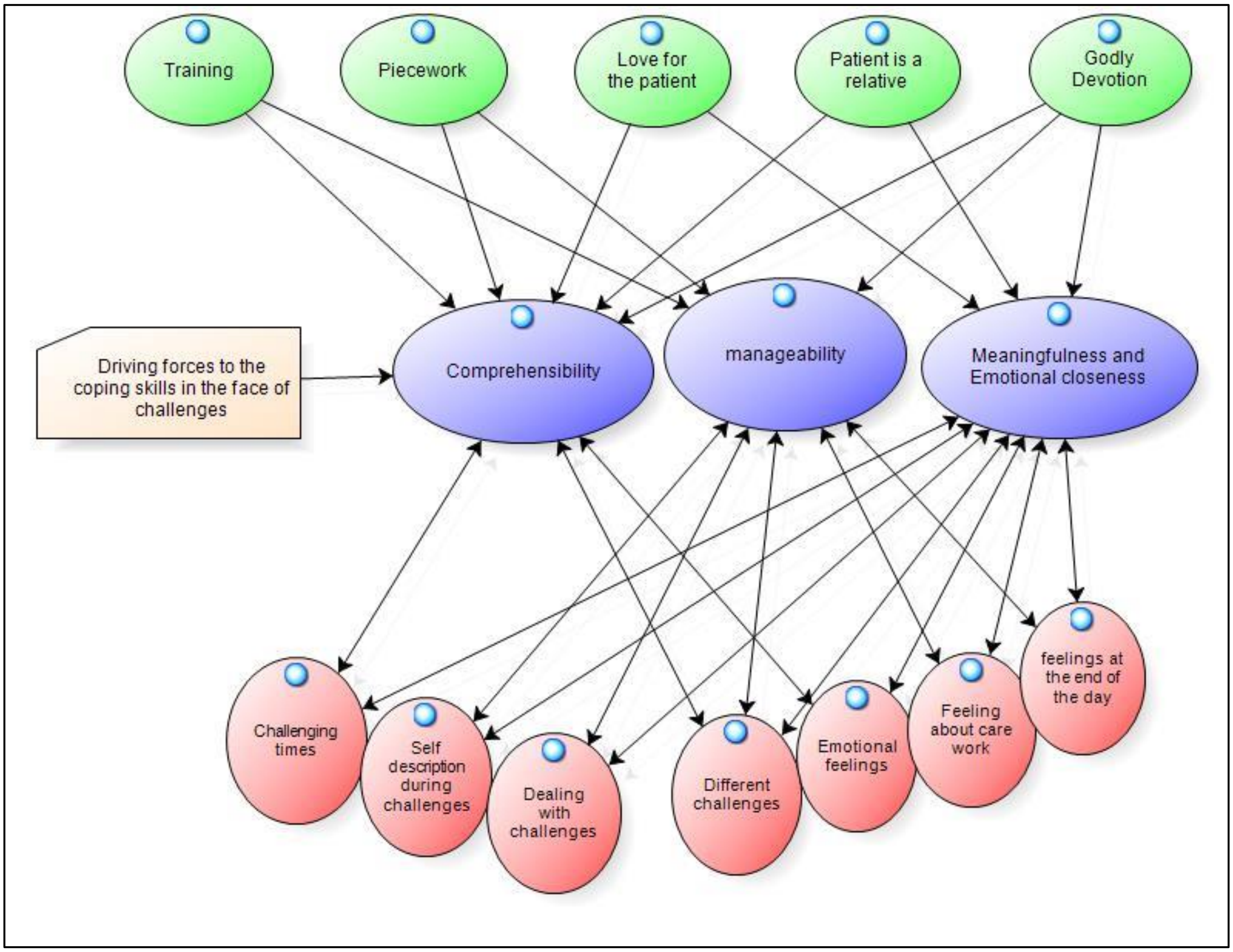
### Explaining the family carer's "fit" into the care environment

Studies explicitly using the salutogenic model as framework to describe what could be happening in the care of different conditions are many globally but none in the SSA. For example, Andershed and Ternesterdt (2001) studied the involvement of relatives in palliative care of dying patients and used Antonovsky's (1987) SOC as a theoretical base to describe the involvement of relatives. The two researchers developed a framework that was aimed at describing the involvement of relatives in palliative care situations. In their study we learn about the concepts of "Involvement in the light and involvement in the dark", where they observed that involvement in the light was characterized by relatives being well informed and experiencing meaningful involvement in the care based on trust and confidence between staff and relatives. The opposite is "involvement in the dark". Using the salutogenic model, they were able to associate a strong SOC to situations related to relative's meaningful involvement when it was in the light and a weak SOC to that associated with non-meaningful involvement when it was considered as being in the dark (Andershed and Ternesterdt, 2001 p. 556). Similarly salient findings in my study is that caregivers describe care work, situations, as challenging especially that they had inadequate knowledge and skills to meet care needs of the patient. Although there was expressed “meaning” to their contribution to caring, they agreed that care provision was happening “in the dark” (Andershed and Ternesterdt, 2001).

Similarly, Milberg and Sprang (2007) studied family members and experience of meaningfulness, comprehensibility and management in palliative care, and described the theory of coping within the context of palliative home care. They found that comprehensibility was facilitated by open information, symbolic information, basic life assumptions and previous knowledge, and these elements were important as a resource to promote and create a congruent inner reality as opposed to chaos. Whereas resources contributing to manageability included power, support, competence, and accessibility which as they observed, on an abstract level resulted in a feeling of togetherness between staff and carers within palliative care. Langeland et al., (2007 p 293), promoting coping Salutogenesis among people with mental health problems, illustrated that salutogenic theory was of value in mental health promotion due to its emphasis on promotion of coping and health. This brings into focus the need for recovery within the principles of mental health interventions to promote SOC and coping. Monica Ericksson and Bengt Lindström (2006, 2007) have done extensive studies and research reviews to understand the application of Antonovsky’s work on Salutogenesis models in different social situations. The two researchers followed up Antonovsky’s work to understand the relationships of health with sense of coherence. They tried to contextualise Salutogenesis within the discipline of public health and they further continued with the work of Antonovsky whose work had abruptly stopped due to an early death. Their objective was to continue with Antonovsky’s work and answer the earlier question on what creates health and search for “the origin of health” (Lindström and Ericksson, 2006 p. 238)

However it was important to note that the above studies were not looking specifically at coping mechanisms in HBC for chronically ill patients. However, by using the salutogenic model they did provide answers related to SOC and GRR and to some extent the emotion based resource.

**Figure 9. 1: Model showing general coping factors based on the Sense of Coherence and General Resistance Resources**

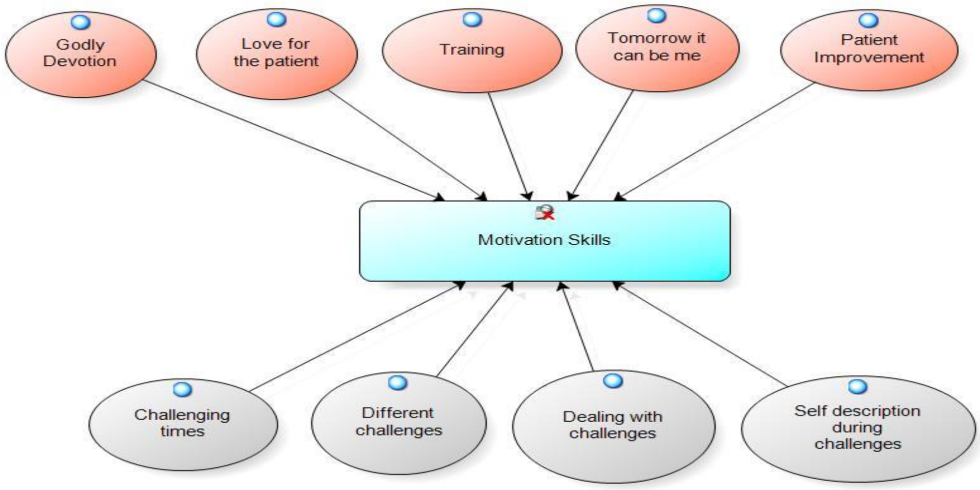


Source: Field Data 2010

Findings represented in Figure 9.1 describe the relationships between the GRR components and the way FCs felt about care work. The coping factors as presented above show that Godly devotion was linked to all GRR components. The Godly devotion as a coping skill was common in all caregivers as there were relationships with spirituality and religion. In the same observation, four factors: “training”, “piece work”, “love for the patient”, and “patient was a relative” were mostly linked to two of the GRR components. Further to the observations, is that all coping factors were linked to comprehensiveness, meaning that when faced with care challenges, these factors of coping were associated with the level of knowledge deriving from the internal and external environment (Antonovsky, 1987) of the caregiver. In the same model, Figure 9.1, we also see a strong link between meaningfulness and emotional closeness and to the different states of feelings of caregivers. Their description of challenges, their feelings about challenges, and feelings about care work invoked in them a sense that motivated them to do something for the patient. As they all saw that doing something "made sense" Antonovsky, (1987 p 18) describes this situation as "…..problems and demands posed by living are worthy investing energy (time, money by doing piece work *-my addition)* are worthy of commitment and engagement". This can be, as explained by Stryker, (1987 p. 335) that the greater the commitment to an identity( role as caregiver), the greater will be the effects of role performance on self-esteem and the likelihood the role performances will reflect institutionalised values and norms".

Caregivers were faced with different challenges associated with care work. Although they did continue to perform their roles as caregivers (their identity) their ability to identify appropriate care resources was high but they expressed weak levels of the "actual reach" to resources to make meaningful contribution to care work. Even when there was meaning attached to their behaviour in meeting the patient's need their ability to do so was weak. However, it was evident that they had attached meaning to their care behaviour, that could have been referred to as "caring in the light" (Andershed and Ternesterdt 2001). They felt they had made positive contribution to the health and well-being of the patient. Caregivers did appreciate the fact that whatever they did for the patient had some form of meaning, although their actual caring behaviour could not meet the expectations of managing care work. We also note from the findings that when the level of identity as "family carer" was affirmed, they believed that the level of performance was expected to improve, but this was not so as caregivers were unfamiliar with most of care related tasks hense lowering their self-esteem. However, despite having a low self-esteem in care situations caregivers were observed to be strong on meaningfulness and their related emotion to caring and coping were high. The different motivation factors kept them "afloat" or "going" with care work. In Figure 9.1 we observe strong links between meaningfulness and emotional closeness and to different state of feeling of caregivers.

**Figure 9.2: Model showing motivating factors for family carers to care work**



Source: Field Data 2010

Figure 9.2 is showing different perspectives of how FCs were reconstructing the lived care experiences. Providing care to chronically ill patients requires that someone has relevant knowledge and skills and appropriate resources to do so. Needless to say, some of these care tasks are easier to manage whereas others are complicated. For example, we learn from the findings that there were patients with generalised body rash or sores who required application of topical drugs on affected areas and one who needed regular attention paid to the catheter. The caregivers also needed to constantly observe the patient for any drug related complications or side effects.

FCs had identified themselves as caregivers (assumed identity), and had different reasons why they were the ones to provide care and no other members of the family. However, despite this identity, they described their ability to provide care as difficult. The care situations as described by caregivers did not give them the feeling of a “strong self” and “firm identity” (Antonovsky, 1987 p 26) to carry out most of those care activities, hence rendering them weak. The environment within which they (caregivers) found themselves did not favour nor recognise their level of care capacities.

### Comprehensibility and Manageability in care functions

*Caring for the chronically ill patients with HIV/AIDS*

Caring for a chronically ill patient is one life experience that may have different effects on those providing that care. However, it was observed in this study how FCs assumed caring roles as a natural development and consistent with other studies, many relatives wanted to be close to their patients and ensure that the patient's situation was good, which gave meaning to those taking care (Andershed and Ternesterdt, 2001). FCs in this study, are in most care situations unsure of their actions and were in most cases grappling with care work in emergent meaningful ways. When an individual is faced with a stressor, the appraisal process will help that individual assign meaning to the effects of the stressor and will deal with that stressor in a manner conceived to be meaningful to the patient. When faced with care challenges the "self" works subjectively to define, understand and make decision on actions and behaviour to be taken to address the challenge (Mazzotta and Myers, 2008). According to Antonovsky (1987), the ability to deal with and manage tension, for example, is believed to have effects (positive or negative) on the health of that individual, and this could be pathological, neutral or salutary (Flensborg-Madsen et al., 2005). Notable about SOC is its ability to be a resource for promoting health, thereby strengthening resilience and development of positive subjective state of health as observed by Ericksson and Lindström (2006). Health promotion is salutary in nature and focuses  direction of perceived good health as a determinant of quality of life (Lindström nd).Typical GRRs as money, behaviour, commitment, social support, cultural capital, intelligence, tradition, and view of life (Lindström and Ericksson, 2006) were also determinants of  mental health as Barry (2009) observes that "mental health was fundamental to good health and quality of life, it is a resource for everyday life and it contributes to the functioning of individuals, families, communities and society" p 4. As WHO (2004) phrase it: 'There is no health without mental health" (in Barry 2009 p. 4).

The caring at household level therefore is filled with a number of challenges. The need for FCs to have the ability to identify resources to facilitate caring is of paramount importance. They, as caregivers, should possess a strong SOC in order to identify resources within an individual's internal and external environment that will assist and promote coping by finding solutions in care needs (Ericksson and Lindström, 2006), As they further observe, a person with a strong SOC can cope with stressful situation and stay well and remain health with improved quality of life.

### Caring as experienced by family carers at Household level.

Data from this study  confirm that  care for chronically ill patients with HIV/AIDS at household level   was being carried out by family members who were caregivers  responsible for providing care to their relatives ranging in relationships from sister brother, mother, niece, uncle husband or wife. Caregivers were driven to care because of the bonds in family ties (Halligan, 2005; Evergeti, 2006; Hossain, et al., 2007)

Consistent with other research, FCs were motivated to provide care as a result of different internal and external factors like having the heart for the sick, religious requirement to help those in need, and there was a strong feeling of compassion for others.

For example R2 in FGD: 02 said "*for me to be a caregiver and be able to give medicine to my patient, I have compassion for the sick, I really wanted to help people in the community that are sick so that they can be in good health*." Another one R5 in the same group said *"I became a caregiver because I had a heart for the sick from childhood. I don't like seeing sick people being neglected, so I had interest of becoming a caregiver". While IDI: 14 said "I am hard working and so do not give up, I love my patient. God has given me brains to think and go out to wash clothes for other people; he has also given me energy."* She went on to say that "*It's not my power alone but the spirit of God that gives me the brains to carry out the work and help others"*

One therefore observes strong emotional forces driving caregivers to carry out care activities even when they claim that they had received no formal orientation to support caring responsibilities. Further, corroborated information from the community based organisations involved in HBC, also confirmed that much as the FCs needed some form of orientation to care work, but claimed that training was provided, but concentrated efforts only on volunteers caregivers (Akintola, 2004, 2008, 2010; Ogden, et al., 2004; Manthorpe, 2007). The study recognises the weakening structure at community level to support households with chronically ill patients. The record for the number of patients and households visited by volunteers as noted from the record reviews were many and this casts doubts on the level of support being given to households and the number of household that may adequately claim to receive constant support as. The NAC (2010) also observes a weak structure in Zambia where HBC systems were still in the process of development.

Family Carers' common method of acquisition of care knowledge was mostly from observations of other relatives giving care and this began as early in life as well as from personal experiences especially for those who have participated in the care of relatives or others within the households. It is very difficult therefore to ascertain the kind of competences acquired during those times as such information on what would be expected of them during different care situations were not formally obtained

### Caring as a responsibility in the household

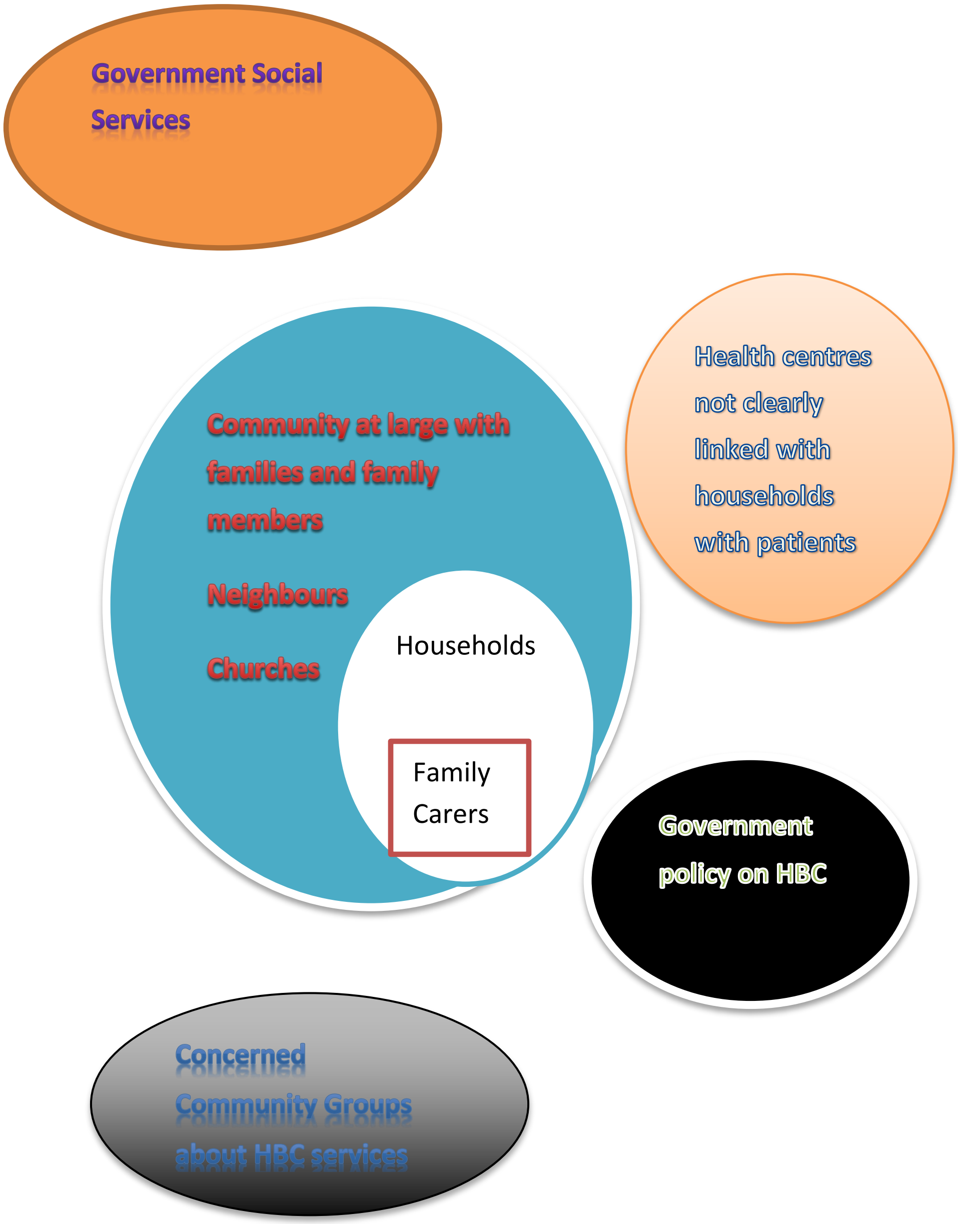
Research by Knodel et al., (2010), viewed filial support as driven by some external constructed ideology of caring. This has to some extent resulted in FCs believing that caring was 'natural' and that women should be the ones to provide this care, as most participants observed. And attributed to this was that, the desire to care was an in - born attribute. The sickness or death that happened in their families made them realize that it was important to care for others. For example R1 in FGD: 04 of caregivers said " *I started taking care of my mother because my father died, my mother then started getting sick, our first born my sister died as well as the second born, am the third, there is no one else to look after my mother*". The caregiver was left with no choice but to provide care to the mother after a number of relatives died. Such narratives were common among the study participants. In another FGD: 05: R5 responded to a question of how they started providing care to patients in their homes said " *when a relative is sick, you can't chase them because they are sick, diseases come in different ways so we try to help them so that they can get help and get well*". IDI: 16 said " *I wasn't chosen, the husband rejected her but I can't reject her because she is my daughter*" These finding therefore demonstrate that caring was compounded with processes of self-appraisal on the ability to provide the patient's need, as expressed during a care encounter. As the present study suggests, FCs were determined "to do something" for the patient and that only they were most appropriate to do so. This feeling of the desire to do so propelled most FCs to go on managing their patients. A caregiver would appraise herself in care situation by acknowledging that "*caring was difficult…. but because I dedicated myself to care work I wanted to know everything…… so I could take care of the patient well……. I had self confidence that I will know what needs to be done" IDI: 12*, This finding and from other caregivers in this study is also consistent with other studies as Johnson, (2004) also illustrated the self-appraisal process as one of the key factors during care encounters and that such actions were mostly associated with self-esteem and hence coping and a positive SOC was achieved. It was a general perception by FCs to self-evaluate their situation from their family point of view, in most households the FCs felt obliged as they thought they were the ones to take charge of caring. They felt there was no one else in the family to do so. That's because of their perceived relationship with the patient and they felt as the only resource available to provide that care.

The study participants demonstrated that taking on care responsibilities did not need anyone to dictate to those who became involved. They believed it was their responsibility and the desire to care was like an automated response to a need within their environment. It was argued by

Stryker (1987 p. 334) that " when the expectations of others are congruent and consistent, revealing few conflicts and disagreements, individuals will be even more committed to the identity presented to these others because they speak the same voice". But we have also learnt that most caregivers did not complain, when faced with care challenges but felt that they contributed some form of meaning to the care of their relative hence their identity as caregivers also became a reality. But again, we also note from findings that most caregivers did not experience much "interference" in care process from relatives because they were not there to provide the much needed support. The expectations of others were "silent" in practice. In one situation, where the caregiver was HIV positive and taking ARVs, and working in the health sector, she voluntarily assumed the identity as "the one" to provide care. Hence she made a decision to bring in her daughter in –law and care for her. She felt she was better placed to provide relevant care for she saw that opportunity to affirm her identity of her role. According to Stryker, (1978) she was merely seeking out a situation to use her identity (as a caregiver).

The study shows that despite the existence of some policy (yet to be formalized) and guidelines for implementation of HBC activities, there was no planned or structured orientation or preparation to care. Health care providers may have misunderstood or misconstrued the willingness of families to take care of discharged patients without question. As this research continues to review the findings, one would inconclusively say that, there existed a strong notion by health care providers that families were always ready to provide for their patients (also Thabethe 2011). Participants viewed taking on care work as something that happened as an "accident" or according to Antonovsky (1987) as a "surprise", IDI: 10 said " *it's not something I chose to do, it just happened by accident"*, as some caregivers had not prepared for the new caring role for the sick. This could have contributed FCs viewing care work as stressful, difficult and that only the strong could manage.

**Figure: 9.3: The care environment as perceived by family carers and identification of their position in that environment**



Source: Field Data 2010.

The findings of this study show how caring had both psychological and physical effects on the life of FCs who in most cases were lacking the support needed from relatives and the immediate environment. They were mentally affected as they faced different difficulties to cope with the many care demands. In their effort to obtain possible care support, FCs were constantly looking for a supportive environment to care work and they were able to identify whom, where and how they could get respite. Figure 9.3 is a resource map as envisioned by FCs. These structures were found not to be supportive and compounded with dysfunctional family structures; FCs cannot receive the social support, a one determinant of mental health (Barry, 2009). She (Barry) observes that good mental health was created where people lived their lives, where the everyday context or settings were supportive like communities. Communities are always known to be supportive and have promoted the Ubuntu however, the level of this support in Zambia has changed with modernisation and effects of HIV/AIDS. Families have become more nuclear and have been preoccupied with money economy while others have lost most family members from AIDS. Aidoo and Harpham (2001) observed a less supportive way of life in urban areas as importance is placed on earning money thus contributing to stress levels especially in women. Therefore, Social determinants like higher income, education, being in paid employment and close supportive relationships were predictive of better mental health (Barry, 2009).

Figure 9.3 tries to describe and represent the perceptions of FCs of the environment that would provide them with the much needed support to accomplish care work. There were no observed linkages in the community to support the household with chronically ill patients. FCs recognise themselves as the immediate resources in the most inner square (labeled family carers) as the first point of an environment that will understand the needs of the patient and FC in any household. There are levels therefore of those structures that have been seen and described by FCs as competent to provide the support in care work but that are not available to participate in helping with care work. What is evident about this perception as reflected in Figure 9.3 is that FCs have the ability to identify source of support as a resource in coping with care work. Whilst others have gone out to find this support some have waited for the support to move to where they are.

This ability was related to manageability, one component of GRR, and this ability was an indicator that FCs did understand and had ideas of where they could find support. This finding is similar as that of Airhihenbuwa and Webster (2004) whose finding in the study looking at the role of culture and the African context of HIV/AIDS prevention and support did take cognizance of the heavy expectations by households of other families, friends, community to provide support. This finding is consistent with Antonovsky’s (1979; 1987) postulation about having a sense of knowing where to identify resources that make caring more manageable and it can contribute to a strong SOC. Other studies by Forsberg-Wärleby et al., (2002), were also consistent with Antonovsky’s salutogenic model that social support and material resources were significant for GRR for creation of SOC.

The ability to identify and appraise their care situation by FCs is another area that has helped those who have been able to manage caring. McCubbin and Patterson(1983) in Kloosterhouse and Ames (2002 p 63) recognise two types of resources " existing resources that the family already have in place and expanded resources that families learn to use when dealing with hardships". The process will involve making decision on the resources to be used or that which is available for the patient and especially in dealing with the presenting challenge.

Behavioural determinants for coping mechanisms, from the cultural point of view as discussed in the framework, requires that there is a transmission and receipt of symbolic communication as one interacts with the immediate surroundings. As people perceive and act within their world, the perception and processes that follow to decide on type of actions to be taken vary amongst individuals. Their decision to act is based on the way they define and interpret the presenting event and the meaning the event holds for them in their social world (Berg, 2004). In view of the differences in the social cultural world of the FCs, their behaviour in terms of use of symbols in form of language were different but they made reference to similar symbols which are developed over time. These are the internal factors as we think about problems, we constantly assess our knowledge, ourselves and others, and we use language to communicate with one another (Kasschau, 1995; Goulding, 1999). The way we interpret the world that surround us and the cultural solutions we determine do change over time, but Mazzotta and Byers (2008), argue that there always seems to be a repetitive pattern of social action that creates some form of cultural solutions. The repetitive pattern of action can therefore, be anchored in the way we understand the situation and respond through behaviour. Stryker (1987) had observed how humans were capable of organizing their behaviour to resolve problematic situations and importantly to verify their sense of self in the eyes of others (Stets and Burke eds 1987). People's behaviour therefore, in interaction with others in social settings is governed by how they feel about and see themselves as a kind of gyroscope for keeping our behaviour in consistence and in line (Hewitt, 1988) with the social expectations. As individuals interact, they use language which is critical to most human interactions and we define what language means to us through cues or symbols (Chrisman et al., 2007).

Rena and Abraham, (1996) observed that SOC was a factor in explaining the strong difference in coping by individuals regardless of the severity of disability. The key factors in this process are that, as FCs interact with their environment, their behaviour is being influenced by society life situations and how we react to those situations and dependent on how we were culturally socialised based on prevailing situations (see Benzl et al., 2014). Which are factors in successful coping and development of SOC (Benzl et al., 2014). The outcomes from this interaction include behaviour that is controlled by some genetic factors and the contextualization of the logic behind the behaviour. Biological like age, sex and physiological elements in the FC were factors in the ensuing behaviour resulting from the stimuli.

These appraisal processes are key factors in identification of GRR in the coping process. Further, culture is fundamental in the development of SOC (Benzl et al., 2014), especially that, the FCs will use internal resources that are in born in trying to understand and address the presenting situation.

### Family Carers' behaviour and caring role

Behaviour of an individual was therefore a key issue when considering a person's sense of coherence. Antonovsky (1987) views identity as a social role complex of the individual, and that a strong "self" makes possible a firm identity. He further asserts that a person with a strong self and a firm identity will be one with a strong SOC (Antonovsky, 1991). Whereas Stets and Burke (2003) also argued that the process of selfhood responses was a form of reflexivity during which an individual reflects back upon themselves as objects, they evaluate themselves, and they are self-aware of their state now and for the future. The behaviour of caregivers in their daily work was a reflection of what they believed their caring role was and the expectation of those watching them. Rosenberg (1979 in Stets and Burke, 2003) did suggest that there was more to the self-concept than self- esteem and further defined self-concept as the "sum total of our thoughts, feelings and imaginations as to who we are" p. 5.

The FC's behaviour in relation to challenges is a result of the effect of the challenge on the human mind and which subsequently results in human behaviour. This behaviour according to Kasschau (1995) is programmed by societal norms that require individuals to behave in a certain manner. During socialization processes, the young are groomed to behave in a specific acceptable manner by society. Further, it is these interactions with the environment and those in the environment which in the case of this study includes: the patient, voluntary caregivers, relatives, neighbours, and sometimes the health care workers. Therefore, an individual's behaviour is based on how they identify themselves with those interactions and how self-identity is nurtured within the relationships with others close or distant but within the community. However, study results showed imbalance in the gender of those providing care and this result was consistent with other study findings in the SSA, that more women and girls are taking on the burden of care roles for those living with HIV/AIDS as compared to men (Thabethe, 2011; Opiyo et al., 2008; Akintola, 2004; Ice, et al., 2009, Demmer, 2006). Having made this observation, it would be right to make another accurate conclusion that, traditional gender norms perpetuate the building of barriers that hinder men and boys becoming caregivers (UNAIDS, 2008). Whilst this may be so, studies in Zimbabwe (Johnson, et al., 2003) and Zambia (Esu-William, et al., 2006) revealed the willingness of men to care. However, there were situations for example when men were seen helping with nursing care work like bathing the patient, cooking, women objected as they felt that household chores were not meant for men. And women accepted men carrying out tasks like hospital visits, buying medicines, transportation to hospital. These results were consistent with the studies carried out by Johnson, et al., 2003) in rural Zimbabwe, Akintola, (2004), in South Africa and Makori, et al., (2011) in a study conducted in Maseno Division, Western Kenya.

### Coping with care work by Family Carers

The findings show varied coping mechanisms devised by FCs. The coping mechanisms were associated with the circumstances facing the household. For example social economic status and internal and external factors had a role to play in devising coping mechanisms. These had direct influence on how FCs managed the processes of caring for the chronically ill and cope with the related challenges.

To cope with the varying challenges of care work requires dedication, commitment and varying degree of understanding of what is expected of the caregiver. FCs were consistent in that they were able to identify own internal resources that they attributed to successful care encounters although levels and the description of what was termed as successful was inconsistent. They said that in most cases there was no one to help them. Most of all they said that they relied on God to help them. Compassion and emotional attachment drove them to do more for their patient as they believed that their efforts would result in a meaningful outcome for the patients and subsequently raise their ego, give an inner feeling of satisfaction on the achievement of having done something for the patient and promote mental health.

In addition when faced with difficult times many said that they relied in God through prayers. Examples given were self-confidence, hard work, compassion, love, having a strong heart and that caring was in- born were some of the attributes that encouraged the FCs to go on. An expression and demonstration of satisfaction from the patient was part of the symbolic language motivating participants to go on and be pleased with caring roles.

Important within this is how individuals form their concept of self, based on their perception and relations with other human beings in the society (Chrisman et al., 2007) in this case we are looking at the relationships of caregivers with their patients and relatives. While Antonovsky (1987) asserts that a person with a strong self and a firm identity will be one with a strong SOC and with Stets and Burke (2003) arguing that process of self-hood responses was a form of reflexivity during which and individual reflects back upon themselves, and they are self-aware of their state now and for the future. This state accordingly was referred to as a “sum total of our thoughts, feelings and imaginations as to what we are” (Rosenberg 1979 in Stets and Burke, 2003 p 5)

As observed in the literature reviewed in this thesis, coping we have learnt from Folkman and Lazarus (1984) was about having the ability to manage external and internal demands and challenges. We further recognise the assertion that resilience was one factor that always comes into play as an individual continues to interact with his/her environment. During this process, one is able to stand up to any challenge and/stressors on any adversity (Walsh, 2002; Windle, 2011). We also learn that the ability to cope was built on lifelong experiences through interactions between, children for example and their parents, mentors (Walsh, 2002).

Family carers were engaged in the care environment that required flexibility as one interacted with the environment. The reaction was therefore purposeful as it was anchored in the realm related to the meaning that it held for the individual. Individuals take actions to do something based on the interpretation of the outcome of the action undertaken. Meaning according to Mazzotta and Myers (2008) were not fixed nor unchangeable but are determined by how a person acts towards an object. FC (as they took action to meet patient needs) were able to address situations when there was no food by going out begging or out to do piece work. This was seen as a coping mechanism to address food situation in homes. Their ability to think and appraise situation and plan for action was a factor that saw some caregivers manage care functions.

Coping was made difficult especially as FCs were expected to manage patients from morning till late in the night, whereas some FCs denied themselves sleep, but stayed awake watching over the patient. A large number of researchers have, for example, examined the different coping mechanisms, strategies or styles in relation to different medical conditions like cancer, diabetes, those affecting the central nervous system and other medical model conditions. Their results show consistency with other research that individuals will adopt different strategies based on social, psychological and economic status (Lazarus and Folkman, 1984; Folkman, 1984; Antonovsky, 1987; Martin, et al., 2004; Burgess and Campbell, 2014). Whilst Chipimo et al., (2011) observed in their participants that coping strategies were determined by factors like perceived duration of illness, family support.

There was a strong sense of reciprocity expressed by FC needed. They were convinced that and expressed their utmost need on their part to return a favour to someone in need when they too may have received direct or indirect favour from others. This behaviour was considered acceptable in the community; they strongly believed that their past experiences in care giving were factors to coping.

The past experiences were one resource illuminated by Cowley and Billings (1999) that FCs used in dealing with challenges. Examples given were those that have always been known to exist in families and communities like anticipated family or social support, self- esteem and positive conviction that a way forward could be found to deal with current problems. These experiences always did exist more especially in the African context, where the Ubuntu concept was an accepted value based approach to living in communal areas.

Coping mechanisms among caregivers were found to be of varied nature and coping was mostly viewed as difficult and sometimes unattainable. In the previous years in Zambia, some households were able to seek support and help from CBOs where they existed and were known. This support included food packs which were distributed through CVs. The existence of CBOs and the type of support available was not privileged information and was generally lacking in communities. However, households who had affiliation to FBOs had opportunities to learn about such support structures existing in communities. Some households that were managing to cope were those closely linked with some support structure more especially from FBOs and other CBOs. Caregivers also narrated selling of assets as a mechanism to cope with financial difficulties. Although there were only a few FCs who may have had possessions that could be sold to raise income, most caregivers expressed the desire to do so.

Caring for chronically patients attract costs that in most cases have to be borne by the care provider. Households in this study were already experiencing financial hardships in terms of finding resources to meet the needs of the patients. This was one resource that affected manageability of care work. The need to purchase food for the patient, transportation to the health facility for regular reviews, to purchase items like gloves, medicines, water and paying for rentals were some resources that were difficult to access. There were also other costs related to social interactions, where the carer find it impossible to socialize with others, fail to go church for fear of leaving the patient unattended, even the time to take care of their own(caregiver's) needs all attract a cost. The costs were not only in monetary form but in social interaction. While some caregivers said that they were denied opportunities to go out and experience some social interaction with others as they spent most of their time looking after the patient. IDI: 11 narrated "*I don't see my friends all the time since I look after the patient",* self-actualization and rest are denied of the caregiver, IDI: 12, "*I work too much, sometimes I don't sleep, I have to be up by 4:30 in the morning*". And another (IDI: 09) said "*the work is tough, it is labour intensive especially drawing water, I fail to work sometimes, it is better to start a business*". The same caregiver further said" *I work hard around the house, I would like to do more like going to sale things for money but there is no one to care for the patient….".* IDI: 10 said "….*I used to work in a Tarven, picking up bottles. I did not manage to do both things because I needed to care for the patient and work at the same time. I couldn't leave him with children. When he gets better I will start again*….". In another situation having the breadwinner as the patient has denied children education as we saw in the family of IDI: 01.

We observed different coping styles among FCs, although the majority in the study devised similar mechanisms. Study results show that caregivers did not have accurate understanding of what was expected of them during some care inventions and hence majority failed to cope.

### Social Support in caring for the chronically ill

Bengtsson and Bengtsson (2005) observed that social support is valuable for a healthy life as it helps people avoid getting into stressful situations and events. For example, the ability to deal with or not deal with a stressful situation may depend on one's resilience. An individual's skill to recognise, find meaning and adjust to social support can be factors in the ability to cope with stressful situations (Klepp et al., 2007; Love, Irani, Themistocleous, 2001). During care interactions, the FC will be in anticipation and expectations of a care environment that will include different players having a hand in the care process. The social support for care, as reflected in this study appeared to be enshrined in the socialisation process, which demands that each one should be a brother's keeper. The nature and magnitude of support differed among individuals and depended on circumstances as observed in the results chapter.

The study also takes note of the lack of control by caregivers of most of the external factors that could be associated with the support structure, for the caring roles they were involved in at household and community levels. The need for social amenities like good housing, clean and regular water supply, proper sanitation, proper lighting and ventilation in the houses, waste

disposal systems were some mentioned by caregivers as key to provision of care to the patients. There were poor out- reach services /activities to household with patients suffering from HIV/AIDS due to low staffing levels at health centres. The effects of HIV/AIDs which had affected many families resulted in a poor social support structure in most communities.
Consistent with other studies, lack of social support in caring for HIV/AIDS was not a new finding, and unique to individuals with HIV/AIDS. This was an observation made by Martin et al., (2004). However, despite such evidence, social support was perceived to make life more manageable and understandable (Heiman, 2004). As observed with caregivers who “lamented” for help from others within or outside the households no one was out there to provide help, they “felt alone” in the caring world (Antonovsky, 1998). The study by Heiman, (2004), revealed that students with strong sources of support demonstrated overall strong SOC, hence were able to use the GRR more positively than those with lowered SOC. Also Chepngeno-Langat et al., (2009), studying the socioeconomic differences between HIV caregivers and non- caregivers of older people in Nairobi (not applying Salutogenesis), and Forsberg-Warleby et al., (2002) studying the SOC in the first phase of spouses of first-ever stroke victims also concluded that social support and materials resources were significant in GRR and that were important for the creation of SOC. In addition a thesis by Mwape (2010) conducted to assess psychological distress during the perinatal period in Zambia also observed the positive role that social support had in coping mechanism amongst mothers. There was a general recognition of the support that could easily come from family and kinship relations in this study as conceptualised by Ubuntu, and more especially in the African context that is known to form the extended family network (Chepngeno-Langat et al., 2009). However, due to social factors like effects of HIV/AIDS on families where the bread winner dies or are chronically sick from AIDS, poverty, lack of formal employment and, the extended family was not available to provide this support. The ubuntu concept that promoted one being available for others has also been eroded by the breakdown of family structures.

To be able to identify and access resource, FC needed to be empowered with the ability to do so. Empowerment was one resource that was expressed as lacking in the study participants. For example Dixey et al., (2013) argue that empowerment resonated with the important sociological concept of “agency” which is believed according to Barnes (2000 in Dixey et al.,, 2013) to suggest that “people have internal powers and capacities which through their exercise make one an active entity constantly intervening in the course of events going on around one..….” p 23. The concept of agency is further observed to be related to ones understanding of how the individual stands in relation to others within the same community. There was general recognition that the status of being economically stable was a resource that was identified to contribute positively to coping with care work. Generally, caregivers were facing difficulties providing for the patients. The levels of household incomes were as low as K10 -K 50 a day as the amount of money that caregivers would make when they go out to carry out some “piece work”. Most caregivers took some initiative to provide services to others like doing laundry work, fetching water, cleaning houses which gave them minimal resources to support care work, and meeting the needs of their patients. For example, Burgess and Campbell (2014) observed in their study that poverty was a driving feature of stories told by women in their study. This was directly linked to emotional distress, which resulted in the mother’s sadness and distress for not being able to provide for the family.

In the theme of manageability, Antonovsky (1979, 1987) highlights the individual’s ability to foresee that things will work out based on what was experienced at the beginning of comprehensibility. Antonovsky’s model of Salutogenesis he describes SOC under the theme, “one perceives that resources are at one’s disposals, which are adequate to meet the demands posed by stimuli that bombard one” (Antonovsky, 1987 p 17). Meaning that, resources were readily available to support care work. That these resources were under one’s own control or controlled by legitimate others within the community. These could be spouses, friends, colleagues, and religion and spirituality; these are resources that one could count on.

Having made the above observation, caregivers in the study felt “alone” in the care work. The anticipated help from others was far-fetched as social support structures that previously were available were no longer there. Their own ability to generate resources had become unattainable. Other research observed that social support reduced at every level of existence among individuals, families, peers as more people were rushing for advice from churches and other community organisation (Yeh et al., 2008). Coping in this area was found to be weak as caregivers were accepting life problems and they were those who stated that sometimes they were able to cope and most times not able to cope. They used different coping strategies like having strong belief in God and spirituality. This belief gave caregivers inner strength to venture on caring for the loved ones for some. This finding was consistent with that of Burgess and Campbell, (2014) the study that aimed to contextualise women’s mental distress and coping strategies in the time of AIDS.

Caregivers felt that people were out there in the environment that would support care work, and were of the view that managing care work should not be an abstract contribution by the support structures but needed to be a real situation. Although others felt that there are many in the families to provide support, they felt ‘alone’ when it came to caring for the chronically ill, the health care system, nor the welfare system did not provide the much needed support as expected in contrast with the Ugandan and South African systems where social welfare was available to provide support (Milberg and Strang, 2004). This was not so in Zambia as there was no existing social services programme to support families especially the support in form of social welfare.

### The roles of Religion and Spirituality in care work the perception of Family Carers.

When asked about how they felt when faced with challenging issues, they said that God through prayer comforted them. Religion and spirituality was recognised by nearly all participants to this study as one major resource facilitating coping.

They felt that a strong belief in God provided them with the motivation to care, a resource to cope, an avenue for generating hope for the patient. The pathway Figure 9.5 for example, provides the process that a caregiver follows as they identify resources to manage care and make their input more meaningful. Religion is universal and African life bound with religious belief in most African countries Jenkins 2007 (in Patterson 2010) and people belong to those beliefs and derive some form of satisfaction when they belong. Religion provides for a strong belief that God was the ultimate provider and the family care believed He would guide them in what they were to do. Antonovsky (1979) recognised that religion and spirituality were viable assets in helping individuals gain a “sense of coherence” (in Kloosterhouse and Ames 2002 p 2) especially when adapting to physical and psychological stressors. Goulding (2010) observed that the value of religion did bring about a strong connection with mental health thereby promoting lower rates of depression, higher self – esteem in an individual. Consistent with other researches, Burgess and Campbell (2014) observed that faith and hope were some coping strategy in care work and hense there was sustained belief in caregivers that things would improve.( see also Chipimo et al., 2011)

The theoretical framework guided this study to explain the process followed by FCs in highlighting the importance of identifying and using resources to support families to counteract the stress processes and devising coping mechanisms. Kloosterhouse and Ames (2002) had earlier used the framework to understand the role of religion and spirituality in families nursing children with HIV/AIDS but in hospital situations.

The research findings were consistent with Kloosterhouse and Ames (2002) findings that families talk about having the belief in supernatural powers of God to intervene in their difficult care situations. Having observed this common element in the FCs' responses, as IDI: 16 said *" I just pray to God to give me strength to handle these hard tasks". IDI:12 said "I just put everything in the hands of God" and further said " I feel very happy because God really takes care of us each and every day…."* it is my opinion that, some of the participants resigned themselves to fate especially where they did not have any basic resources to facilitate care work. They would decide to sit and "wait for God" to do something for them. This behaviour put most FCs in weaker position in terms of SOC as compared to those who would take the initiative to go out and find resources from external environment. The family carers, who had the stronger drive to do something for their patients, went out and were engaged in activities that gave caregivers opportunities to identify and find resources for care work.

Kloosterhouse and Ames (2002 p 62), reported that Benson (1983) 30 year work concluded that the belief in a higher power provided a critical contribution to an individual's well- being and healing. He suggests that humans are "wired for God" and that each individual is genetically encoded with a need for nourishment from faith.

Research studies also agree that religion and spirituality can act as a resource to help a family cope with stressors (Kloosterhouse and Ames 2002; Antonovsky, 1979; Burgess and Campbell, 2014). My research also made similar conclusions as nearly all participants looked to God for answers to their situations. The feeling was positive when they were able to identify and access resources for their patients and they had strong belief that God had made it possible and still felt it was God's wish when resources were not found.

The clinical care guide manual for supportive and palliative care for patients with HIV/AIDS (Puchalski and Sandoval chapter 13 in O'Neill et al., 2003), views spiritual care as an important element, as any illness was viewed as a major life event that disrupts for example their careers, family life and their ability to enjoy themselves. Their work demonstrated that people will cope better with suffering when they find meaning and a purpose in what they were doing. For example, individuals are known to continuously engage in the process of interpretation as they move from one situation to another. These situations, especially when they have a value of meaning attached, subsequent actions are then determined by the meaning they create while interpreting those situations (Mazzotta and Myers, 2008). This feeling was expressed by most respondents in the study. However, the study did not specifically ask questions related to spirituality, but why the FCs continued to provide care even when they experienced situations that were difficult to manage. Zambia was declared a Christian nation and as such issues of Christianity were respected and observed.

It is therefore noted from the findings that most of FCs had a very strong belief that through prayer, God would provide them with answers to their difficulties. Noting from the discussion above, the “ultimate meaning or belief in God” gives FCs meaning in what they are doing for the patients. This strong belief in God and being prayerful helped caregivers face challenges in care work. Their belief was that through spirituality their efforts to find some resources for example by engaging in “piece work” became possible. They believed God created the opportunity to find such jobs. Subsequently, believing that God would always provide for them, even where there was lack of knowledge to carry out care work, there was belief that God will give them the required knowledge. The act of being religiously and spiritually strong was further believed to be an attribute in caring for patients. Perceived bible teaching on the principle of helping one another was an important motivator upon which the desire to care was presumed anchored. This notion was further strengthened by the concept of Ubuntu which individuals were taught to observe (Broodryk, 2006).

The identification of religion and spirituality as a resource provided caregivers with the ability to view life from a perspective of principles based on Christianity. Faith based organisations in these communities formed a common part of the care environment and took a leading role in teaching religious principles of communal life.

However, it was further noted from the models in this thesis that despite nearly all participants describing their closeness to God, having faith in God for help, engaging in prayer to God for help, we observes that very few caregivers see the church as a source of support (see chapter 8 for details)

Family Carers strongly believed God was responsible for providing cure for their patients. In view of Zambians being quite traditional and having strong cultural beliefs in ancestral powers, there was no association to witchcraft as cause of illness. One caregiver who knew the diagnosis of the patient but kept the status confidential, disputed allegations from relatives that the patient was bewitched. Neither did caregivers think of traditional healers as those that could help cure their patients. In a related topic of use of tradition medicine, in a study conducted in the SADC region, Isaacs, Mundeta and Masunda (2010) did find that care providers encouraged their HIV/AIDS patients to use herbal therapies, nutritional supplements including medicinal plants which were easily accessible and cheap. This was not the case in this study, they all believed in ART although access to health facility was not easy.

The progressive improvements in the patient’s condition made the care giver even stronger. When they saw the patient eating and responding well to treatment it encouraged them to continue. Symbolically the FC was generally displaying the feeling that as a caregiver, the “I” in them was organised as depicted in their behaviour to resolve care situations affecting their patients, and by being able to define this situation, it helped them understand who they were as caregivers in those situations. Additionally their ability to define and resolve a problematic care situation involved assigning meaning to the behaviour as may be expected by the self and others (Stryker, 1987) and whilst also recognising the special roles they played in care functions. As again noted from the findings, the pathways 9.4, 9.5, 9.6, 9.7 describe the different ways that FCs will take when dealing with situations and challenges related to care work. The pathways show different characteristics of FCs and their situations which are shaped by their environment and different past experiences.

**Figure: 9.4: Pathway taken by family carers when faced with resources based challenges**

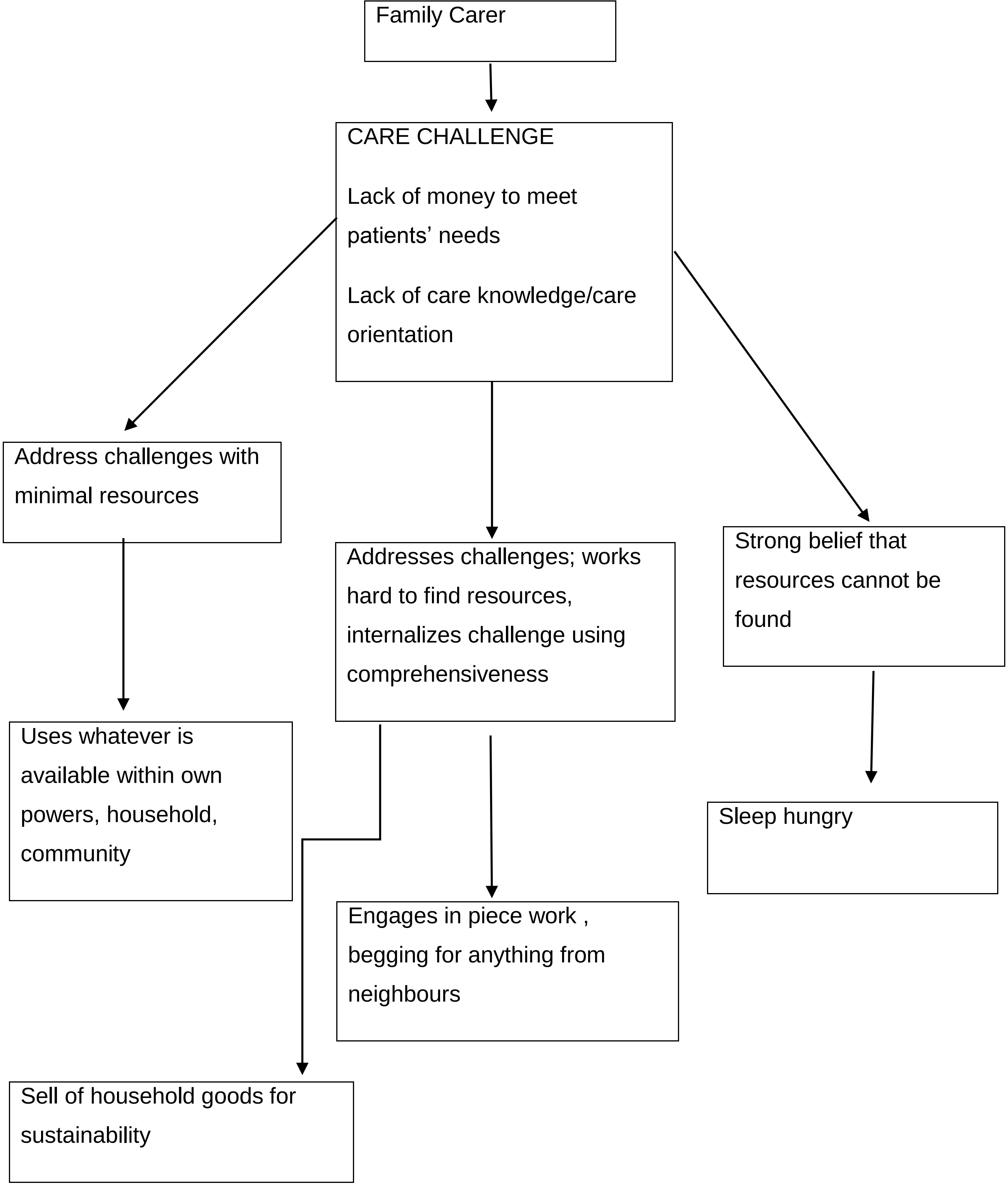


**Figure 9.5: Pathway describing a scenario when the family carer appraises the situation and decides to do something and another pathway, when the family carers feel there is nothing that can be done**

**Figure 9.6: Pathway when family carer is faced with challenges related to provision of care to the patient.**

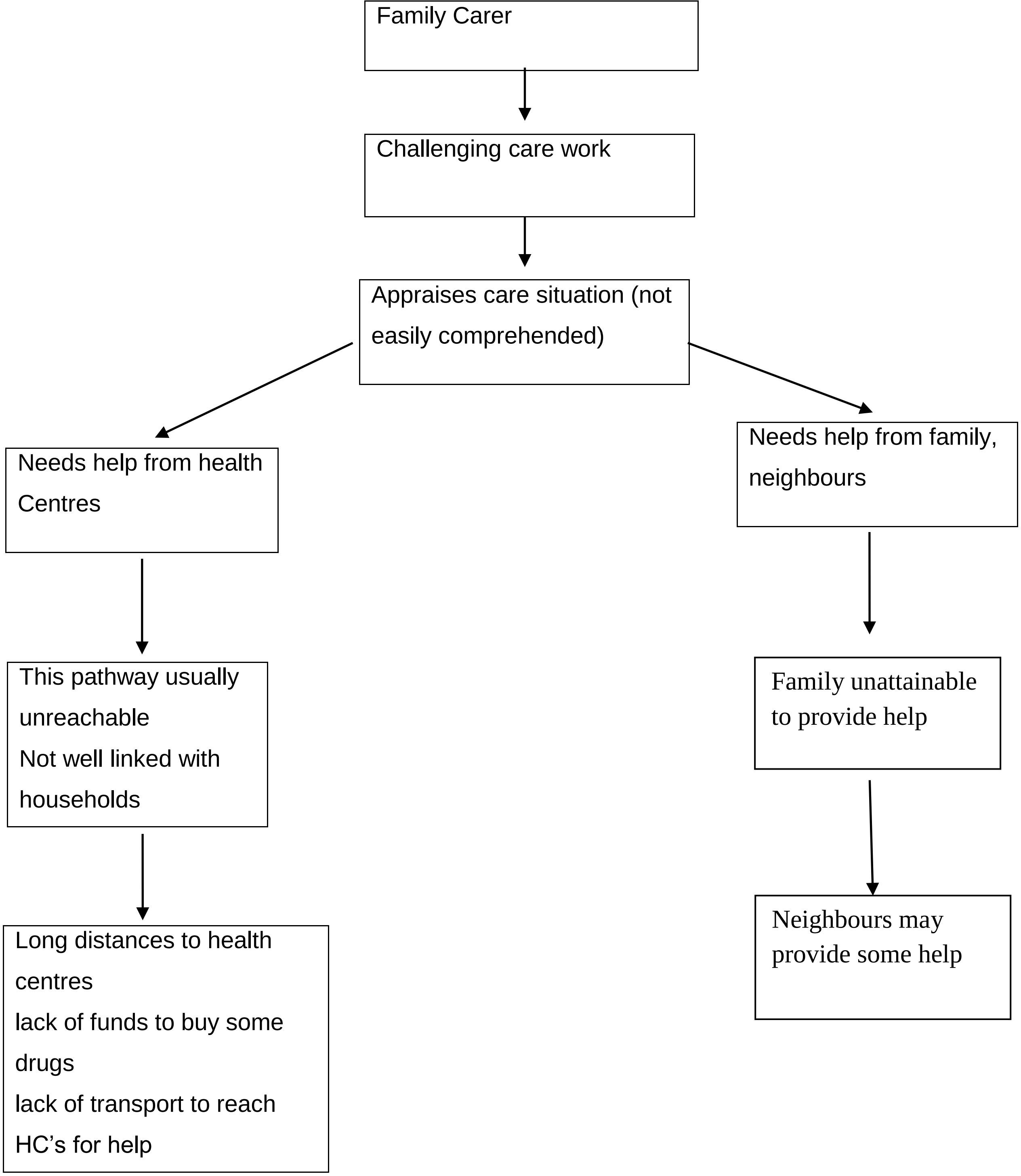


**Figure 9.7: Pathway taken by family carers in relation to comprehension of care work**

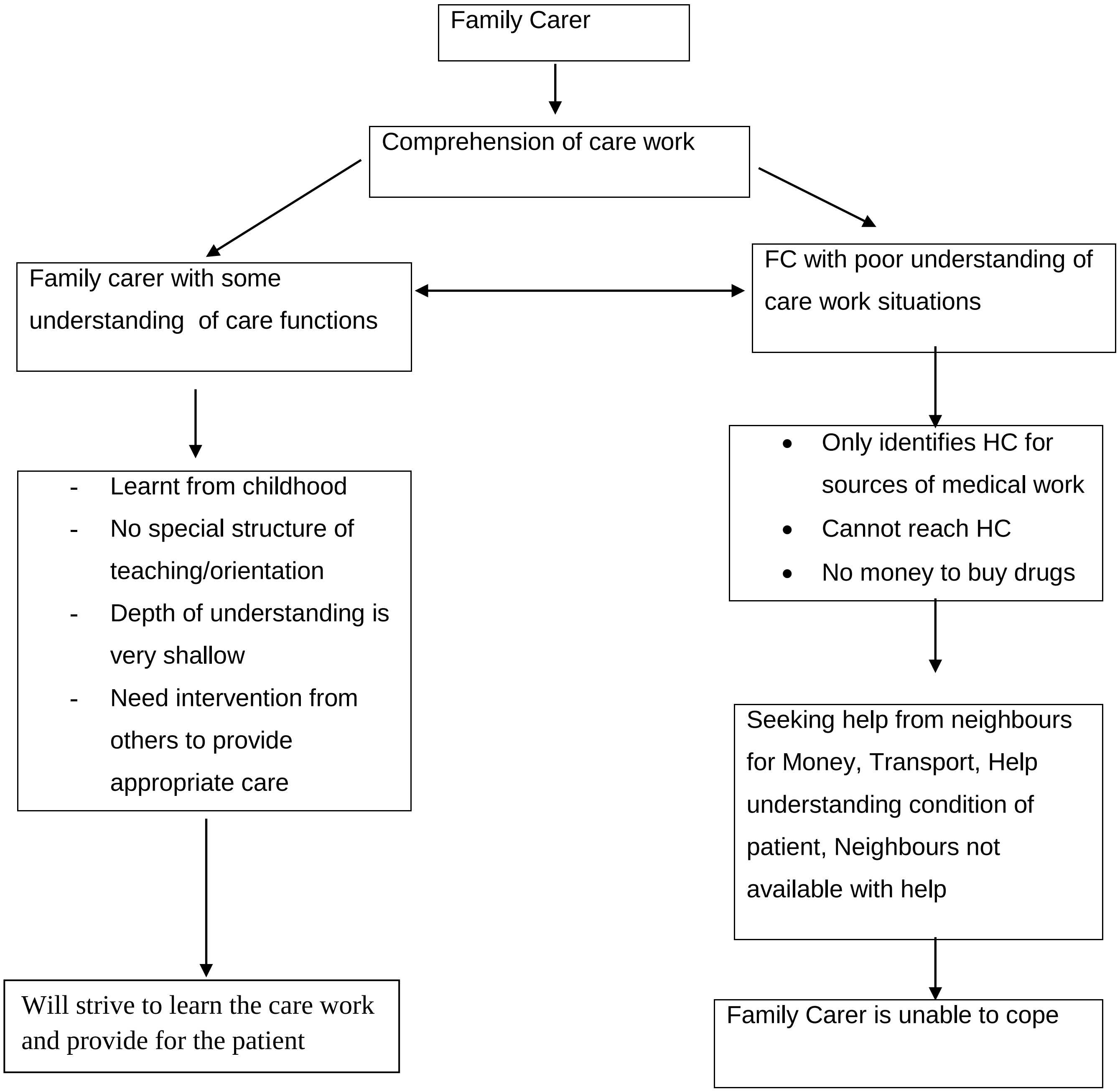


**Figure: 9.8 Hierarchy of coping by Family carers**

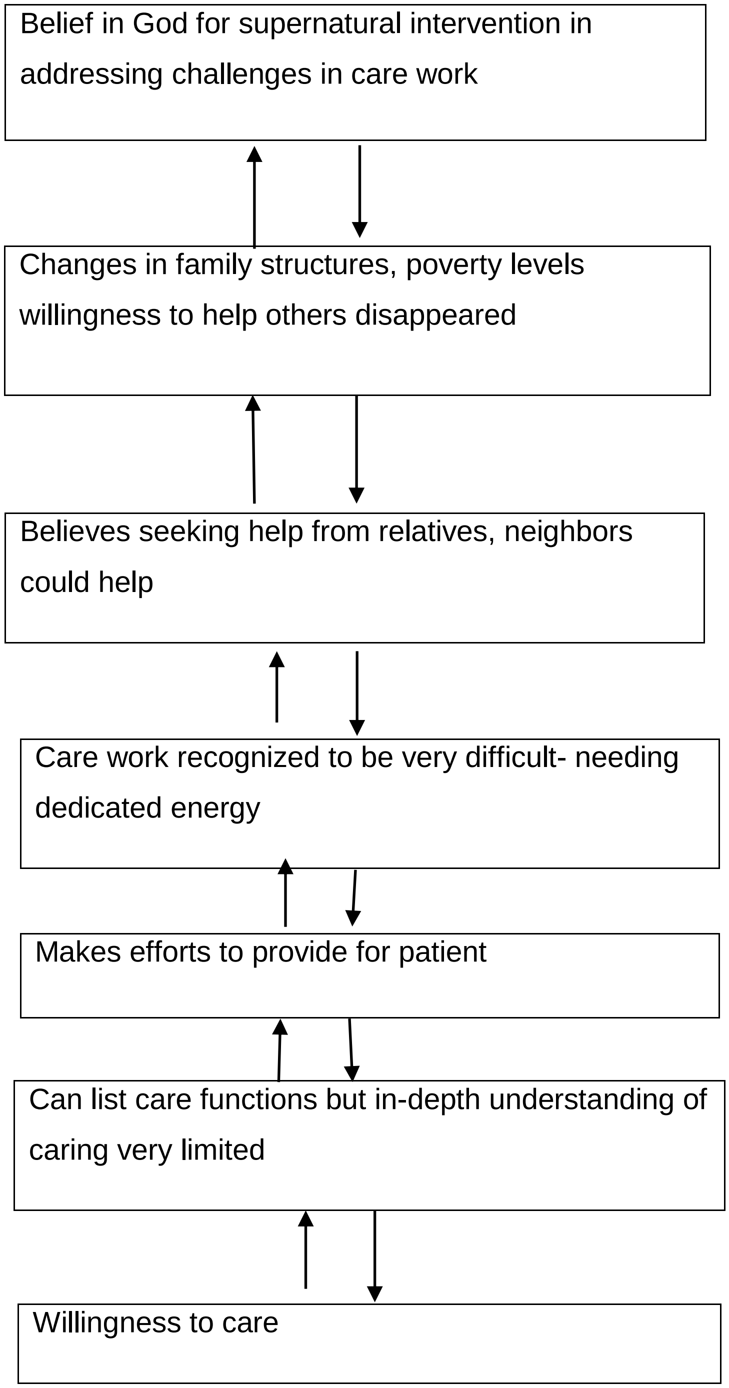
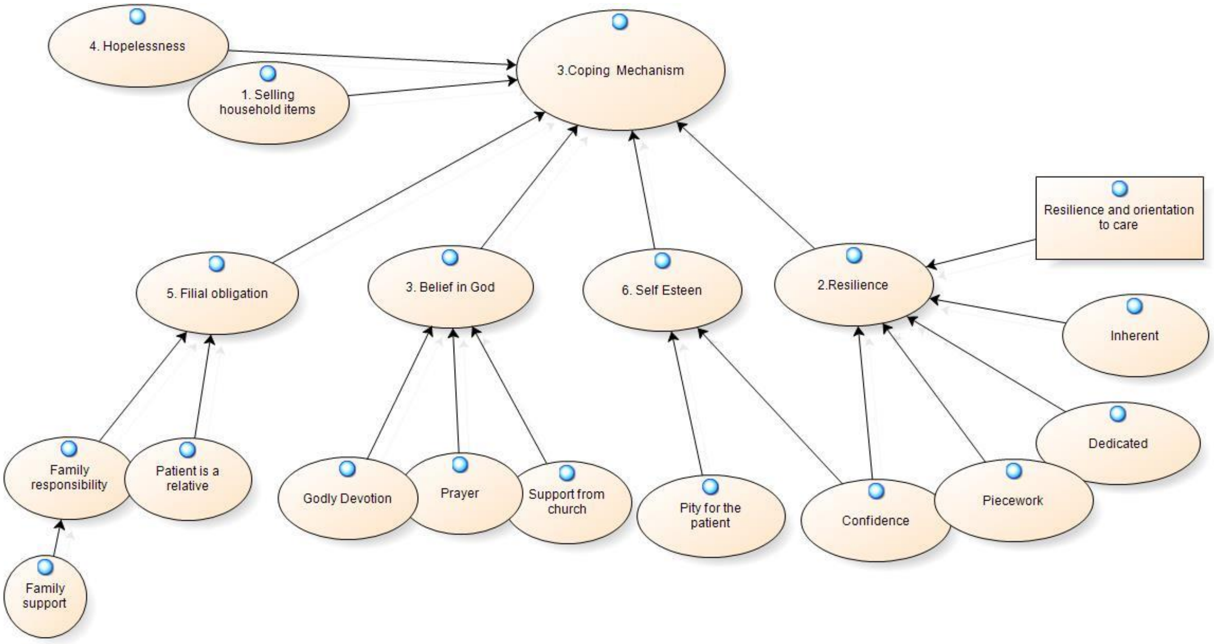


Figure 9.8 provides a visual conceptualization of what may be happening to the caregiver as they contemplate caring for the patient. The arrows show the different perceptions of the caregiver and decision making processes that could be at play at different levels of the hierarchy. Action taken based on the arrow upwards may denote the desire to do something positive. However, despite that desire, there may also be other negating factors that may result in negativity in the appraisal-action process.

The study demonstrated the existence of many factors within households and communities that have a bearing on HBC services. FC dealt with care challenges differently. This was mainly due to internal factors that govern an individual's interpretation of the life around their existence. Caring was a life event and as such its effects on the individual was varied. Interpretation of these life events were integral to the process of caring. This is demonstrated in the models. There are factors or individual skills which were the driving forces that made one either be able to comprehend, manage and/or display the emotional feelings associated with care situation.).

Nearly all participants did lack this skill where they did not understand the care demands and most needs of patient. However, despite the low levels of comprehensibility among FCs, they strived to manage caring needs. Models in Figures: 9.1, and 9.2 show the different coping situations and the variable that contribute to the levels of understanding GRR and facilitating FCs carry out their work.

**Figure 9.9: Model showing care attributes from research findings as described by family carers as those supporting coping mechanisms**



Source: Field data, 2010

Cowley and Billings (1999) reported communities displaying attributes of empathy as that is a cultural expectation to support one another. This finding was also consistent with the finding in this research where the desire to help others and not wanting to see others suffer were some attributes that were commonly mentioned by caregivers in their care and family situations.

**How Family carer's manage care challenges**

The behaviour of individuals also relate to the SOC factors that help one determine his/her abilities to cope with the challenging situation.  FCs find themselves having to deal and engage in different processes making them deal with challenges. As noted from the findings, most FCs were observed to remain as stated in "healthy status" (they did not complain of ill health unless those expressing fears of contracting the disease). The FCs were merely denying, minimizing or repressing the effects of a care challenge (Kasschau, 1995 p 333). FCs for example talk about "*praying to God", "seeking God's guidance", " asking God for help", "letting God take control of situation"(IDIs: 02, 08, 10, 13, 15)* as mechanisms they have used for coping with care challenges. However, they do not give clear explanation to what extent religion/spirituality worked to help them deal with unclear care situations, nor did they even understand how such belief helped them address challenging situations. Behaviour from the cultural point of view as discussed in the framework requires that there is transmission and receipt of symbolic communication as one interacts with the immediate surroundings. As people perceive, and is mostly differently every individual, as they will act (behaviour) based on their understanding of what the message is as appraised. Mazzotta and Myers (2008) observe that culture is the world of objects in which humans live. Caring is associated with special meaning that caregivers associate with their action(s) as they are trying to meet the needs of their patients. Caring which is an object in the lives of caregivers, takes on special meaning due to "when, why, and how they were placed in someone's life" Christopher, (2001 in Mazzotta and Myers, 2008 p.22). The ability to use one's consciousness has been associated with the betterment of understanding people, around us and our ability to react towards their actions (Hewitt, 1988). It is noted in this study that most caregivers talked about relatives "giving" them responsibility to take care roles. The caring roles were accepted even when they did not have any idea on the expectations and the means to do so. According to Meltzer, Petras and Reynolds (1978 p 45) these "were impulsive tendencies of an individual". We have noted in this study that most caregivers took on caring roles without due thought on associated caring consequences. The "I" being a key factor in the process, as caregivers had "self-conviction" that for example "being the mother", "the daughter" "a woman" provided the propulsion to do something for the patient in the household. While the "Me" (for example, "I have what it takes to provide care", "I have done this before" provides direction to what action to take (Leary and Tangney, 1978 (eds)

Therefore the individual's thinking- mind is set to view the challenging situation cognitively and appraise it, and take appropriate action. These are the internal factors as "we think about problems, we constantly assess our knowledge, ourselves and others, and we use language to communicate with one another (Kasschau, 1995).

In application of the salutogenic approach in care work, according to Goulding (2010) states that the main thrust of the approach was sensitive to a sense "Being, thinking, acting and the feeling of inner trust that things will be in order". It appears from the study that most FCs expressed in their narrations this strong belief that things will be in order. The GRR in Salutogenesis, originate from the biological, material and psychosocial factors that are a determinant of how an individual will view the world around them and make decisions to create an understanding of the world and subsequently structure their lives around that understanding. For example, Goulding (2010) views the GRR as money, social support, knowledge and tradition. Hence, we see an overlap between GRR and the “protective factors” identified in mental health. It is also believed that if people have such resources available, to them or in their immediate surrounding/ communities there are greater chances that they will deal with their challenges of life better. This was evidently missing in the study population. Most respondents in the study indicated that such factors like money, knowledge, social support, family  were not within reach, hence, their existence meant that, most FCs were having  difficulties to cope with meeting the needs to support care functions.

It was also noted in this research that there were extreme cases in the ages of those involved in caring one aged 12 and another 75 (narrated in FGD). A number of studies (Andersen, 2012; Ice et al., 2010; Chepngeno-Langat et al., 2010, Aldington, et al., 2010) have demonstrated how age of caregivers had become a subject for research. These extremes in caring roles are mostly due to the effects of HIV/AIDS, a pandemic that has left communities with more orphaned children to be cared for, or elderly parents have been left to take care of the sick (Klemz et al., 2010; Williams, Knodel and Lam, 2010; Cheng and Siankam 2009;) . This may contribute to the assertion among women that the experience gained in caring was from within the family life time experiences, as the act of caring especially for girls started long before their adult life. Examples were set on how to provide care, as most FCs learnt from other family members especially mothers who were perceived as role models in care work.  Hence without having any special teaching sessions, mothers socialized their children especially girls to take on such roles whenever someone was sick in the household. It was easier for family members to take on care work whenever someone was sick in the household and did not need to be asked to do so.

### Empowerment as a caring resource

Ability to provide care is an empowerment issue as for example, it relates to levels of care knowledge, levels of resources to support caring activities. There are basic requirements for one to fulfill that role. There are attributes in an individual like self-confidence, self-worth, self-esteem developing coping mechanisms on enhancing personal skills (Woodall, et al., 2010). These attributes were not evident in the FCs and this research did not see a revelation of such abilities. It is true that caring was taking place, but the views of FCs were of the feeling of inadequacy to comprehensively provide care as their understanding of how to manage care situations and understanding disease progression was limited. There was a general lack of choice in the matter as we have observed and they in most cases were not given opportunity to deny the responsibility nor, were they consulted on the matter of taking care of the “relative” the patient. In such situations, the “Self” became more pronounced and led to acceptance of the care responsibility without question. It was human to observe and converse within ourselves then respond in accordance with what would be expected of us as imagined (Burke, 1980). For example, Dixey, (2013)(ed) observe that empowerment fits with humanistic approaches during which people are assumed to be competent and capable of making changes in their own lives. That competence was gained through life experiences and not from being told what to do.

The general lack of structures to assist households to provide and manage the continuum of care in households was a factor that negated the almost “positive” contributions of FCs to the care of chronically ill patients. For example, as we observed in the study by Andershed and Ternestedt (2001). Relatives needed meaningful involvement in care work and they could only obtain knowledge to care from the social structures within the communities. This was a great fear expressed by FCs who did not understand how they were to execute their roles as caregivers in households. They viewed caring as unhappy situations as the effects of HIV/ AIDS had affected most families, where family structures were altered from the many deaths. There was constant fear of losing the patient under care as they had no support to manage the opportunistic infections, fears of losing other children from the HIV, and fears of getting infected with HIV. However, it should be noted in this study that, despite the social disadvantaged situation, all FCs continued with care work. They could not conceive of any suitable reasons to give up care work. Many factors both internal and external were affecting FCs who may not even appropriately interpret the intervening factors that could form part of the care environment and facilitate comprehensibility status. Findings from this study confirm that caring was dynamic and FCs described caring as consisting of different facets all having influence of the outcome of the care input. Resulting from this dynamism of care work, FCs could not give any reasons for giving up as they felt compelled to do something for the patient, hence, the desire to go on and on.

Antonovsky’s (1987) described SOC, as a unique relationship with how individuals manage life events. Individuals will make decisions and take actions based on the appraisal process and take action which they will consider appropriate to address the presenting circumstances. FCs work to provide care to their patients mainly because they are striving to do what was best for the patient and as they reported in the study, to find relief that will reduce suffering of their patient. This striving for achieving results was considered by FCs as a positive factor in the daily care encounters in households and needed to be encouraged. For example, Johnson (2004) also observed that a striving factor of self –esteem, though combined with factors such as love for the patient, desire to see the patient get better, filial obligations and responsibility, fear of reprisals from others contributed to a sense of meaning, engagement and purpose in one’s life. These were some factors that could facilitate the development of some sense of competence and self- pride in an individual, and propel the FC to continue providing for the patient. However, much as FCs wanted to meet the needs of the patients, they were in the majority of cases not able to do so.

It has been observed in this study that caring required an initial process of appraising the presenting care situation. The decision to take action and how the action will be taken was dependent on the understanding mentioned above. However, there were other factors that could have influenced the outcome of any action taken. In this study, it has been established by participants that FCs took on caring roles and responsibilities mainly due to family situations. The situations constitute changing family structures, where it was evidenced by changes in the key roles of family members who previously were available to provide support through the extended family system. However, resulting from the effects of HIV/AIDS on families, more and more households were taking care of their own immediate family members when sick. This kinship supports collective family values which are disturbed when changes occur in the family structures especially in the immediate and extended family.

Hence due to such developments in families( Taylor, 2006) the family situations and structure did not provide for any opportunity to decline or propose alternatives as to who was to provide care in the family (Lindsey, et al., 2003). Females and in some cases young girls found themselves taking in this caring role without any related preparations and some form of programme to empower them with knowledge and skills. There are specific roles for men and women in every household and the observation of those roles is heavily dependent of the male figure in the household. Men are considered the heads of the households and the family as a unit in the community. The roles vary within and between cultures and from a social group to the other. There are roles that are specific for men and are not expected to be performed by women, whereas the roles for women are also specific for women (Taylor, 2006). For example, Mweemba, (2014) observed that sons were trained to live up to roles that perpetuated their beliefs that they were the heads of households and that of breadwinners. Therefore, fathers would not sanction sons to participate in roles that were considered to be for women. Caring role has been known to be woman’s role and men would not be sanctioned to be found doing tasks that are a mandate for women like taking care of the sick.

This research has illuminated the important fact of empowerment to help FCs operate at household level. It is recognised that FCs' potential for improved self -efficacy and self- esteem, greater sense of control of care situations and challenges were issues needing to be addressed. FCs were faced with limited opportunities to increase their knowledge and awareness of related care information. The expected behaviour change with the new role as a caregiver towards care functions, in this case positive in nature could only be acquired when general broadened social networks and social support, were attainable for FCs, However, observations by South and Woodall (2010) indicate that when such social networks and social support were unattainable they contributed to unfavorable conditions that FCs found themselves in.

Consistent with other research findings, this research confirmed that caring to be a "natural" instinct for females (Akintola, 2004). This fact could be linked to the belief that women were carers and is perpetuated by the socialization process especially of female children (Mwewa et al., 2013; Thabethe 2011; Opiyo et al., 2008). The lower number of men participating as carers could be confirming what other social scientists have observed that there were fewer men actively involved as primary caregiver in the households. For example, it was argued by Esu-William, et al., (2006); Ogden et al., (2004); WHO (2005), that more women by "natural instinct" took on the care responsibilities than men. And that familiar support affected provision of long term care as it was considered a familial task and that this task was again mostly performed by women and young girls (UNAIDS, 2008).

FC's behaviour was further seen to be controlled by different social expectations. The need to conform to cultural dictates was another factor observed to be the driving force for FCs. Baron and Byrne (2006) wrote that the need to conform was one factor in behaviour that sometimes did not need to be explicitly written but can also be unwritten rules or social norms. They further wrote that individuals want to behave as others in the community. However, it can also be argued that, to take on a challenge and conform to a situation an individual needed to have a cognitive understanding that the task was clear, that they are knowledgeable, have resources to address the different facets of the need. Once the initial conceptualization of the situation was clear, the individual would be expected to then have an understanding that the responsibility was also clear (Baron and Byrne, 2006). These are roles of GRR themes in promoting SOC. The theme- gauges how one will perceive the external stimuli as encountered by caregivers who are constantly faced with different care situations. The FCs may view the situation according to Antonovsky (1987 p.17) as "ordered, consistent, structured and clear, rather than as noise, chaotic, disordered,  This behaviour can be termed as salutary, as the FC is viewing the situation from the ease-end and not as an encounter that will complicate their lives. During this interaction, the caregiver acted based on the perception of what they believed their role was in care work and what they believed others thought about their contribution to the health of the patient.

Knodel, et al., (2010) argued that the success in caring for chronically ill patients will heavily depend on how well informed, preparedness of family members in care of their loved ones. These family members were some support structures that would further require “long term and psychological support” Knodel, et al., (2010 p 20) also (Pirralgia, 2005; Kipp, et al., 2006; Esu-William, et al., 2006)

According to the study, specific programmes to help FCs in HBC roles were not a common feature in the Zambian situation. Only those funded by large NGOs were able to do so, but then the question of sustainability was always featuring in the discussions between different groups.

Thus, most FCs viewed caring for their sick relatives as an activity that they believed and consistently generated the desire to continue providing regardless of the situation they were in. Despite not having been consulted on their willingness to be involved nor having been trained or oriented to care work, they generally felt obliged “to be there” for their husband, mother, son, daughter and even daughter/mother-in-law. The conviction that the community expects them to do so appeared to be one of the driving forces to continue caring.

FCs were further convinced that their past experiences in taking care of patients in households as active participants or as general observers, was believed to have built the sense of confidence and empowered them to reciprocate when faced with similar situations. The feeling or strong belief that “one good turn deserves another” was one principle that made FCs go on providing care. In one Zambian language they say “mayo mpapa naine nkakupapa” meaning (you carry me today, one day I will also carry you).

### Self – Esteem to manage care work

Johnson (2004) observes that self-esteem, combined with other factors contribute to sense of meaning, engagement and purpose in one’s life.

These are some factors that may facilitate the development of some sense of competence and self-pride in an individual. However, there is no evidence that specific programmes had been designed to assist with actualizing the levels of comprehensibility in FCs. FCs haboured a strong belief that, they could do something for their patient. Their self - identity was being actualised through provision of care. The belief that is as observed from the findings is imbedded in the type of personality, for example; the way the caregiver feels about the condition of patient, feeling about the presenting situation requiring to be addressed and; the feeling of pity for the patient. And thereafter the factors associated with the genetic makeup of the FC and the social cultural interactions which determine how they view the presenting encounter (Benzl et al., 2014) and their ability to appraise and the resultant of the appraisal process and subsequently the emotional attachment to the anticipated results were some key factors that influenced provision of actions to be taken during the care process (Johnson, 2004)

### Filial obligation a reason to continue providing care

Family Carers viewed caring as an obligation in view of the relationship with the patient. The study showed a very strong sense of obligation and women were more obliged to and felt as their responsibility to provide care. This result was consistent with Chipimo et al., (2011). However there were instances when some caregivers could or couldn't think of not taking on the responsibility. They did not have the opportunity to shift the responsibility to other family members. Although observed by participants, this culture of filial obligation was being altered due to changes in the family structures. Extended family system is non- existent, economic hardship negates the desire to help other relatives nursing patients. Therefore, caregivers observed that the nuclear family was now more pronounced than before.

It was noted by Lowenstein and Daatland (2006) studies on filial obligations show some degree of consistent high involvement of families in care giving to older people and a modest input of care for weak older people.  However, Aboderin (2006) observed a decline in family support and her findings also suggest a decline in customary filial obligations norms. The declines, Aboderin (2006) suggests have been compounded by a decrease in resource capacity from economic strain, whilst Burgess and Campbell (2014) recognise and rising retaliation resulting from embitterment about the past behaviour of the patient/person in need of such help. Hence care and support in those circumstances may not be forthcoming.

Knodel et al., (2010) observed that filial support was driven by an externally constructed public ideology of caregiving and familism that wrongly portrayed family caregiving as a natural responsibility especially for women; hence the ideology was internalized and compelled women to provide care or eliciting social disapproval and feeling of guilt where they for some reason did not conform. For example according to Knodel, et al., (2010), parents recognise their obligation to ensure the well-being of their children. Whereas, Keller et al., (2005) argued that obedience and fear of sanctions was seen as predominant moral concern in unilateral child-parent relationships. They concluded that principle of fairness and principle of care were important aspects of morality in close relationships (Keller et al., 2005).

Aboderin (2006) argues that the religious, familial or economic authority and functions of the old people in the extended family system were major factors in ensuring that children conformed to their filial obligations regardless of the children's situation. The coming of modernization however, has led to individualism, secularization, weakening the traditional norms of filial obligation and consequently reducing the enforcing mechanism that may have existed against those who disobeyed (Aboderin, 2006), with education, urbanization and the development of new technologies resulting into an apparent erosion of the power of the parent to enforce filial obligations norms on the children. Participants in this study generally talked about filial obligation as one driving force for a sustained continuum of care to their patients. Scharlach et al., (2006) observed a feeling of happiness and joy as caring was viewed as an opportunity to help other family members. However, studies have shown that despite this strong sense of being there for their relative, other studies have shown a decline in the levels of filial obligations (Aboderin, 2006; Nodding, 1984). The ideology of filial obligation compelled women, as observed in this study, to internalize the concept and be the driving force in management of care situations.

A driving force that has been described by FCs as the main reason they will go on providing care despite their social and economic circumstances. Even when there were no written sanctions related to caring in families, those providing or expected to provide care to patients in household feared that they would be looked upon with scorn or feared eliciting social disapproval and feeling of guilt as they were seen as not conforming to the societal norms or expectations (Aboderin, 2006; Manthorpe, 2007). The study therefore did reveal this strong belief and was seen to be regulating the behaviour of Caregivers.

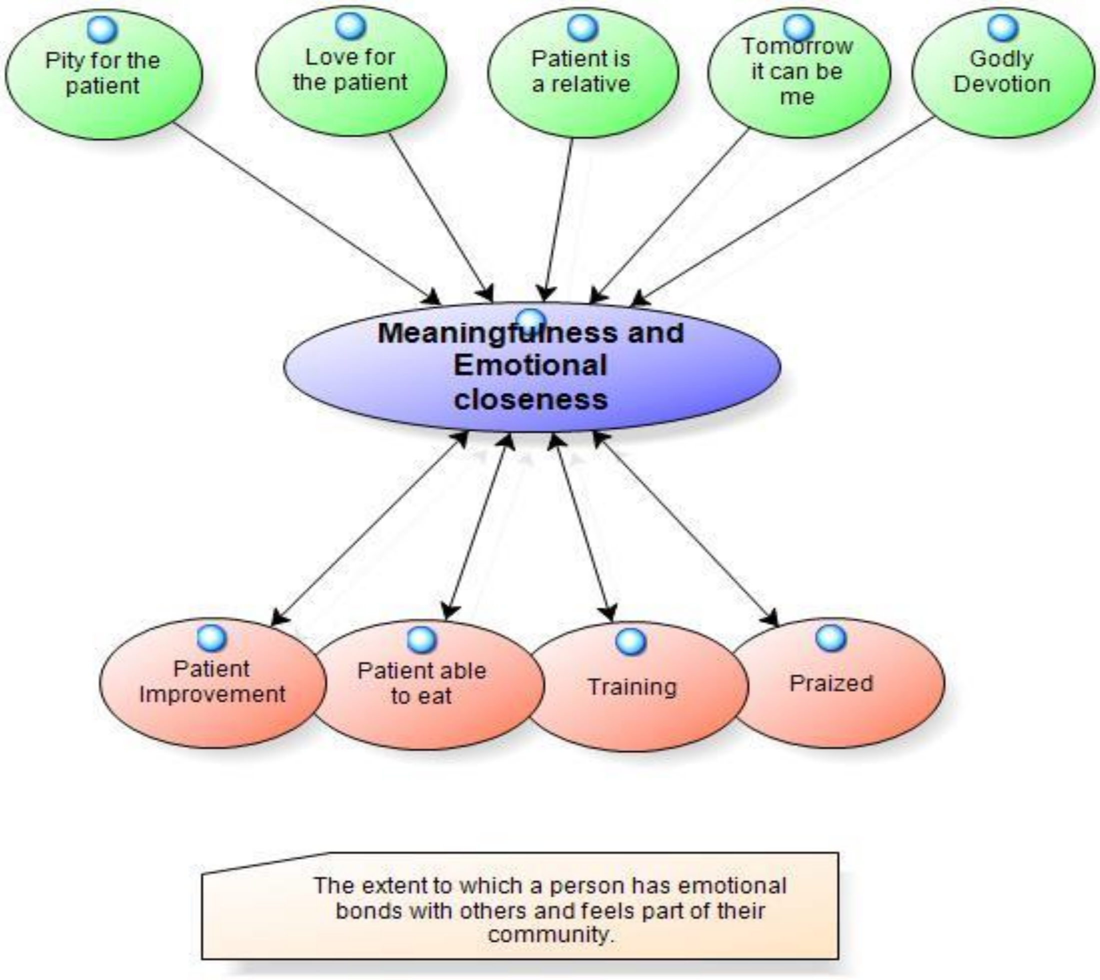
Caring according to Hilary Rose (1986 in Mitchell and Oakley 1992 p 169) , was seen to be a mixture of words and silence, favorite food, and drink, hard work in cleaning up wet or dirty beds, of special way of doing things, often tiring, but satisfying. As these were the feelings that you had taken care of someone who needed you, with all senses being involved, the person looked good, felt good, sounded good, smelled sweet and yet the pleasure did not just belong to the carer, it belonged also to the cared for. Participants in this study alluded to these outcomes of their input and invoked a sense of meaning of their actions that benefit the patient.

Caregivers spoke highly of the special attributes they possessed to manage care work. Consistent with other research, FCs felt that self-confidence, hard work, compassion, love, having a strong heart and that it was an “in born” quality were some of the attributes that encourage the FC to go on and cope with care work. There was the self-affirmation as caregivers, accepting situations as inevitable that made them feel like coping with care work. Using different language and expressions, they symbolically talked about their satisfaction in care work especially when there was positive response from their patient. Consistent with other research findings, was that caring for ill or disabled family members was seen as a responsibility fulfilling cultural norms (Scharlach et al., 2006). Caregivers felt proud of their work when others outside the household recognised their contribution to the health of the patient. Caregivers felt happy when they saw the patient’s health improving, was able to eat and take their medicines. These were some factors contributing to development of self-worth in the care scenario. In addition, other care givers who had been patients before were cared for by others hence they had lived experiences of what it meant to be cared for and its benefits.

### Meaningfulness in caring for the chronically ill:

Antonovsky, (1987) viewed this component as one that was closely connected to personal emotions. During the process of deciding on meaningfulness, an individual goes through mental interactive processes. In this process the individual will view the intended actions or choices as those that are worthy of the energy being to be exerted. The individual will rationalise their action(s) as making sense as observed by the FC and hence will not view the patient’s condition and related work as burdensome. For example, Antonovsky, (1987) says that this observation does not conclude that those high on meaningfulness could be viewed as happy when a loved one dies, but will seek meaning of the outcome of the event. This has been seen in the Zambian situations where comments like “let him go and rest”, “he has suffered for long” (anecdotal evidence) especially where a person who has been ill for a long time dies, he could be viewed as having had suffered for too long and needing to end the state of suffering. However, this may seem morbid and crude for any person who respects human life and existence.

**Figure 9.10: Model showing emotional factors related to coping with care work.**



Source: Field data, 2010

Caregivers expressed a great desire to continue caring for their sick because of their relations with the patients. They viewed caring as an obligatory action or a duty that needed to be carried out by someone in the family (Keller et al., 2005). There was a general empathetic recognition of their role in caring. The level of emotional factors associated with the desire to care and the associated reasons to carry out that role and the meaning attached to care are reflected in Figure 9.10. There was an evident strong belief that the associated factors were both internal and external.

The theme of meaningfulness is anchored in the belief that when one appraises a situation, challenging or otherwise, will take action based on what the results will mean to the individual. Meaningfulness therefore describes the result and of the thinking that action to be or being taken will make “sense emotionally” (Antonovsky, 1987 p. 18). Additionally, it is an orientation that may help address new challenges or demands posed to the caregiver as worthy to invest energy, commitment and engagement, and welcome the presenting challenges

Caregivers expressed the existence of strong bonds with their patients, which was attributed to the fact that the patient was a relative. For example in this study context “relative” is used when describing those close to the caregiver. Relatives were those patients who shared common family features like blood relations, brother, sister, parent, child, uncle, aunts and in others like in- laws. Caregivers felt a great need to care for their sick relative and that they could not imagine abandoning their relatives and felt motivated to do so.

It was a general feeling of caregiver that, their input in care of the patient provided meaning to the health and wellbeing of the patient. This was noticed when caregivers felt happy to see the patient eating, showing signs of recovery and feeling of being praised Figure 9.10. The study by Lindsey et al., (2003), one of their findings in a study in Botswana related to HIV/AIDS, their participants said “it is my daughter, I love her. “I cannot wear gloves- wearing gloves would be like putting a barrier as if I don’t love her” p 495. This was in a situation where even when there were fears of contracting HIV, they still felt the instinct of close relations negating the- would- be reasons to behave differently as the action maybe be misconstrued to mean the opposite.

As noted from this study, participants mostly welcomed the care situation and generally did not view care work as a burden in that sense, but accepted the role because they were the only ones available or expected to provide that care. Esu-William et al.,( 2006) in their study findings on Involving youths in HIV/AIDS caregiving in rural Zambia, showed that despite evidence that caring for the chronically ill did have greater challenges, in another description they thought it has to be done by someone. The final result in this encounter was to ensure the caregiver’s input into care was for the purpose of providing meaning especially to the patient.

Caregivers felt emotionally attached to provide care despite having poor cognition of the patient’s problems and own skills. Others were attached to caring after having had experiences observing care provision in their homes or active participation in providing care. With such experiences they, slowly with time did built self-confidence and self-esteem which helped caregivers cope with carer work. It was the development of such attributes in caregivers’ disposition that enable them to ‘quietly’ continue providing care. The feeling or expression of satisfaction by the patient was one motivation factor.

### Study Limitations

The salutogenic model was being applied in research in Zambia and the region for the first time. The salutogenic model has been used a lot more in research in the Scandinavian countries and gained more recognition as a health promotion concept. Due to lack of related studies using the model in and Africa, comparison of results with other studies were not possible. There may be cultural issues that may create differences in the way the model can be applied to research. Further, there was no literature from SSA to facilitate further understanding of how results from such studies would provide explanation of the phenomenon under study. Because the study was to adapt the salutogenic model, the construct of interview guides, was based on Antonovsky's GRR and sense of coherence (SOC) scale (SOC 29-scale and SOC-QOL13-Scale).

Interview guides for both IDIs and FGDs elicited similar questions in terms of the content of understanding and description of what went on during care situations. However, questions for KIs although somewhat different, they too focused on their understanding of FCs' experiences of care work and also how they described coping mechanisms adopted by FCs. Future studies should consider using SOC.

Zambia has 73 languages with seven being officially used. I speak three of the official local languages. I was able to conduct interviews, translate scripts and verify participants' responses. Future studies of similar nature should be undertaken in areas where languages originate as the Lusaka environment may create a mix of certain expressions.

A few participants had received some form of support in their care work and therefore, were in advantageous situation in describing their care experiences. Hence future studies should consider economic status of participants and the literacy levels to compare responses in terms of preparedness and actual strength or weaknesses in care provision in households.

The study sample included one man as a primary caregiver. However, those who participated in FGDs were those considered as CHW/ FCs and were volunteers who visited households with chronically ill patients and were linked to FBOs and CBOs.

### Conclusion

In conclusion, in this chapter, I was able to discuss the results in the context of SOC and GRR. I used symbolic interactionism to describe the behaviour of caregivers and how they perceived their "fit" in the whole process of caring. I also tried to provide visual presentation of the different models of coping, factors associated with coping and the different pathways of dealing with care work. In the next chapter, I will give my conclusions derived from the study, and make recommendations for future activities or programmes related to HBC in Zambia.

I found the use of the salutogenic model and SI to have provided a clear understanding of describing and reconstructing the environment within which care for chronically ill family members was provided. The salutogenic theory allowed for an easy compartmentalisation of what constituted caring in households. The three components of GRR facilitated the understanding of unique association of comprehensibility, manageability and meaningfulness to the way caregivers carry out care work. The theories were able to mirror the different mental state of caregivers when describing their lived interactions and experiences in the care world. The theories further provided for an opportunity for considering how the self-assessment by caregivers explained their “Fit” in caring for their sick relatives. Through the adaptation of the theories, it was easier to reveal the mental state of caregivers. I agree with other findings that SOC was a coping resource which facilitated the reflection of calmness, self- trust, and improved quality of life and as a resource for health promotion (e.g. Johnson 2004; Eriksson and Lindström, 2007) that adequately and conclusively described the care world of HBC in the Zambian context.

## CHAPTER TEN: Conclusion and Recommendations

### Introduction

This chapter outlines conclusions and limitations of the study which had set out to investigate how Caregivers in HBC programme in Zambia used their mental capacities to devise coping mechanisms in care work. Recommendations derived from the reconstructed daily events and in the life of caregivers will be outlined. The research further tried to describe the conditions and situations within which HBC was being provided in households. The study adapted Antonovsky's salutogenic model to describe and reconstruct the caregivers' care environment and how they were coping or not coping with care work. This research has succeeded in adding new knowledge to literature on coping more especially in resource poor environment. The study has adapted the salutogenic model to understand coping mechanism during the care of chronically ill patients with HIV/AIDS.

### Conclusion derived from the study

Results of this study support findings of other studies conducted in the region and other developing countries carried out to understand coping of caregivers at household level.

The limited gender participation in the study is recognised in terms of men as carers at household level in HBC services, especially that only one man participated as a caregiver whilst the rest were women of different age groups.

The study provided the opportunity for caregivers to conduct a self-evaluation of their role in caregiving. The salutogenic model helped highlight the different processes involved in caring and compartmentalized caring into GRR as postulated by Antonovsky, (1979,1987).

In addition, this study revealed that study participants found care work stressful, within a non-supportive environment, however, the study did not investigate the extent of the stress and how it affected their lives in general. Caregivers felt inadequate as they could do nothing for the patient as they did not possess knowledge, skills and power to perform. Other studies have also shown that there were differences in how men and women viewed stress, and therefore the choices in coping would also differ (Eaton and Bradley, 2008). Study reports on care related to HIV/AIDS in the households show that care work disproportionally falls mostly on women and girls (Guyer, 2008; Morwe, Klu and Tugli, 2013; Isaacs, Mundeta and Masunda, 2010; Opiyo et al., 2008; Akintola, 2004b, 2006). With UNAIDS (2008) observing that studies in most Southern African countries show that two thirds of those providing primary care in the household were women and that one quarter of these were over the age of 60. Men were mostly volunteers in HBC programmes (UNAIDS, 2008).

A study in Zambia (Esu-Williams et al., 2004) observed that youth participating in the study did challenge the female-based caring roles, which they felt could comfortably be carried out by males. This could be an area for further exploration.

Furthermore FCs talked about having greater difficulties in coping especially where the economic status was perceived by the participants as low. And they were all not able to meet the needs of the patients even when the desire to do so was greater than imagined by caregivers. Only one participant was in gainful employment and she was able to bring into her home her daughter –in law who was HIV positive whilst she (the caregiver) too was positive. It was her view that being in employment could help facilitate provision of different patient needs since one had means to do so. It is my observation from the research findings that, FCs continued to experience different levels of care related challenges, difficulties and sometimes emotionally gratifying moments.

The majority of participants sustained their “resources base” through unstructured means. The study did not venture into ascertaining and describing the income levels to understand the economic situations of the majority households. Nevertheless, anecdotal information indicates that caregivers, nursing close family relatives and who are in employment do experience similar challenges as those in the sample. Although challenges may not be economically based, it is the case that they have to juggle time between work to raise funds to support the family and time to provide care to the patient. However, it was not the objective of the study to compare the effects of caregiving between groups with different socio-economic status and conditions. There was anecdotal evidence from my experience and other members of the community close to me having experienced similar care burden during caring of chronically ill family members. These revealed different experiences in caring for their loved ones, for example, two of these were nurses, and had in their households chronically ill patients. Despite their professional background they had experienced severe drawbacks in meeting the needs of the patient and caring also proved to be burdensome. There is need for future research to establish how groups of different social standing compare in relation to understand their coping mechanisms.

The two groups as revealed from the study did not have any structured orientation to continuity of care work in the household. But they were expected to carry out skills that would enhance better health for the patient. For example Feldt et al., (2005) recognised that studies showing relationships between high parental socioeconomic status and the level of SOC in a child's later life remain very few. It would be important for future studies to include questions on how socioeconomic status affects coping mechanisms.

This research further makes a serious observation that studies applying the concept of Salutogenesis in the SSA were scarce and therefore, the findings of this study do not have any related studies in this field to compare with what has happened elsewhere in the region to accurately understand how HBC in other countries has been managed at household level. However, it is important to note that studies in the region to understand coping mechanisms are available and show consistency with findings in this study. More research in the region would be required to understand the application of Salutogenesis in care work and how that affects coping and at the same time to add to what this research has contributed. Finally, Zambia has 7 official languages including English. The ability of the participants to express themselves when giving information seemed to be difficult for some of them. There were cultural factors that especially women were socialized to uphold, therefore could not say any negative experiences or even say "no" to giving care to family members.

Antonovsky designed SOC scales to measure levels of SOC which are: SOC-29 and QOL: SOC-13 scales. However this study could not use them as levels of coping were not being measured in the study. However, the tools were used during the construct of the study instruments. The SOC scales guided the identification of parameters in feelings and emotions of FCs to be asked during interviews

The study revealed the fact that in most care situations described in this research, the health care system may have assumed that families did possess cognitive attributes in caring and had the competences to adequately provide the continuum of care to their patients. This seemingly could be seen as some form of "perceived or perceptive blindness" on the part of the health care system on how households could participate in caring for patients. As noted earlier, patients were being discharged early from hospitals to be cared for in homes. Much as available literature does recognise the positive contribution of home care to general management of chronically ill AIDS patients, it is in my opinion and conclusion that the related actions to HBC services did not take a number of issues in care work or the context into consideration before making HBC as a strategy to encourage home care. We have learnt from this study of the existing hostile environment within which CHBC was being provided. Only a few lucky ones that have access to NGOs, FBOs are accessing some form of support though this is very limited or non-existing especially for primary caregivers. Most of those providing care in households did not receive training or support to facilitate involvement in care responsibilities (Campbell and Foulis, 2004). Caregivers were left on their own by the health care system with the task of constructing the care reality when faced with challenging care situations needing their intervention. The health system has left much of the contextualizing of care in households to FCs.

### Understanding the application of GRR in care work

This study did highlight a gap in comprehensibility as a resource that enables FCs to cognitively understand their caring role. Caring as noted earlier is both instrumental and emotional (du Preez, 2010). Caring evokes some emotional feelings and hence will require some form of preparation, or awareness creation by health care system to facilitate building of confidence and empowerment in the caregiver on information on how to deal with care situation. Although the study revealed an existence of some degree of comprehensibility among FCs, it was conclusively viewed as a disorganized process of identifying important components related to GRR that made it possible for caregiver to understand care work, and this was dependent on caregivers' situations and conditions. Those caregivers, who had been previously involved in caring for other family members, did describe their caring roles as less stressful. They were certain of the care environment and believed they could make sense of situation confronting them. They felt mentally stable, and did not view care situation as very challenging (Langeland, et al., 2007). Caregivers felt that their self-identity was being heightened, as they perceived that members of the communities appreciated their efforts in caring for others within the family (Burke, 1980; Antonovsky, 1991; Stryker, 1987).

However, due to limited information shared by the health workers and inadequate preparation for care work, caregivers did not fully understand what was expected of them and as a result they were providing care "in the dark". They did not have the appropriate knowledge and insight of what was happening to their patient, thereby denying them the opportunity to make appropriate choices in terms of care actions. Caring comes from understanding what it means to an individual and norms and values attached to what constitute caring. Most caregivers did not have this attribute. Further, the environment did not make available the necessary tools to manage care work for one to live up to the norms and values attached to patient care and finally the caregivers, though they had strong sense of value for the people being cared for and needed to provide more, they were incapacitated due to lack of proper and adequate preparation for care work of such magnitude.

Resulting from the paucity of information from the health workers, caregivers resorted to look into their family circles, to source for related care information that may have been learnt and experienced over a period of time especially on how to deal with hardships (Kloosterhouse and Ames, 2002). Unfortunately, families were also not there to provide that information.

### Comprehensibility in caring for chronically ill patients

Accordingly, Antonovsky (1987) had concluded that the component of comprehensibility in SOC required a cognitive approach to care situations, one of which involves the element of preparedness of caregivers to the caring roles. The type of key care messages shared with caregivers was therefore important.

Preparedness at the start of caring roles was one factor in influencing the future burden of care in households. We have learnt from this research that most FCs did not choose to become carers as they had no choice or control on whom and how the patient was to be cared for. Others had to relocate to where the patient was residing, or the patient was brought to them. Using Antonovsky's ideas (1987), the ability of FCs viewing care work as 'ordered' was mostly resulting from their previous experiences in caring for such patients in the families., For most of caregivers, when such caring encounters were experienced, they had fewer complaints about what they were experiencing as they tried to find ways of dealing with the situation. When such encounters come as a surprise, one who is strong on Comprehensibility will "not" complain about the encounter but will always find ways of dealing with it as it will be "orderable and explicable" (Antonovsky, 1987). Caregivers, we have learnt in this study, were at various levels of responses to care encounters in terms of comprehensibility. For example, the male participants (IDI: 5) was caring for his brother as a "forced" responsibility by his relations, who did not consider his levels of preparedness to care and levels of knowledge and skills essential for providing care. In this case comprehensibility was low though he did accept to take care.

In other situations, like caregivers in IDIs 04 and 09 had previous experiences providing care to close relatives. Therefore, most of the care demands did not come as surprises and what they were going through was "known" and "lived" experiences.

When a patient is admitted to hospital, it is part of care plan to initiate the process of preparing relatives and the patient for possible discharge depending on the condition. However, there appears not to have any systematic approach to the realization of this need by the professionals in the hospital to help carers (Nolan and Grant, 1992b; Stewart, et al., 1993).

### Manageability in caring for chronically ill patients

To some extent, one could say that caregivers were able to recognise the importance of managing their patients. Caring requires that one understands both what is expected and the tools required in order to provide comprehensive care. This ability to manage a care situation relates to manageability, a second component in GRR. This attribute was found to be very weak amongst the majority of caregivers. Caregivers experienced difficulties to examine whether they possessed their own resources to deal with and strive to towards managing care situation whether complicated or not. Their mental states though stable helped them to assess situations and make decisions as to manage or not manage caring. However, despite such assessments, the majority felt it was their responsibility to provide care though they did not have the means and ability to do so, and they had rather heavy expectations from the family, friends, and communities to provide support (Airhihenbuwa and Webster, 2004; Serpe, 1987). The research revealed that not many caregivers did receive support from those they expected would provide it. However, caregivers had this strong belief that they were “strong enough” to go on and on providing care. The appraisal process of situations and making decisions took predominant position within the environment of the majority of FCs. The decisions included either the process of minimizing, avoiding, tolerating or just accepting the situation (Lazarus and Folkman, 1984). The study therefore revealed that FC’s position was compromised as most of them said “what can I do”, “ patient is my child”, “I can’t neglect the patient”, “ I should do something for the patient”, God demands me to do something” “ there is no one else to help me”. These related self-efficacy elements were some factors that made the caregivers continue with care work. As Clark (1995) had suggested, carers were always seen to be striving to redefine their domestic situations as normal in order to allow life to continue. This notion was also shared by participants in my research who strived to continue caring for their patients even when the care situations were challenging both in terms of having knowledge to provide appropriate care and providing necessary food or carrying out care tasks. Nolan (1996) also observed that parents were known to adopt varied and changing strategies to prepare the way for the inevitable like seeking help, or transfer of responsibilities.

### Meaningfulness in caring for chronically ill patients

The third component was meaningfulness, which according to Antonovsky, (1987), is viewed as a component closely associated with personal emotions. During which, through mental interactive processes, an individual will view the intended actions or choices as those that are valued to be worthy of the energy being or to be exerted. Firstly, that those choices or actions made more sense and that should not be viewed as burdensome but accepted as they happened. Secondly, the patient who may have been oblivious to what was going on may have suffered long enough and death for example would be a welcome event. However there were also positive experiences among caregivers, who felt that providing care, resulting in better health of the patient was one motivating factor. It boosted their feelings that their efforts made sense for the patient and the need to do more became more pronounced in their actions. They galvanized their own and other external resources from outside their households to facilitate addressing the needs of their patients. This feeling gave them the strength to go on because their input into care made sense and was worth the investment. This gave and built in them the resilient factor to do more. Despite the lack of key resources to meet most needs of the patient, just the fact that they were the ones in charge of the care made more sense and made them emotionally stable. In conclusion the study did find differences in the way they devised coping mechanisms, as they did cope in some situations but experienced difficulties in others.

## Recommendations

The study has revealed findings that provide for inclusion in the recommendations for the government to address and strengthen HBC programmes with a notion that HBC was the major strategy in continuum of care for chronically ill patients with AIDS.

These recommendations are centered mostly on policy, service provision, capacity building and social support. However, in view of the fact that the Zambian government was already aware of HBC services for patients with HIV/AIDS and have put in place some policy statements and guidelines, It was imperative that the government goes further to review the current HBC programme and services and address those measure that would in a way provide for minimal support to households with HIV/AIDS patients.

The evidence based study findings support the need for strengthening the enabling environment within which HBC services through a social welfare cash transfers (through grants to vulnerable households), health care strategy can be provided. The MCDMC should urgently complete drafting CHBC policy, draft and approve the implementation guidelines for all partners. The ministry to further disseminate the Minimum standards for CHBC and through a consultative forum, constitute CHBC Coordinating Committees at all levels of health care. Through HCs, establish a system of accountability for all providing CHBC and for each community have ways of registering those who are HIV positive and are on ART. Increase support HBC Kits to benefit all household with AIDS patients and registered with the HC.

**Comprehensibility**

This study recognises the fact that FCs expressed concern in the non-supportive nature of the interactions and linkages between their work in households, health facilities, health care workers, families and households with chronically ill patients with HIV/AIDS. Whenever a patient is admitted, family members should form part of the care team and be informed of the care plan from the early stage of hospitalisation. Health care workers have provided limited insight to family members of the medical issues affecting their sick relatives and how they were to be cared for at home. Health care workers have not provided a supportive environment to enhance care on the patients when discharged from the hospitals. The need for FCs to understand their caring roles and functions should form part of the nursing care discharge plans for any patient admitted into hospital. It is recommended in this research that any information that will benefit the FC to actualize continuum of care should form part of the nursing care process and should be emphasized when preparing for the patient discharge. Therefore, relatives should be provided with information relating to:

- Nutrition and what foods to be encouraged for a patient with HIV/AIDS and the importance of boosting the immune system.
- Simple nursing care activities like general hygiene, infection preventions, counseling, and education on reduction of HIV and social stigma, as a way of addressing isolation and creating a conducive environment for households with AIDS patient and encourage disclosure and uptake of ARVs.
- The government should consider including caregivers in households as beneficiaries of community based educational activities that are being implemented and funded.

Programmes on care and coping mechanisms should be accessible to all, as they not only provide caregivers with critical information on care practices and coping strategies, but they also help caregivers give their patients the best care. The research findings show a major gap in the strategy to support HBC services. This means that, a review of the national HBC guidelines and training materials be conducted to include aspects of coping mechanisms and other related factors like community support mechanism and networks for community based care activities.

Family carers observed that training activities related to HBC was mostly planned for, and targeted others, like volunteer caregivers and not family carers. These were mostly coordinated by HBC organisation and those trained were expected to go back in communities and train family carers. This follow up trainings did not happen mostly due to financial difficulties and no proper mechanism to ensure follow-up training took place. Government should monitor and support local NGOs, FBOs to integrate training and education of FCs in their programmes. There should be an established system to support FCs experiencing psychological, physical and social difficulties facing caregivers:

- When nursing loved ones with little understanding of what they need to do for the patient in relation to meeting the emotional needs
- Where family structures that previously had provided for respite no longer existed, adding on the burden and strain of care on the caregiver.
- When they have knowledge that the disease was incurable and that their loved ones would eventually die from the disease and when they have fears of contracting the disease as there were no facilities to support infection prevention.

Given the findings of this study, there would be need to support further research and policy debates on coping strategies in HBC of FCs and the role of the government and other stakeholders in the provision of care to the chronically ill.

**Manageability**

There has been an observed change in the needs of people living with HIV/AIDS. This change can be attributed to improved health care systems, especially with the availability and of accessibility to ARVs. More patients are living longer, and with a shift from extensive nursing care and end of life care to a situation where there is wider range of support needs in households to care for chronically ill patients living longer (Mwewa et al., 2013). They further observed in their study in Zambia that the major need for people living with HIV/AIDS was “ensuring access to sufficient food and maintain a healthy diet” (Mwewa et al 2013 p 5). This study revealed an extensive need for support in all households sampled in the study as they were barely managing to meet the basic needs of their sick. It is therefore imperative that the Zambian government extends the Cash transfer policy meant for widows, orphans and other vulnerable individuals to include households with chronically ill patients. The Ministry of Community Development, Mother and Child Health should take the leading role in ensuring the policy is revised to include support for HBC services.

Literature has showed that most HBC programmes are driven by NGOs especially FBOs. These organisations have made tremendous effort to coordinate HBC activities. The coordination is stronger at the national level than at the community. It is therefore recommended in this study, that the government of Zambia take the leadership role in coordinating and harmonizing HBC programmes as Mwewa et al., (2013) also observed. However, it has to be noted that some strides have been taken by the government through the MOH and NAC to develop guidelines that were to guide all organisations with the intention of providing or supporting HBC programmes. The implementation of guidelines will need to carefully coordinated as research in Zambia and high level discussions with key informants has revealed that despite having a political will to address HBC related service issues through the development of training guidelines and specifically having policy statement in the Ministry of Community Development Mother and Child (MCDMC) MOH and NAC Strategic documents, this is not matched with implementation and monitoring plans. More research on coping in Zambia should be conducted and use the qualitative approach to describe the environment within which HBC was being provided and compare coping mechanism between urban and rural and across socioeconomic factors.

The study highlighted the kind of interventions associated with programmes and initiatives supported by NGO, FBO and MCDMC and MOH. Further, there is need to ascertain the differences existing when coping with care of children compared with adults with HIV/AIDS. This study recognises the effort being made by the government of Zambia through the policy pronouncement by ensuring that HBC has included strategies to support care for HIV/AIDS patients in the fight against the HIV/AIDS epidemic. However, the budgetary allocations have fallen short of what should specifically support HBC programmes. It is therefore recommended that with the re-alignment of the MOH and MCDMC, the government should ensure strengthening of partnership with other organisations especially NGO, FBO supporting HBC initiatives and ensure that support to households and that a framework to monitor HBC activities was more meaningful.

The research findings that nearly all FCs were not managing with resources to meet the many needs of the patients, let alone the ability to identify sources of support. This therefore requires that deliberate efforts to create an environment that support the introduction of community networks, like caregivers' support groups to benefit households with chronically ill patients.

Some of the activities to include for example, Income generating activities, to build entrepreneurship skills for caregivers through community organisations

There should be deliberate programmes aimed at empowering caregivers and encourage self-reliance which would also contribute to building of their self-esteem. It was therefore the self-esteem factors that contributed to the affirmation of the SOC as it had more influence in building the self-worth (as observed by Stet and Burke ,2003) an attribute that the study observed in most caregivers. This attribute therefore was one major factor in promoting health as described by Barry (2009) that cognitive and emotional resources such as self-esteem, identity, self-efficacy and resilience that enhance abilities to cope.

### Manageability and Meaningfulness

Findings strongly indicated poverty as being one of the major challenges faced by family carers during care work. Accordingly, most of the FCs are failing to provide for their patients due to economic reasons. There was a strong desire to go on providing for their patients was illuminated by the meaning caregivers found in caring for their sick relatives.

This forced the FCs to engage themselves in activities (such as stone crushing, piece work, and selling merchandise at markets or streets) that enable them to supplement the physical needs of the patients and their households. The FCs, more often faced challenges in terms of finding food for their patients. Thus, the patients are not provided with adequate food and proper nutrition a requirement for balanced diet. Family carers showed inclination towards religion as one factor providing them with reason to go on and generate energy to care. However, their need for social and psychological support to enhance their physical and emotional wellbeing, were never satisfactorily met. As they went through providing care work without salutogenic factors that would promote coping. The need for such support mechanisms within the community was evidently a much required need by all FCs in the study.

The study participants made an earnest request for the government to look into their commitment and help them do this work especially that girls and women were taking on the major task of caring. They requested for some income generating activities which most of them talked about domestic business of selling food staffs. However they said that government should help them by providing food for the patients.

## Conclusion

In conclusion, I would like to confirm that I was able in this chapter to provide information that supports the key findings that framed the basis for the recommendations, and the various experiences during the process of the entire research. One other limitation of the study was the fact that, the study instruments specifically enlisted information on coping mechanisms and did not extensively probe the discussions of spirituality and how that was a key factor in the coping process. Though however, a number of respondents did without being asked reveal their belief in how spirituality was a factor that helped them cope better with daily care events. Data to show how religion and spirituality was viewed by FCs is visually reflected in the models and pathways and does show how FCs symbolically the "I" in the FCs ascribed to their identity in caring for their patients and their ability to cope with care work through the perceived established relationship with God and mostly religion and spirituality.

For example Nolan et al., (1996) discussed keys to understanding coping and find out the influence of beliefs, values and culturally determined factors, and variables such as age, gender and socioeconomic groupings be exposed to further exploration, and determine the role they play in influence coping processes. More especially those caregivers in the study were women and girls aged between 12 and 65 years old. Studies have also shown that women carers could be older as evidenced in the studies carried out by Manthorpe (2007; Chepngeno-Langat, 2009; Ice, et al., 2009 and Knodel et al., 2010).

This study has successfully adapted the Antonovsky's Salutogenic model to socially construct the care environment in HBC. The model assisted in understanding coping mechanisms devised by caregivers. Also important to note are the facts that in adapting the salutogenic model, a critical understanding of the following was important:

- The role that self-esteem had played in the caregivers over the many years of care work.
- The way filial obligation and reciprocity influenced the decisions made by caregivers in the level and intensity of the input into care
- Life-time experiences and the various social and psychological factors that had influence during the socialization process
- Social structures both within and outside the family that had the greater bearing on the social status of the household with a chronically ill patient and how such structures affected the abilities of caregivers to cope or not cope with care challenges

The theoretical framework used to understand coping mechanisms of caregivers in this study, did provide the research and the subsequently the reader on the different levels of actualizing care and coping with caring for the chronically ill. The themes guided and highlighted the stages of understanding the phenomenon that was not clear in describing the major components of care management in households. Caregivers in the households were mentally conditioned to the caring role that they had undertaken. Although the majority could have been complaining of the stressful nature of taking care of the chronically ill, there were also times that they had fears of contracting the disease. They did not stop providing care even when they were convinced that they did not have adequate knowledge to understand emotional, physical and psychological needs of the patient

The study allowed participants to make their own assessment of their input to caring for HIV/AIDS patients. Their roles were examined to understand their individual social creation of the care world and use that to understand the strategies devised to cope with care work. The works of FCs in relation to the salutary beliefs as postulated by Antonovsky, (1997), does not show the disease end of the health - dis-ease continuum. Despite there being no deliberate intention to measure the effects of caring, the majority of FCs did not view caring as stressful, but did associate the effects of stress to poor health/disease related outcomes. However, due to the nature of the focus of the study in relation to the subject of HIV/AIDS, participants expressed fears of contracting the disease. The fears were mainly associated with lack of protective clothing especially when dealing with body fluids or during care encounters like bathing, changing soiled linen, disposals or dealing with excreta. Sometimes they have expressed fears of carrying out conjugal obligations or requirements especially when the spouse made demands for such.

Family Carers continued to make daily efforts to cope with stress related to caring. According to Antonovsky, (1999), social support was cardinal in the coping process needing different resistance resources to manage situations. These factors could also include SOC which enables one to be able to select a mode of how to cope with the situation.

Understanding sources of challenges is one attribute that strengthens the caregiver’s ability to assess and appraise their internal and external environment. Especially that, the caregiver will use internal resources that are biological in nature in trying to understand the presenting situation. While also making decisions on the nature of the challenge as to whether it is a threat that he/she can't deal with or a challenges that he/she can confront and deal with. Source of challenges can be attributed to the level of knowledge of the disease sequel, the lack of understanding of the potency of drugs and how TB drugs and ARVs can be taken by the same patient. Generally, the lack of orientation of caregiver to care work was the main root causes of the challenges faced by caregiver health professional who have discharged patients early from health facilities to be cared for by relatives have not put in place mechanisms for provision of support for caregivers. The general existence of poverty in the community, high unemployment levels in the country. The high levels of illiteracy could be a factor although the study was not looking at this variable contributing to challenges.

Health centres where patients are expected to find help, are not easily accessed, either because they are far, the household has no money to meet transport costs. When the patient finally gets to health center and are given medications, they have fear of taking the drugs due to lack of food. Other times drugs are not available at the health center and are given prescription to buy medicines and have not money to do so. These are many frustrating situations being faced by caregivers and patients. Finally caregivers attached meaning to care work, and interpreted their position, intentions and motives in the environment of caring as what propelled them to go on despite poor coping mechanism

## *Bibliography*

Aantjes Caroline, Quinlan Tim and Bunders Joske (2014). *Integration of community home based care programmes within national primary health care revitalisation strategies in Ethiopia, Malawi, South Africa and Zambia: a comparative assessment* Globalization and Health , 10: 85 doi:10.1186/s12992-014-0085-5

Aboderin, I. (.2006). *Intergenerational Support and Old Age in Africa*. New Brunswick, New Jersey, Transaction Publishers.

Aidoo, Magna and Harpham, Trudy (2001). *The explanatory models of mental health amongst low-income women and health care practioners in Lusaka, Zambia.* Health Policy and Planning; 16(2): 206-213 © Oxford University Press

Airhihenbuwa CO and Webster JD (2004). *Culture and African Contexts of HIV/AIDS prevention, care and support.* Journal of Social Aspect of HIV/AIDS Research Alliance, 1(1): 4-13

Akintola, O (2004) *A Gendered Analysis of the Burden of Care on Family and Volunteer Caregivers in* Uganda *and South Africa.* Durban, South Africa, Health Economics and HIV and AIDS Research Division (HEARD) University of KwaZulu-Natal. *http://*www.heard.org.za. Funded by: United States Agency for International Development (USAID)

Akintola, O (2006). *Gendered home-based care in South Africa: more trouble for the troubled.* African Journal of AIDS Research 2006, 5(3): 237-247

Akintola, O. (2008) *Defying all odds: coping with the challenges of volunteer care giving for patients with AIDS in South Africa*. Journal compilation 2008 Blackwell Publishing Ltd *Journal of Advanced Nursing*, *63*(4), 357-365..

Akintola, O. (2010) *Perception of rewards among volunteer caregivers of people living with AIDSS working in faith- based organisations in South Africa: A qualitative study*. Journal of the International health AIDS Society. , m Vol 13:22

Akintola O, Hlengwa W.M. and Dageid W (2013*). Perceived stress and burnout among volunteer caregivers working in AIDS care in South Africa*. Journal of Advanced Nursing 69(12), 2738-2749.

Akintola Olagoke and Hangulu Lydia (2014). *Infection Control in home-based care for people living with HIV/AIDS/TB in South Africa.* Global Public Health Vol. 9, No. 4, 382-393, Andersen Buhl Louise (2012). *Children's caregiving of HIV- infected parents accessing treatment in Western Kenya: challenges and coping strategies.* African Journal of AIDS Research 11(3): 203 - 213

Andershed Birgitta and Ternestedt Britt-Marie (2001) *Development of a theoretical framework describing relatives' involvement in palliative care* Blackwell Science Ltd, Journal of Advanced Nursing, 34(4), 554 - 562

Antonovsky, Aaron (1979). *Health, Stress and Coping.* The Jossey – Bass Publishers, Second Edition, San Francisco, California.

Antonovsky, A. (1980). *Health, Stress and Coping: New Perspectives on Mental and Physical health*. Jossey – Bass Publishers, London

Antonovsky, A. (1987). *Unravelling the Mystery of Health. How People Manage Stress and Stay Well.* Jossey-Bass, San Francisco.

Antonovsky Aaron (1996). *The salutogenic model as a theory to guide health promotion*. Health Promotion International, 11(1), 11-18

Antonovsky, A. and Sourani, T. (1998). *Family Sense of coherence and family adaptation*. in Walsh, Froma (2002). *Ecological and Development Perspective: Family coping, Adaptation, and Resilience. Family Relations Vol. 51.No. 2,*

Ardington Cally, Casey Anne, Islam Mahnaz, Lam David, Leibbrandt Murray, Menendez Alicia and Olgati Analia (2010).*The Impact of AIDS on Intergenerational Support in South Africa: Evidence from Cape Area Panel Study*. Research on Aging 2010; 32(1) 97-121.. Online version found at: http://roa.sagepub.com/cgi/content/abstract/32/1/97

Ashford, L. S. (2006). *How HIV and AIDS affects populations*. (A brief). Population Reference Bureau. BRIDGE

Attride-Stirling, Jennipher (2001). *Thematic networks: an analytic tool for qualitative research.* Qualitative Research Copyright ©2001 SAGE Publications (London, Thousand Oaks. CA and New Delhi) vol. 1(3): 385 -405.

Bandura, Albert. (Eds) (1995). *Self- Efficacy in Changing Societies*. Cambridge University Press

Barnes, B. (2000). *Understanding Urgency: Social theory and responsible action*, in Dixey R.,(2013)(ed). Health Promotion: Global Principles and Practice, CABI Nosworthy

Way, Wallingford, Oxford shire OX10 8DE, UK.

Barry, M. Margaret (2001).Promoting Mental Health: Theoretical Framework for Practice International Journal of mental health promotion, 3(1), 25-34

Barry, M. Margaret (2002).*Challenges and Opportunities in strengthening the evidence base for mental health promotion*. IUHPE- Promotion and Education VOL.IX/2 44-48

Barry, M. Margaret (2009). Addressing the Determinants of Positive Mental Health: Concepts, Evidence and Practice. International Journal of Mental Health Promotion 11(3), 4-17.

Baron, A. Robert and Byrne Donn (2006), *Social Psychology.* Tenth Edition Prentice-Hall of India Private Limited New Delhi- 110 001

Becker, M Craig, Glascoff, Alice Mary, Felts, W. Michael (2010). *Salutogenic 30 years later: where do we go from here?* International electronic Journal of Health Education, 2010, 13; 23-32

Bell, Judith (2005). *Doing your Research Project. A guide for first-time researchers in education, health and social sciences*. 4th edition Open University Press

Blackburn, Robert and Stokes, David (2000). '*Breaking Down the Barriers: Using Focus Groups to Research Small and Medium Sized Enterprises'.* International Small Business Journal, Vol. 19, No. 1, p 44-67.

Blackie, Norman (1993). *Approach to Social Enquiry.* Polity Press, Blackwell Publishers, UK.

Blackie, Norman (2000). *Designing Social Research*. Oxford: Polity Press

Blackie, Norman (2010). *Designing Social Research. The Logic of Anticipation*. 2nd edition. Polity Press Cambridge CB2 IUR UK.

Blanche, Martin Terre and Durrheim, Kevin, (1999). *Histories of the present: social science research in context*. Research in Practice. Applied methods of Social Sciences. 1999. 1-16 University of Cape Town Press ISBN 1-919713-35-2 511pp

Bernardi Fabrizio, González J Juan, Requena Miguel (2011). *The Sociology of Social Structure*

Chapter 15. “The Sociology of Social Structure” 21st Century Sociology. 2006. SAGE Publications.

Bengtsson, E. and Bengtsson, I. (2005). *Where we can’t cure we can care”: A participatory evaluation of Home Based Care project in Zambia*. Master Program in Peace and Development Work, Minor Field Study. Vaxjo University, School of Sciences.

Benner, P. and Wrubel, J. (1989). The Primacy of Caring: Stress and Coping in Health, Illness. In Cheung and Hocking, P. (2004). Caring as Worrying: the experience of spousal carers. Journal of Advanced Nursing, 47(5), 475-482

Benson, H. (1996). *Timeless Healing*. New York: Scribner in Kloosterhouse, Vicki and Ames, D. Barbara, (2002***). Families’ Use of Religion/Spirituality as a Psychosocial Resource. Holistic Nursing Practice 2002; 17(1):61-76***

Benzl, Carina, Bull, Torrill, Mittelmark and Vaandrager, Leneke (2014). *Culture in Salutogenesis Scholarship of Aaron Antonovsky.* Global health promotion 1757 - 9759 Vol 0(0): 1-858550

Berg, L. Bruce (2004). *Qualitative Research Methods for the Social Sciences*. Fifth Edition. International Student Edition. Pearson, Boston

Bhengu, M.J. (1996). *UBUNTU: The Essence of Democracy* in Broodryk, Johann (2006). Ubuntu African Life Coping Skills: Theory and Practice. Conference paper delivered 12-17 October, 2006 Nicosia, Cyprus. Accessed May, 2014

Bloor, Michael, Frankland, Jane. Thomas, Michel. Robson, Kate (2001). *Focus Groups in Social Research. Introducing Qualitative Methods.* SAGE Publications London.

Blumer, Herbert. 1969. *Symbolic Interaction: Perspective and Method.* Englewood Cliffs, N.J.: Prentice-Hall.

Blum Wn. Robert (1969). *Risk and Resilience: a Model for Public Health Intervention for Adolescents.* www.acsa-caah.ca/Portals/0/Member/PDF/**en**/documents/**risk** (retrieved 2014)

Billings, J. and Hashem, F., (2010). *What does the salutogenic approach offer for mental health* *promotion and positive mental health in older people?* Literature review; EU Thematic Conference " Mental Health and Well-being in older people making it Happen" 19th – 20th April, 2010 Madrid www.2010aging (accessed 2014)

Braun, V. and Clarke V. (2006). *Using Thematic Analysis in Psychology.* Qualitative Research in Psychology, 3:2, 77-101. http://dx.doi.org/10.1191/1478088706qp63oq.

Brazil, K. and Krueger, P. (2002). *Patterns of Family adaptation to childhood asthma*, Journal of Paediatric Nursing, 17 (13) 167 -173 in Martin et al., (2004) *families of children with HIV infection. AIDS CARE,* Vol. 16, No. 3, pp. 283-292. Taylor and Francis, health sciences

Broodryk, Johann (2006). Ubuntu African Life Coping Skills: Theory and Practice. Paper delivered at CCEAM Conference. 12 – 17 October, 2006: Nicosia, Cyprus. Accessed: 2014

Bryman, Alan (2001). *Social Research Methods* in Mikkelsen, B (2005). Methods For Development Work and Research, A New Guide for Practioners, Second Edition. SAGE Publications, Thousand Oaks, London.

Burgess, Rochelle and Campbell, Catherine (2014). *Contextualising women's mental distress and coping strategies in the time of AIDS: A rural South African case study.* Transcultural Psychiatry 2014, Vol. 51(6) 875-903.

Burke, J. Peter (1980). "*The Self: Measurement Implications from Symbolic Interactionist Perspective",* Social Psychology Quarterly 43(1980): 18-20

Buus, Hebo Camilla (2013) (Ed) *Millennium Development Goals, Progress Report, Zambia*. New Horizon Printing Press, Lusaka

Campbell, Catherine and Foulis, C. (2004).*Creating context for effective home- based care of people living with HIV/AIDS.* Curationis, 27(3). p5-14. Copy© 2004 Democratic Nursing Organisation of South Africa. http://eprints.Ise.ac.uk/archive/00000340

Campbell, Sue (2004). *Care of patients with HIV and AIDS in developing countries*. Primary Health care, Vol 14 No. 8

Cassidy, Tony. (1999). *Stress, Cognition and Health*. Routledge, London

Cattan, M. and Tilford, S, eds. (2006). *Mental Health Promotion: A life Span Approach*. McGraw Hill, Open University Press. Berkshire, England.

CSO, MOH, UNZA and MEASURE Evaluation (2010). *Zambia Sexual Behaviour Survey 2009*. Chapel Hill, North Carolina

CSO et al.,(2009).*Zambia Demographic and Health Survey* 2007.Maryland, Calverton. Orc Macro

CSO/ MOH, (2009). Zambia Sexual and Behaviour Survey (2009). Macro 11785 Beltsville Drive, Calverton, Maryland, USA.

CSO CBOH: *MEASURE/Evaluation,* (2000). *Zambia Sexual and Behaviour Survey*. Chapel Hill, North Carolina

Chang, E. C., and DeSimone, S. L. (2001). *The influence of hope on appraisals, coping, and dysphoria: A test of hope theory*. Journal of Social and Clinical Psychology, 20, 117-129.

Chaava T. H., (2005) *Skills, Training and Support for Carers in HIV/AIDS Community Home-Based Care: A case study of carers in Chikankata, Zambia.* Unpublished mini-thesis Master's Degree in Public Health University of the Western Cape

Chiwele Denis, K. and Syampungani Stephen (2011) *Millennium Development Goals Progress Report*. Produced by UNDP, New Horizon printing press

Cheng Sheung – Tak and Siankam Benjamin (2009). *The Impacts of HIV/AIDS Pandemic and Socioeconomic Development on the Living arrangements of Older Persons in Sub-Saharan Africa: A Country –Level Analysis.* Am J Community Psychol 44:136 - 147

Cheung, Jenny. and Hocking, Peta. (2004). *Caring as worrying: the experience of spousal carers* Journal of Advanced Nursing 47(5), 475–482.

Chepngeno-Langat, G., Falkingham, J, Nyvani, J., Evandrou Madise and Maria (2009)

*Socioeconomic Differentials between HIV Caregivers and Non caregivers: Is There a Selection Effect? A case of Older People Living in Nairobi City Slums*. Research on Aging. http://roa.sagepub.com/cgi/content/refs/32/1/67

Chipimo, J. Peter, Tuba, Mary and Fylkesnes, Knut (2011). *Conceptual models for Mental Distress among HIV-infected and uninfected individuals: A contribution to clinical practice and research in primary- health- care centers in Zambia*. BMC Health Services Research 2011 11:7. Doi:10.1186/1472-6963-11-7.

Clarke M. David and Stone Louise (2007). *Adjusting to illness and other major life events How can GPs help*? Reprinted from Australian Family Physicians Vol. 36 No. 4,

Clarke, L.F. (1993). *Stress and the cognitive-conversation benefits of social interaction*. Journal of Social and clinical Psychology, 12, 25 – 55.

Chisman Cassie, Shirley Chu, June Hucke, and Emily Nelson (2007). *Symbolic Interactionism* Communication Theory 220, November 19, 2007

Chopra, Mickey and Coveney John (2006). *Health System Research I Module Guide*. Copyright @SOPH School of Public Health, UWC, 2000.

Christopher, F. (2001). "*To Dance the Dance: A Symbolic Interactional Exploration of Premarital Sexuality* In Mazzotta and Myers (2008, Language and Meaning: Symbolic Interactionism, USC Upstate Undergraduate Research Journal Volume 1, Spring

Coffey, A. and Atkinson, P. (1996*). Making Sense of Qualitative Data: Complementary Research Strategies.* SAGE Publication, Thousand Oaks, California

Cowley, Sarah and Billings, Ruth. Jennifer (1999). *Resources revisited: Salutogenesis from a lay Perspectiv*es. Journal of Advanced Nursing 29(4), 994-1004. Health, Nursing and Policy issue.

Creig, A., Kimmel M., and Lang, J. (2000) "*Men, Masculinities and Development: Broadening Our Work Towards Gender Equality* in Johnson et al., (2003) *Man Enough to Care: Involving Men in Home Based Care Services for People Living with HIV/AIDS in Rural Zimbabwe.* Africare, Africare House, 440 R Street, N.W. Washington, D.C. 2001-1935, USA. Ww.africare.org

Creswell, J. W. (2013). *Qualitative Inquiry and Research Design: Choosing among the five Approaches.* 3 rd. ed. London. Sage Publications

Cullinan, K. (2000). Community- based care[Editorial Health Systems Trust series] In Ncama B. P. (2005). *Models of Community/Home-Based Care for People Living with HIV/AIDS in Southern Africa*. Journal of the Association of Nurses in AIDS Care, Vol. 16 (3), 33-40.

Danner, D.D., Snowden, D. A., and Friesen, W. V. (2001) *Positive emotions in early life and longevity: Findings from the nun study.* Journal of Personality and Social Psychology, 80, 804 -813.

De-Figueiredo, R. M. and Turato, E. R. (2001). *Needs for assistance and emotional aspects of caregiving reported by AIDS patient caregivers in a day- care unit in Brazil*. Issues in Mental Health Nursing 22(6), 633 -643

Demmer, Craig (2006). *Caring for a Loved with AIDS: A South African Perspective*. Journal of Loss and Trauma, 11: 439- 455.

Denzin, K. Norman and Lincoln, S. Yvonne eds. (2011). *Strategies of Qualitative Inquiry*. 4

edition. SAGE.

Denzin, N.K. and Lincoln, Y. S. (eds) (2000). *Handbook of Qualitative Research*, Second edition, Sage, Thousand Oaks, California

Denzin K. Norman and Lincoln, S. Yvonne (2000). The discipline and practice of qualitative research. In Denzin, N.K. and Lincoln, Y. S. (eds) (2000). Handbook of Qualitative Research, Second edition, Sage, Thousand Oaks, California .

Denscombe, M. (2002). *Ground Rules for Social Research*. Open University Press, Buckingham.

Denscombe, M (2010). *The Good Research Guide: for small-scale social research projects*, 4 th Edition. Open University Press, McGraw-Hill Education

Desmond E. Mary, Horn Suzen, Keith Kathryn, Kelby Susan, Ryan Linda and Smith Janice (2014). *Incoporating Caring Theory into Personal and Professional Nursing Practice to improve Perception of Care.* International Journal for Human Caring Vol. 18 No 1, 35 – 44

Dixey Rachael, (2013) (ed). *Health Promotion: Global Principles and Practice.* CABI Nosworthy Way, Wallingford, Oxford shire OX10 8DE, UK.

Du Preez, C.J. (2010). Living and Caring Arrangements of Non-urban Households in KwaZulu-Natal, South Africa, in the Context of HIV and AIDS. Thesis submitted in fulfillment of the requirements for the degree of doctor at Wageningeni University.

Dyer JG and McGuiness TM. (1996). *Resilience: Analysis of the concept*. Arch Psychiat Nursing 10: 276- 82

Eaton, J. Rebecca and Bradley Graham (2008). *The Role of Gender and Negative Affectivity in Stressor Appraisal and Coping Selection,* International Journal of Stress Management 2008, Vol. 15, No. 1, 94–115.

Ehrenreich, Barbara and English, Deidre. (1979). *For her Own Good: 150 years of the Experts'*

*Advice to Women.* (Anchor/Doubleday, New York.

Endler N. S., and Parker, J. D. A. (1990*). Multidimensional assessment of coping: A critical evaluation. Journal of Personality and Social Psychology, 58,* 844–854.

Endler, N. S., and Parker, J. D. A. (1994). *Assessment of multidimensional coping: Task, emotion, and avoidance strategies*. *Psychological Assessment, 6,* 50–60.

England, Kim, V. L. (1994). *Reflexivity, Positionality and Feminist Research.*The Professional Geographer 46(1), 80-89

Erikson, M, and Lindström, B., (2007). *Antonovsky's sense of coherence scale and its relation with quality of life: a systematic review. J Epidemiol Community Health, 61: 938-944.*

Erikson M, Lindström B. (2006) *Antonovsky's sense of coherence scale and the relation with health: a systematic review.* J Epidemiol Community Health. 2006 May; 60(5):376-81.

Erikson, M. and Lindström (2005). *Validity of Antonovsky's sense of coherence scale: A systematic review.* Journal of Epidemiology and Community Health, 59, 460-466

Esu-Williams, E., Schenk, K.D., Geibel, S., Motsepe, J., Zulu, A., Bweupe, P., and Weiss, E. (2006). '*We are no longer called club members but caregiver': Involving youth in HIV and AIDS caregiving in rural Zambia*. AIDS Care*,* 18(8): 888 – 894, Routledge

Evergeti Venetia (2006). *Living and Caring between two Cultures*. Community, Work and Family

Vol. 9, No. 3 pp. 347 -366

Feldt, Taru, Metsäpelto, Riitta-Leena., Kinnunen, Ulla, and Pulkkinen, Lea (2007). *Sense of Coherence and Five-Factor Approach to Personality. Conceptual relationships*. European Psychologist 2007, Vol. 12(3): 165- 172

Feldt, T., Kokko, K., Kinnunen, U., and Pulkinen, L. (2005). *The Role of Family Background,*

*School Success and Career Orientation in the Development of Sense of Coherence*. European Psychologist; 10(4): 298-308.

Fereday, Jennifer and Muir-Cochraine (2006*). Demonstrating rigor using thematic analysis: A*

*hybrid approach of inductive and deductive coding and theme development*. International Journal of Qualitative Methods 5 (1), Article xx. Retrieved November, 2013 from http:www.ualberta.ca/˜iiqm/backissues/5_1pdf/fereeday.pdf

Flensborg-Madsen, Trine., Ventegodt, Søren., and Merrick, Joav. (2006*). Sense of coherence* *and health. The construction of an Amendment to Antonovsky's Sense of Coherence Scale (SOC II).* TSW Holistic Health & Medicine 1, 169- 175.

Flensborg-Madsen, Ventegodt, Søren and Merrick, Joav (2006). *Why Antonovsky's Sense of Coherence Not Correlated to Physical Health? Analysing Antonovsky's 29-item Sense of Coherence Scale* (SOC-29).The Scientific World Journal 5. 767-776

Flensborg-Madsen, T., Ventegodt, S., and Merrick, J. (2006*). Sense of Coherence and physical health. Testing Antonovsky's theory.* TSW Holistic Health & Medicine 1, 248- 255.

Folkman, S. (1984). *Personal control and stress and coping processes: A theoretical analysis*. *Journal of Personality and Social Psychology, 46,* 839–852.

Folkman, S., Lazarus, R. S., Gruen, R. J., & DeLongis, A. (1986). *Appraisal, coping, health status, and psychological symptoms*. Journal of Personality and Social Psychology, 50, 571–579.

Folkman, S., and Moskowitz, J. T. (2004). *Coping: Pitfalls and promise*. Annual Review of Psychology, 55, 745–774.

Folkman, S. and Chesney, MA (1992). *Coping with caregiving and bereavement in the context Of AIDS.* A paper presented at the American Psychological Association Centennial Meeting. August 16, 1992. In Lazarus, S. Richard (1993). Coping theory and Research: Past, Present and Future. Psychosomatic Medicine 55:234-247

Forsberg-Wärleby, G., Möller, A., and Blomstrand, C. (2002). *Spouses of First Ever Stroke Victims: Sense of Coherence in the First Phase after Stroke*. J Rehabil Med 2002; 34: 128-133

Fox, P. Matthew, Mazimba Arthur, Seidenberg, Crooks. Denise, Sikateyo Bornwell and Rosen Sidney (2010).*Barriers to initiation of antiretroviral treatment in rural and urban areas of Zambia: a cross – sectional study of cost, stigma, and perceptions about ART.* Journal of the International AIDS Society 13:8.

Freeman, M. and Nkomo, N. (2006*). Assistance needed for the integration of orphaned and vulnerable children – views of South African family and community members* .Journal of Social Aspects of HIV/AIDS 3(3):503-509

Gibbs, R. Graham (2002). Qualitative data analysis: Explorations with NVivo, open University Press- Buckingham.

Gilbert, N. (2008). *Researching Social Life (3rd edition)*. London: Sage.

Giske, T., and Artinian, B. (2007). *A Personal Experience of Working with Classical Grounded Theory: From beginner to experienced Grounded Theorist.* International Journal of Qualitative Methods. 6(4)

Golafshani, N. (2003). *Understanding reliability and validity in qualitative research*. *The Qualitative Report,* 8(4), 597-606.

Green, J. and South, J. (2006). *Evaluation.* Open University Press.

Griffins, J. (1983). *Homer on Life and Death*, New York, Oxford University Press.

Goulding, C. and Domic, D (2009). Heritage, Identity and Ideological Manipulation. Annals of Tourism Research: A Social Science Journal of 38(January), 85-102 DOI;10.1016/journals.2008.10.004

Goulding, C. (2005*). Grounded theory, ethnography and phenomenology: a comprehensive analysis of qualitative strategies and marketing research*. European Journal of Marketing 39(3/4), 294-308

Goulding, C. (1999). *Grounded Theory: some reflections on paradigm, procedures and misconceptions.* Management Research Centre 1999, Working Paper Series, June 1999, Number WP006/99, ISSN Number ISSN 1363-6839

Guyer, Levy. Anya (2008). *Beyond Unpaid Caregiving: Strategic Partnering to Support and Sustain Grassroots Women's Groups' Home-Based care Work (in the context of HIV).* Background paper: Huairou Commission, Women, Homes & Community

Halligan Phil (2005). *Caring for patients with of Islamic denomination: Critical care nurses' experience in Saudi Arabia.* Journal of Clinical Nursing, 15, 1565 – 1573.

Hardy, D. F., Power, T. G., and Jaedicke, S*. (1993). Examining the relation of parenting to children's coping with everyday stress.* in Martin et al 2004, Coping styles among families of children with HIV infection. AIDS CARE Vol., 16, NO. 3, pp. 283- 292

Hayes, Sally and Llewellyn, Anne, (2008).*Fundamentals Of Nursing Care, A textbook for Student Nursing and Health Care.* Reflect Press, Exeter, UK.

Hastrup, K. (1992). *Writing ethnography: State of the art. In, Oakley & H. Callaway (Eds),* *Anthropology and Autobiography*. London and New York: Routledge, 116-33. In England, Kim, V. L. (1994). *Reflexivity, Positionality and Feminist Research.*The Professional Geographer 46(1), 80- 89)

Heiman, Tali (2004). *Examination of the Salutogenic Model, Support Resources, coping style and Stressors Among Israel University Students.* The Journal of Psychology. 138(6), 5005-520

Held, M.B. and Brann, M. (2007). *Recognizing HIV/AIDS volunteers' stressors and desire for support.* AIDS Care. 19(2): 212 -214

Hewitt, J. (1988). "*Self and Society: A Symbolic Interactionist Social Psychology"* in Mazzotta and Myers (2008) Language and Meaning: Symbolic Interactionism. USC Upstate Undergraduate Research Journal Vol.1, Spring 2008. Accessed February, 2014

Hogan B. Kay (2013), Shattel Mona and Cleary Michelle (eds). *Caring as a Scripted Discourse versus Caring as an Expression of an Aunthetic Relationship between self and other*. Issues in Mental Health Nursing Vol. 34 issue 5. P 375 – 379. DOI: 10.3109/01612840.2013.768734.

Holstein, J. and Gubrium, J. (1997). *'Active interviewing'*, in Silverman, D. (2001) (ed.), Qualitative Research: Theory, Method and Practice. London: Sage publications.

Homan Rick, Searle Catherine, Esu-Williams, Eka Aguirre, and Marc Mafata, Sibongile.,Meidany, Farshid , Ndwende Corrie Oostbuizen, and, Towel, Liz., (2005). *Exploring the role of family caregivers and home- based care programs in meeting the needs of people living with HIV/AIDS*. Horizon Research Update. Johannesburg: Population Council

Homan, R. (1991). *The Ethics of Social Research* in Denscombe, M (2010). *The Good Research Guide: for small-scale social research projects*, 4 th Edition. Open University Press, McGraw-Hill Education

Hornby, A. S. (2000). *Oxford Advanced Learner's Dictionary of Current English*. Sixth edition. Wehmeier Sally(ed) and Ashby Michael(Phonetics ed.). Oxford University Press

Horowitz, J. M. (2000, February 21). Pangloss power Time, 138.

Horowitz, L. M., Krasnoperova, E. N., Tatar, D. G., Hansen, M. B., Person, E. A., Galvin, K. L., and Nelson, K. L. (2001).*The way to console may depend on the goal: Experimental studies of social support.* Journal of Experimental Social Psychology, 37, 49 -61.

Hossain Ziarat, Roopnarine L. Jaipaul, Ismail Rosnah, Hashmi I. Shaiza and Sombling Agnes(

2007*). Fathers' and Mothers' Reports of Involvement in Caring for Infants in Kadazan Families in Sabath, Malaysia*. Fathering, Vol. 5, No. 1, Winter 2007, 58 - 72

Ice, Gillian. H., Yogo Jaja. , Heh Victor and Juma Elizabeth (2009). *The Impact of Caregiving on the Health and Well-being of Kenyan Luo Grandparents*
*Research on Aging* 2010; 32; 40

Isaacs Evelyn, Mundeta Bongai and Masunda Lloyd (2010). *Scaling Up HIV and AIDS prevention, Treatment, Care and Support in Community and Home-Based Care Programmes by Reducing the Burden of HIV and AIDS Care on Women, Girls and Older Carers in SADC*. Research Report. Caregivers Action Network. www.caregiversactionnetwork.org. accessed 2014.

Jenkins, P. (2007). *The Next Christendom: The Coming of Global Christianity* in Patterson, A.S. (2010). Church mobilization and HIV/AIDS treatment in Ghana and Zambia: a comparative analysis. African Journal of AIDS Research, 9(4): 407 – 418.

Johnson, Carry Alan, Fleming Oscar William, Chipere, Cassie, Matinhure, Nelia, and Myllynen, Karen (2003). *Man Enough to Care: Involving Men in Home Based Care Services for People Living with HIV/AIDS in Rural Zimbabwe.* Africare, Africare House, 440 R Street, N.W. Washington, D.C. 2001-1935, USA. Ww.africare.org.

Johnson Maarit (2004). *Approaching the Salutogenesis of sense of coherence: The role of 'active' self-esteem and coping.* British Journal Health Psychology 9, 419 – 432. The British Psychological Society

Joppe, M. (2000). *The Research Process* in Golafshan (2003) *Understanding reliability and validity in qualitative research*. The Qualitative Report, 8(4), 597-606. Retrieved , from http://www.nova.edu/ssss/QR/QR8-4golashani.pdf)

Kalimo, R., and Vuori, J., (1990). *Work and sense of coherence: Resources for competence and life-satisfaction.* Behavioral Medicine, 16, 76 - 89

Kasschau, A. Richard (1995). *Understanding Psychology*. GLENCOE, Macmillan/McGraw-Hill Columbus, Ohio.

Keller, Monika, Edelstein Wolfgang, Krettenauer Tobias, Fu-xi Fang and Ge Fang (2005). *Reasoning about Moral Obligations and Interpersonal Responsibilities in Different Cultural Contexts*. In W. Eldelstein and G. Nunner – Winkler(Eds). Morality in context (pp. 317-337). Amsterdam: Elsevier, 2005. (Accessed August 2014).

Kendal, Lori (2002). Hanging out in virtual Pub: Musculinities and Relationships Online. Berkley, CA: University of Carlifonia Press

Kipp Walter, Nkosi Matukala Thomas, Laing Lory, and Jhangri Gians (2006).*Care burden and self-reported health status of informal women caregivers of HIV/AIDS patients in Kinshasa, Democratic Republic of Con*go. AIDS Care, October 2006; 18(7): 694_697

Kiragu, K., Nyumbu, M., Ngulube, T.J., Njobvu, P., Mwaba, C., Kalimbwe, A. and Bradford, S. (2007). *Caring for Caregivers: An HIV/AIDS workplace intervention for hospital staff in Zambia. Evaluation Results. Horizon Final Report*. Washington, DC: Population Council

Kleinman, A. (1988). *The illness narrative: Suffering, healing and human condition*. New York, Basic Books. In Lazarus, S. Richard (1993). Coping theory and Research: Past, Present and Future. Psychosomatic Medicine 55:234-247

Klemz, R. Bruce, Boshoff Christo and Mazibuko Noxo-Eileen (2010). Business Development In Emerging Markets: The Impact on the Spending Behaviour of Elderly Caregivers of Family Members with HIV/AIDS in South Africa. SAJEM NS 13 No 4 464-475za

Klepp, O. M.; Mastkaasa, A., So (character O) rensen, T., Sandanger, I., and Kleiner, R., (2007). *Structure analysis of Antonovsky's sense of coherence from an epidemiological mental health survey with a brief nine-item sense of coherence scale*. International Journal of Methods in Psychiatry Research V16 (1):

Kloosterhouse, Vicki and Ames, D. Barbara, (2002***). Families' Use of Religion/Spirituality as a Psychosocial Resource. Holistic Nursing Practice 2002; 17(1):61-76© 2002 Lippincott Williams & Wilkins, Inc.***

Knodel John, Kespichayawattana Jiraporn, Saengtienchai Chanpen and Wiwatwanich Suvinee (2010). *The Role of Parents and Family Members in ART Treatment Adherence: Evidence from Thailand.* Research on Aging 32(1), 19-39. http://roa.sagepub.com/cgi/content/refs/32/1/19

Knodel, John E., Napaporn Chayovan (2009). *Older Persons Integenerational Relationships and Family Care and Support for Thai Elderly*. Ageing International, 33(1-4) 15 – 27.

Knodel John, E. (2008) "Poverty and the Impact of AIDS on Older Persons: Evidence From Cambodia and Thailand". Economic Development and Cultural Change 56(2): 441- 475

Knodel, E. John and Wassama Im-em (2004). *The Economic Consequences for Parents losing an Adult Child to AIDS: Evidence from Thailand*, Social Science and Medicine, 29: 987 - 1001

Kombo, Donald, K. and Tromp, L. A. Delno (2006). *Proposal and Thesis Writing: An*

*Introduction.* Pauline's Publications Africa.

Kobasa, S. C., (1979). "*Stressful life events, personality, and health- inquiry into Hardiness"* Journal of Personality and Social Psychology 37 (1): 1-11

Krueger, R.A., and Casey, M. A., (2009). *Focus Groups: A practical guide for applied 9k-Research* (4th Ed.). Thousand Oaks, CA: Sage Publications. 4th ED.

Kuperminc P. Gabriel, Jurkovic J. Gregory and Casey Sean ( 2009). *Relation of Filial Responsibility to the Personal and Social Adjustment of Latino Adolescents From Immigrant Families*. Journal of Family Psychology Vol. 23, No. 1, 14-22.

Langeland, E., Wahl, A., Kristoffersen, K. and Hanestad, B. R., (2007). *Promoting Coping: Salutogenesis among people with Mental Health Problems.* Issues in Mental Health Nursing. 28:275 – 295. Copyright information Health care.

Lanre-Abassi, A. Bolatito. (2008*). Poverty and Maternal mortality in Nigeria: towards a more viable ethics of modern medical practice*. International Journal of Equity in Health. 7:11 doi :10.1186/1475-9276-7-11. http://www.equityhealthj.com/content/7/1/11 BioMed Central Ltd. Accessed December, 2008.

Lakey, Brian and Cohen, Sheldon (2000). *Social Support Theory and Measurement.* www.psy.cmu.edu/ scohen/lakey (2000).

Lawton PM, Moss M, Kleban MH, Glicksman A, Rovine M (1991) *A two-factor model of caregiving appraisal and psychological well-being.* In Akintola(2010).Perception of Rewards among volunteers caregivers of people living with AIDS working in faith-based organisations in South Africa: a qualitative study. Journal of the International AIDS Society13:12

Lazarus, R.S and Folkman (1984). *Stress, Appraisal, and Coping.* Springer Publishing Company, Inc. New York, NY 10012, United States of America.

Lazarus, S. Richard (1993). *Coping Theory and Research: Past, Present and Future.* Psychosomatic Medicine 55: 234 -247

Lazarus, R. S. and Launier, R. (1978). *Stress dynamics Transactions between Persons and*

*Environment.* Plenum Press, London, UK.

Liamputtong, P. R. and Ezzy, D. (2005). Ch. 2- *Rigor, Ethics and Sampling. In Qualitative Research Methods.* Sidney: Oxford University press: 44-52

Lincoln, Y. S., and Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Lindelow Magnus and Serneels Pieter(2006).*The performance of health workers in Ethiopia: Results from qualitative research.* Social Science and Medicine 62 (2006) 2225-2235. www.elsevier.com/locate/socscimed

Lindström, B. and Eriksson, M (2007*). Antonovsky's sense of coherence scale and its relation with quality of life. A systematic review*. J. Epidemiol. Community Health 61: 938 – 944.

Lindström, B., Eriksson, M. and Wikstrõm, P.O (2011). How to construct a salutogenic framework for adolescent health. Folkhasan Research Center, Finland

Lindström, B. and Eriksson, M., (2006). *Contextualizing salutogenesis and Antonovsky in Public health development.* Health Promotion International, Vol. 21 No. 3

Lindström, B and Eriksson, M. (2012). *Salutogenesis-an Introduction*. www.centerlearoback.org/assests/PDF/04_activities/clr-GCPB121122-lindstom_pub_introsalutogenesis.pdf. (Accessed 9-1-2014)

Lindström, B. and Eriksson, M (2005). Salutogenesis. Journal of Epidemiology and Community Health. Journal of Epidemiology of Community Health 59, 440 - 442

Lindsey, E. Hirschfeld, M. Tlou. S. and Ncube, E. (2003). *Home-Based Care in Botswana: Experiences of older women and young girls.* Health Care for Women International, 24 (6):486–501.

Love, Peter E.D., Irani, Zahir, Themistocleous, Marinos, (2001) *An Exploratory Study of Psychological Adjustment and Coping among Information Technology Personnel in Australia*

Lowenstein, A. and Daatland, S. O. (2006). *Filial norms and family support in a comparative Cross-national context: evidence from OASIS study*. Ageing and Society 26, 203 – 223. Cambridge University Press.

Leary Mark and Tangney June, Eds (1978). *Handbook of Self and Identity*, Chapter 16. 2nd Edition Guilford Press.

Macbeth Douglas (2001). *On "Reflexivity" in Qualitative Research: Two Readings, and a*

*Third. Qualitative Inquiry,* Volume 7 Number 1, 2001 35-68©2001 Sage Publications, Inc.

Macwan’gi, M., Sichone, M., & Kamanga, P.N. (1994). *Women and AIDS in Zambia: Situation Analysis and Options for HIV/ AIDS Survival Assistance*. Study commissioned by the Ministry Of Health, National AIDS Prevention and Control Programme, Zambia

Makasa, M. Emanuel (2008). *The Human Resouirce Crisis in the Zambian Health Sector- a discussion paper.* Medical Journal of Zambia. Volume 35 number 3

Magnus, L. and Serneels, P. (2005). *The Performance of Health Workers in Ethiopia:* Study of African Economies, University of Oxford, Manor Road Building, Manor Road, Oxford OX1 3UQ, UK. Available online 23 November 2005

Manchester, J. and Barnes, M. (2000). *Supporting Community Carers.* AIDS action issue 50 October – December 2000. *The International Newsletter on AIDS Prevention and Care*. Available on http://www.aidsaction.info//aa/aa50html [accessed 2013]

Manis, G. Jerome and Meltezer, N. Bernard (1978) (eds). *SYMBOLIC INTERACTION: A Reader in Social Psychology.* Third Edition, Allyn and Bacon, Icon Boston

Manthorpe J. (2007). *Culture, caregiving and older people. (Editorial)* Aging and Mental Health 11(1): 1-2. Routledge

Martin, S.C., Wolters, P.L., Klaas, P.A., Perez, L. and Wood L. V., (2004). *Coping styles among families of children with HIV infection. AIDS CARE,* Vol. 16, No. 3, pp. 283-292. Taylor and Francis, health sciences

Masadeh, A.Mousa (2012*). Focus Group: Reviews and Practices*. International Journal of Applied Science and Technology Vol. 2 No. 10; December 2012

Masten, AS, Hubbard, JJ, Gest, SD, Tellgen, A, Qarmezy, N. Ramirez, M (1999). *Competence in the context of adversity. Pathways to resilience and maladaptation from childhood to late adolescence;* Development Psychopatho, 11: 143 -69, in Schoon, I (2006). *Risk and Resilience :Adaptations in Changing Times* Excerpt. Cambridge University Press, 1st Edition

Mazzotta, Tina and Myers, W. Benjamin, Myers (2008). *Language and Meaning: Symbolic Interactionism.* USC Upstate Undergraduate Research Journal, Volume 1, Spring 2008.

Mauthner, Natasha and Doucet, Andrea (2003*).Reflexive Accounts and Accounts of Reflexivity in Qualitative Data Analysis.* Sociology, BSA Publication Ltd®. Volume 37(3): 413-431 SAGE Publications London, Thousand Oaks. New Delhi

McConatha, Douglas and Michael Lynch. "*Hyper-Symbolic Interactionism: Prelude to a Refurbished Theory of Symbolic Interaction or Just Old Wine?*" Sociological Viewpoints 22 (2006): 87-96.

McCubbin, H. Patterson, J. Eds (1983), *The family stress process: the double ABCX model of adjustment and adaptation.* In: *Social Stress and the Family*. New York: Haworth Press; 1983:7–37 in (Kloosterhouse, Vicki and Ames, D. Barbara, (2002***). Families' Use of Religion/Spirituality as a Psychosocial Resource. Holistic Nursing Practice 2002; 17(1):61-76© 2002 Lippincott Williams & Wilkins, Inc._*

McNabb, E, D (2009). *Research Methods for Political Science: Quantitative and Qualitative Methods.* PHI Learning Private Limited New Dehli-110001

Meltzer, B. N., John W. Petras and Larry T. Reynolds (1978). "Variety of Symbolic interactionis." A Reader in Social Psychology 17(1978): 70-77

Merton, R.K., Fiske, M., and Kendall, P.L. (1956). *The Focused Interview*, Free Press, Glencoe in Blackburn, Robert and Stokes, David (2000).*Breaking Down the Barriers: Using Focus Groups to Research Small and Medium Sized Enterprises.* International Small Business Journal, Vol. 19, No. 1, p 44-67.

Mieh M. Theresa, Iwelunmor, Juliet and Airhihenbuwa, O. Collins (2013). *Home-Based Caregiving for People Living with HIV/AIDS in South Africa.* Journal of Health Care for the Poor and Underserved, Volume 24, Number 2, p 697 – 705.

Mikkelsen, B. (2005). *Methods for Development Work and Research, A New Guide for Practitioners,* second edition, SAGE publication, New Delhi.

Milberg, Anna and Strang, Peter (2004). *Exploring Comprehensibility and Manageability in Palliative Home Care: An interview study of dying cancer patients' informal carers.* Psycho-Oncology 13: 605–618

Miles, Mathew B., and Huberman Michael. A. (1994). *Qualitative Data Analysis: A Sourcebook* *of New Methods*. Beverly Hills

Mitchel, Juliet and Oakley, Ann (1986). *What is Feminisms*? Blackwell Publishers

Mittelmark, B. Maurice and Bull Torill (2013). *The Salutogenic model of health in health promotion research.* Global Health Promotion 1757- 9759; Vol 20 (.2); 30-38

MOH (2013). *National Health Policy, "A Nation of Healthy and Productive People*. Guardian Suppliers.

MOH/NAC (2013). Global AIDS Response Progress Report, Zambia Country Report 2013. January 2012 – December, 2013

MOH (2010). National Health Strategic Plan (NHSP), 2011 -2015. Republic of Zambia

MOH/ CBOH (2005). *Comprehensive Home Based Care HBC Client Kit Reference Manual. Zambia, Lusaka.*

Mohammed, Ibrahim Alhojailan, (2012). *Thematic Analysis: A Critical review of its Process and Evaluation.* WEI International European, Academic Conference Proceedings. October 14-17, 2012 Zagreb, Croatia. www.westeastinstitute.com/.../ZG12-191- **Mohammed-Ibrahim- Alhojailan** (accessed, June 2013)

Momsen, Janet. (2010). *Gender and Development*. 2nd edition, Routledge, Taylor and Francis group. London and New York.

Monat, A. and Lazarus, R.S.,(1991). *Stress and Coping :An anthology*. In Johnson , M. (2004). Approaching the Salutogenesis and sense of coherence: the role of 'active' self-esteem and coping. British Journal of Health Psychology 9, 419- 432

Morgan, D.L. (1988). *Focus Groups as Qualitative Research,* Qualitative Research Methods Series 16, Sage, London

Morrison, Paul and Burnard, Philip (1997). *Caring and Communicating: The Interpersonal*

*Relationship in Nursing.* Second Edition, Macmillan

Morwe, K. G., Klu E. K. and Tugli, A. K. (2013). *The Plight of HIV and AIDS Care Givers in Thohoyandou in South Africa*. J Hum Ecol, 44(3): 281-286 © Kamla-Raj 2013

Muecke, M. (2001). *Volunteer Care giving in Northern Thailand*.

in Chaava, T. Skills, training and support for carers in HIV/AIDS community home-based care: A case study of carers in Chikankata, Zambia

Mugumbate, Jacob and Nyanguru, Andrew (2013).*Exploring African Philosophy: The Value of UBUNTU in Social Work*. African Journal of Social Work, Volume 3, Number1, 82 – 100

Muñoz, Jaime Phillip (2007). *Culturally responsive caring in Occupational Therapy*.

Occupational Therapy International 14(4):256- 280. Wiley InterScience.

Musheke, Maurice, Bond Virginia and Merten Sonja (2013). *Deterrents to HIV-Patient Initiation of Antiretroviral Therapy in Urban Lusaka, Zambia: A qualitative Study*. AIDS PATIENT CARE and STDs Volume 27, Number 4. Behavioural and Psychosocial Research

Mwape Lonia (2010). *Psychological distress during the Perinatal Period in Zambia: A Case of Early Detection and Intervention.* Unpublished PhD Thesis, Leeds Beckett University.

Mweemba Oliver (2014). *The Social Construction of Masculinities, Sexual Behaviour and Acceptability of Microbicides in Zambia*. Unpublished PhD Thesis Leeds Beckett University.

Mwewa, AM., Saili, G. and Simbaya, J. (2013*). Multi country research on community caregivers: the backbone of accessible care and support- Zambia report*. The Caregiver Action Network. Accessed 2014.

Myfanwy, Morgan, Gibbs. Sara, Mazwell and Britten Nicky (2002). *Hearing children's voices:*

*methodological issues in conducting focus groups with children aged 7 -11 years*. Qualitative Research 2002 2: 5 DOI: 10.1177/468794102002001636. http://qrj.sagepub.com/content/2/1/5.refs.html

NAC (2014). *Zambia Biennial Country Report January 2012 – December*

*2013: Monitoring the Declaration of commitment on HIV and AIDS and the Universal Access.* Submitted to the United Nations Special Session on HIV and AIDS, Lusaka March 2014. www.unaids.org/sites/default/files/.../ZMB_narrative_**report**_2014.pdf

NAC (2012). *Zambia Biennial Country Report January 2010- December 2011:*

*Monitoring the Declaration of Commitment on HIV and AIDS and the Universal Access*. Report Submitted to the United Nations general Assembly Special Session on HIV and AIDS

NAC (2010). National AIDS strategic Framework (2011-2015). Towards Improving the quality of life of the Zambian people. Zambia.http://www.k4health.org/…/zambia…/zambia-national-aids-strategic-framework. Accessed 2014.

NAC (2007). *Minimum standards for community and home-based care organisation, Lusaka*. Ministry of Health. Online www.nac .org.zm/index.php publications guidelines.

NAC (2006). Zambia National HIV/AIDS Strategic Framework 2006- 2010.

NAC/MOH (August 2005). *Trainers Guide for Home Based Care,* Zambia, Lusaka

NAC (2005): National HIV and AIDS Strategic Framework (2006-2010). Republic of Zambia

NAC (2004). *The HIV/AIDS Epidemic in Zambia: Where Are We Now? Where Are We Going?*

Lusaka, Zambia

Ncama, B. P. (2005). *Models of Community/Home-Based Care for People Living with HIV/AIDS in Southern Africa*. Journal of the Association of Nurses in AIDS Care, Vol. 16 (3), 33-40.

Nodding, N., (1984) *Caring: A feminine Approach to Ethics and Moral Education Berkeley*. University of California Press

Nolan Mike, Grant, Gordon, and Keady, John (1996). *Understanding Family Care: A*

*Multidimensional Model of Caring and Coping.* Open University Press, Buckingham

Nolan Mike, Davies Sue and Grant Gordon (1997). *Working with Older people and their families*. Open University Press Buckingham

Nolan, Mike and Grant, Gordon (1992b). *Mid-ranging theory building and nursing theory-practice gap. A respite care study. Journal* of Advanced Nursing Vol. 17 issue 2. 217 - 223

Nsutebu, E. F., Walley, J. D., Mataka, E., Simon, C. F., (2001). *Scaling Up HIV / AIDS and TB in Home Based Care : Lessons from Zambia:* Health Policy and Planning; 16(3): 240-247, Oxford University Press.

Ogden, Jessica. Esim, Sind., Grown, Caren., (2004). *Expanding the Care continuum for HIV/AIDS: Bringing* Carers *into Focus.* Health Policy and Planning*,* Vol. 21, No.5, p. 333-342. Population Council and International Centre for Research on Women.

Olenja, M. (1999). *Assessing Community attitude towards home- based care for people with AIDS (PWA in Kenya.* J. Comm. Health, 24(3):187-199.

Omaswa, F. (2006). *Informal health workers — to be encouraged or condemned*? Bulletin of the World Health Organization, February 2006, 84 (2).

Opie, A. (1994). *The instability of the caring body: gender and caregivers of confused older people*. Qualitative Health research, 4(1):31-50

Opiyo, A. Pamella, Yamano Takashi, and Jayne TS. (2008). *HIV/AIDS and home-based care* International Journal for Equity in Health, 7:8 doi:10.1186/1475- 9276-7-8

Orner, Phyllis. (2006). *Psychosocial Impacts on Caregivers of People Living with AIDS*. AIDS Care*,* 18(3): 236-240.

Orford, J. (1992). *Community Psychology: Theory and Practice*. Chichester: John Wiley and Sons in Barry 2001, Promoting Positive Mental health: Theoretical Frameworks for Practice

Oxland, Mellisa, Miller – Lewis Lauren and Wade D. Tracey (2004). *The measurement of coping responses Validity of Billings and Moos Coping Checklis*t. Journal of Psychosomatic Research 57(2004) 477 - 484

Pallant, J. E. and Lae, L (2002). *Sense of Coherence, well-being, coping and personality factors,* in Johnson, M. (2004) Approaching the Salutogenesis and sense of coherence: the role of 'active' self-esteem and coping. British Journal of Health Psychology 9, 419-432

PANOS Institute of Southern Africa (1996).*Home–based care, not home–based neglect*: http://www.aegis.com/news/panos/1996/PS960701.html.

Pattersen, Amy (2010). *Church mobilization and HIV/AIDS treatment in Ghana and Zambia: a comparative analysis.* African Journal of AIDS Research 9(4): 407 - 418

Patton, M.Q. (2002). *Qualitative evaluation and research methods* (3 rd. Ed.). Thousand Oaks, CA: Sage Publication, Inc.

Pearlin, L.I, Mullon, J. T., Semple, S. T. and Skaff, M.M. (1990). *Caregiving and stress process: An overview of concepts and measurements.* The Gerentologist 30(5); 583-594

Pirraglia, A. P., Bishop, D., Herman, S. D., Trisvan, E., Lopez, A. R., Torgersen, S.C., Van Hof,

A. M., Anderson, J. B., Miller, I., Stein, D. M. (2005). *Caregiver Burden and Depression Among Informal Caregivers of HIV-infected Individuals.* J GEN INTERN MED 2005; 20:510–514. DOI: 10.1111/j.1525-1497.2005.0073.x

Puchalski, Christina.M. and Sandoval, Carlos(2003). *Chapter 13 Spiritual Care in O'Neill, F. Joseph, Selwyn, A. peter, Schietinger, Helen (Eds, 2003) Clinical Guide to Supportive and Palliative Care for HIV/AIDS.U.S. Department of* Health and Human Services. Health Resources and Service Administration, HIV/AIDS Bureau. www.aidforaids.org 212.337.8043. Downloaded: 6/3/2014, 12:51pm

Qarmezy, N. (1991). *Resiliency and Vulnerability to adverse developmental outcomes associated with poverty.* American Behavioural Scientist, 34, 416-430.

Roach, M.S. (1987). *The Human Act of Caring: A Blue print for the Health Professionals*. In Cheung, J and Hocking, P. (2004). Caring as worrying: the experience of spousal Carers. Journal of Advanced Nursing, 47(5), 475 – 482.

Rena F, Moshe S Abraham, (1996). *Couples' adjustment to one partner's disability: the relationship between sense of coherence and adjustment*. Soc Sci Med. 1996 Jul; 43(2):163-71.

Rose, Hilary. (1986). *Women and the Restructuring of the Welfare State in E. Oyen, The Future of the Welfare State*. Gower, London

Roopnarine Ziarat, Hossain Jaipaul l, Ismail, Rosnah, Hashmi, Shazia, I. and Sombuling Agnes (2007). *Fathers' and Mothers' Reports of Involvement in Caring for Infants in Kadazan Families in Sabah, Malaysia.* Fathering, Vol. 5, No. 1, Winter 2007, 58-72. © 2007 by the Men's Studies Press, LLC. http://www.mensstudies.com. All rights reserved. fth.0501.58/$10.00 DOI: 10.3149/fth.0501.58

Rosenburg, M. (1979). *Conceiving the self* in Stets, E. Jan and Burke J. Peter (2003). *A Sociological Approach to Self. A Sociological Approach to self and Identity, Leary Mark and Tangney, Jun (Eds) Guilford Press.* Social Psychology Quarterly

Rosengard C, Folkman S. (1997*) Suicidal ideation, bereavement, HIV Serostatus and psychosocial variables in partners of men with AIDS.* In Pirraglia et al., 2005, Caregiver Burden and Depression Among Informal Caregivers of HIV-Infected Individuals. J GEN INTERN MED 2005; 20:510–514.

Russell, M., and Schneider, H. (2000). *A rapid Appraisal of community based HIV/AIDS care and support programmes in South Africa*. in Ncama, B. P. (2005). *Models of Community/Home-Based Care for People Living with HIV/AIDS in Southern Africa*. Journal of the Association of Nurses in AIDS Care, Vol. 16 (3), 33-40.

Sagy S. Antonovsky H. (2000). *The development of the sense of coherence: a retrospective study of early life experiences in the family*. Int J Aging Hum Dev.; 51(2):155-66.

Sammallahti, R. Pirkko, Holi, J. Matti, Komulainen, A, Erkki, and Aalberg, A. Veikko (2003). *Comparing Two Self-Report Measures of coping-The Sense of Coherence Scale and Defense Style Questionnaire*. Journal of Clinical Psychology Vol. 59(12), 1325- 1333.

Sankar, A. (1999). *Dying at home*. Baltimore. John's Hopkins University Press.

Sargent, Andrew (2012). *Reframing caring as discursive practice: a critical review of conceptual analyses of caring in nursing.* Nursing Inquiry 19 (2): 134 – 143 ( Epub ahead of print)

Scharlach E. Andrew, Kellam Roxanne, Ong Natasha, Baskin Aeran, Goldstein Cara and Fox J. Patrick (2006). *Cultural Attitudes and Caregiver Service Use: Lessons from Focus Groups with Racially and Ethnically Diverse Family Caregivers*. Journal of Gerontological Social Work, Vol. 47(1/2)

Schmolke, Margit (2005). *The Concept of Resilience in Psychological Research.*

Paper presented at the World Congress of Psychiatry of WPA, Cairo, September 10-15, 2005, at the Inter-Sectional Symposium including the WPA Sections on Preventive Psychiatry, Public Policy and Psychiatry, and Psychoneuroendocrinology on „Resilience in Mental Health Promotion: Interdisciplinary Perspectives"; www.wpanet.org/uploads/sections/Preventive_Psychiatry/concepts-of-resillience-slides.pdf. Accessed 2011.

Schoon Ingrid (2006). *Risk and Resilience :Adaptations in Changing Times* Excerpt. Cambridge University Press, 1st Edition

Schneider R. Tamera (2008). *Evaluations of stresful transactions: what's in an apraissal?* *Stress and Health* **24**: 151–158

Sehume, Odila, Zungu, Lindiwe and Muhammad Hoque (2012). *Attitudes and Willingness of Nursing Students towards Caring for patients infected with HIV in South Africa*. Ife PsychologIA, 20(2).

Seyle, H. (1956) *The Stress of Life* in Kasschau, (1995) Understanding Psychology. GLENCOE, Macmillan/MacGraw-Hill, Ohio.

Serpe, T. Richard (1987). Stability and Change in Self: A Structural Symbolic Interactionist Explanation. Social Psychology Quarterly, Vol. 50, No. 1, 44 - 55.

Silverman, D. (2006). *Intepreting Qualitative Data. Methods for Analyzing Talk, Text and Interaction*. Third Edition SAGE Publications

Silverman, D. (2005). *Doing Qualitative Research. A Practical Hand book*. Second edition,

SAGE Publications.

Silverman, D. (2001). *Interpreting Qualitative Data: Methods for Analysing Text, Talk and*

*Interaction*, 2 nd edn, London Sage

Silverman, D. (2000). Doing qualitative research: a practical handbook. Sage Publication,

London

Singh Dinesh, Chaudoir R. Stephanie, Escobar Cabrera Maria, and Kalichman Seith (2011). *Stigma, burden, social support, and willingness to care among caregivers of PLWHA in home based care South Africa*. AIDS Care. Jul 2011; 23(7):839-845.

Skinner, A. Ellen, Edge Kathleen, Altman, Sherwood (2003) *Searching for the Structure of*

*Coping: A review and critique of category systems for classifying ways of coping*: Psychological Bulletin 2003 Vol. 129, No. 2, 216-269.

Society for Women and AIDS in Zambia (2007). *Situation Analysis of the care giving role of Zambia.* Financed by African Woman Millennium Initiative of Poverty and Human Rights (AWOMI)

Spier, A and Edwards, M. (1990).Facing AIDS: A strategy manual. McGregor, South Africa: SYNCOM Publishers. In Ncama, B. P. (2005). *Models of Community/Home-Based Care for People Living with HIV/AIDS in Southern Africa*. Journal of the Association of Nurses in AIDS Care, Vol. 16 (3), 33-40.

Stenbacka, C. (2001). *Qualitative research requires quality concepts of its own*. Management Division, 39(7), 551-555

Stets, E. Jan and Burke J. Peter (2003). *A Sociological Approach to Self-Identity.* Social Psychology Quarterly

Stewart, D. W. and Shamdasani, P. N. (1990). *Focus Groups Theory and Practice*,(Applied Social Research Methods Series, Vol. 20) Newbury Park CA Sage, London in Blackburn, Robert and Stokes, David (2000).*Breaking Down the Barriers: Using Focus Groups to Research Small and Medium Sized Enterprises.* International Small Business Journal, Vol. 19, No. 1, p 44-67.

Stryker, Sheldon (1987). "*The Validation of Symbolic Interactionism"* Social Psychology Quarterly Vol. 50, 83- 94

Sultana, Farhana (2007). *Reflexivity, Positionality, and Participatory Ethics: Negotiating Fieldwork Dilemas in International Research.* Journal compilation © *ACME* Editorial Collective, 2007 http://http//links.jstor.org/sici?sicihttp:www.jstor.org/journals/asa.html; http//www.jstor.org/journals/asa.html;

Thabethe, Nompumelelo (2011). *Community home-based care- a cost effective model of care: who benefits?* AIDS Care Vol. 23, No. 7, 787-791.

Taylor, D. Scott (2006). *Culture and Customs of Zambia*. Greenwood Publishing Group.

Tselebis Anthanassios, Moulou Aikaterini, and Ilias Ioannis (2001). *Burnout versus depression and sense of coherence: Study of Greek nursing staff.* Nursing and Health Sciences. 3, 69-71

Tali, H (2004). *Examination of the Salutogenic Model, Support Resources, Coping Style, and Stressors among Israeli University Students* The Journal of Psychology, 2004, *138*(6), 505–

Twigg, J and Atkin, K. (1994). *Carers Perceived: Policy and Practice in Informal Care.* Buckingham, Open University Press.

Underhill Motzer, S., and Stewart, B. J., (1996). *Sense of coherence as predictor of quality of life in persons with coronary heart disease surviving cardiac arrest* in Johnson, M. (2004) *Approaching the Salutogenesis of sense of coherence: The role of 'active' self-esteem and coping.* British Journal Health Psychology 9, 419 – 432. The British Psychological Society

UNDP (2007). Zambia Human Development Report, *Enhancing Household capacity to respond to HIV and AIDS* p.vii.

UNDP (2013). *Strengthening National Capacity to Fight AIDS, TB and Malaria.*

UNAIDS (2000). *Caring for carers: Managing stress in those who care for people with HIV and AIDS*. UNAIDS Case Study, Best Practice Collection, Geneva

UNAIDS (2008). *Caregiving in the context of HIV/AIDS*. Joint United nations Programme on HIV/AIDS. Division for Advancement of Women, Department of Economics and Social Affairs, United Nations, New York. http://www.un.org/womenwatch.daw

UNAIDS (2010). Global Report on AIDS epidemic. update,www.unaids.com

UNAIDS (2012). UNAIDS World AIDS Day Report. www.unaids.org/resources/campaigns/2012 **1120_globalreport 2012**

UNAIDS (2013). UNAIDS AIDS Epidemic Updates. www.unaids.com

Uys, L.R.,(2003). *Aspects of the care of people with HIV/AIDS in South Africa*. Public Health

Nursing 20(4), 271 - 280

UNICEF (2003). http://www.childreninfo.org/, UNICEF

Vaismoradi, Mojtaba, Turunen Hannele and Bondas, Terese (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. Nursing and Health Sciences vol. 15, 398-405. 2013 Wiley Publishing Asia Pty Ltd.

Varkevisser, C. M., Pathmanathan, I., and Brownlee, A., (1991). *Designing and Conducting Health System Research projects; health Systems research Series*. Volume 2 part 1. International Development Research Centre, Canada and WHO Geneva.

Venetia Evergeti (2006,) *Living and Caring between Two Cultures narratives of Greek women in Britain.* Community, Work and Family Vol. 9, No. 3, August 2006 pp. 347- 366

Walker, L.O and Avant K C (2005). *Strategies for Theory Construction in Nursing*. New Jersey: Pearson Prentice Hall. ( in Windle, Gill ( 2011). *What is resilience? A review and concept analysis*. Reviews in Clinical gentology 21; 152-169. ©Cambridge University Press

Walker, Diane and Myrick, Florence (2006). Grounded theory: An Exploration of Process and Procedure. Qualitative Health Research Vol. 16 No. 4 547 - 559

Walsh, Froma (2002). *Ecological and Development Perspective: Family coping, Adaptation, and Resilience. Family Relations Vol. 51.No. 2, Apr., 2002 A Family Resilience*

Walsh, Froma (1998 b). *Strengthening family resilience*. New York: Guilford Press.

Wangmo Tenzin (2010). *Changing expectations of care among older Tibetans living in India and Switzerland.* Aging and Society 30, 2010, 879-896.Cambringe University Press.doi:10.1017/So144686X10000085

Watts, Diane (2007). *On Becoming a Qualitative Researcher. The Value of Reflexivity*. The Qualitative Report Volume 12 Number 1 March 2007, 82-101.

Wennerberg M.T. Mia, Lundgre`n M. Solveig and Danielson Ella (2012). *Using the Salutogenic approach to unravel informal caregivers' resources to health: Theory and Methodology.* Aging and Mental Health Vol. 16, No 3, 391-402

Williams Nathalie, Knodel John, and Lam David (2010). *HIV/AIDS and Older Persons: Shifting* *the Focus From the Infected to the Affected.* Research on Aging, 32(1); 3 - 18

Williams, N., Knodel, J and Lam, D. (2009). *HIV/AIDS and Older Persons: Shifting the Focus from the Infected to the Affected.* Research on Aging, 32(1) 3-18

Windle, Gill (2011). *What is resilience? A review and concept analysis*. Reviews in

Clinical gentology 21; 152-169. ©Cambridge University Press

Woodall James, Gary Raine, South Jane and Warwick-Booth Louise (2010).*Empowerment and Health and Well-being: Evidence Review*. Centre for Health Promotion Research, Leeds Metropolitan University, Leeds, UK C *September 2010*

WHO (2005). *Promoting Mental Health Concepts, Emerging Evidence and Practice Report*.

Herman Helen, Saxena Shekhar and Moodie Rob (Eds). Report of WHO Department of Mental Health and Substance Abuse in collaboration with the Victorian Health Promotion Foundation and The University of Melbourne. (Accessed 2014).

www.who.int/mental_health/evidence/MH_Promotion_Book.pdf

WHO (2004). *Promoting Mental Health Concepts, Emerging Evidence_* Practice Summary

Report. Herman, Helen, Shekhar, Saxena and Moodie, Rob. (eds). A report of WHO Department of Mental Health and substance Abuse in collaboration with the Victorian Health Promotion Foundation and the University of Melbourne.

WHO (2002) *Community/home based care in resource-limited settings: A*

*framework for action.* Geneva, Switzerland: Author Elizabeth Lindsey

WHO Study Group (2000). *Home –based long-term care*. World Health Organ Tech Rep Ser,

898:i-v, 1-43

Yeh, J. Christine, Kim, B. Angela, Pituc, T. Stephanie and Atkins Marc (2008). *Poverty, Loss,*

*and Resilience: The story of Chinese Immigrant Youth*. Journal of Counseling Psychology. Vol. 55, No. 1, 34 -48.

Young Rebecca (2008). *What is meant by reflexivity in the context of ethnographic research?*

*Does reflexivity have limits*? https:/www.essex.ac.uk/sociology/…/RebeccaYoung_sc203_2008 (accessed 06/02.2014)

Ziarat Hossain Jaipaul l. Roopnarine, Rosnah Ismail, Shazia i. Hashmi, and Agnes Sombuling (2007). *Fathers' and Mothers' Reports of Involvement in Caring for Infants in Kadazan Families in Sabah, Malaysia*. *Fathering*, Vol. 5, No. 1, Winter 2007, 58-72.

ZDHS (2007) Zambia Demographic and Health Survey, ORC Macro 11785 Beltsville Drive, Calverton, Maryland, USA.

## Appendices

APPENDEX A: Consent Form

**Changing Family Roles: Coping Mechanisms of Family Carers in HBC in Zambia.**

Greeting: Morning/Afternoon

My name is Muriel Muwaika Syacumpi, I am a student studying with the Leeds Metropolitan University in the United Kingdom.

I am collecting information on coping mechanisms of family carers in HBC in Zambia. The study that this information is being collected for aims at exploring the coping mechanisms of family carers in meeting the needs of chronically ill AIDS patients at household level.
The study will involve conducting interviews with individuals providing care in homes and key stakeholders in HBC activities. The interviews will focus on understanding roles and responsibilities of family carers, how care functions are managed, challenges being faced, and how coping mechanisms are devised.

The study findings will inform HBC practice in Zambia on challenges being faced by family carers coping mechanisms and suggest possible interventions required to meet the needs of family carers
The study will not expose participants to any major risks, however, a participants may experience extreme emotional feelings during interviews as they describe different past uncomfortable situational experiences during care functions. Such situations will be addressed by either allowing the participants some time to express such emotions if such action will provide relief or the interview will be postponed to another day or the participant will be linked up to counseling services available in the community. Participants will be allowed to withdraw from the study if they do not wish to continue.

Participants will be provided with refreshments during interviews and will be reimbursed for transport costs.

The highest level of confidentiality will be maintained at all times throughout the interview and the data handling process. Access to data will be limited to those with specific roles in the study. All information provided during the course of the interview will remain confidential and anonymity of individuals participating will be maintained as participants will be assigned numbers and not names.

With an understanding of the statement above:

I_______________________________________________

Of ____________________________________residence/compound

Aged __________________________Sex________________________

Agree to participate in the study titled: Changing Family Roles: Coping **Mechanisms of Family Carers in HBC in Zambia.**

Provided the study observes the following conditions:

a. Detailed study information will be provided to me

b. Will respect my views as stated

c. Will respect confidentiality of any information given

d. No disclosure of the source of information

e. Interviews will be conducted during convenient times to the carer

f. Will share findings with HBC

Signed ..........................................................................................
OR
Thumb print......................................................................................

Date..................................................................................................

**NB.** In the event that you have any complaint related to this study, please contact
The Secretary,
University of Zambia Biomedical Research Ethics Committee
Ridgeway Campus
P. O. Box 50110
Lusaka
Tel: 260-1-256067

Or the Researcher on 0977-822-507

APPENDIX B: In-depth Interview Guide for Family carers

**Interview guide for Family carers** **Interview No.............................**

**Changing Family Roles: Coping Mechanisms of Family Carers in HBC in Zambia.**

Date: ..............................................................................

Start Time: ............................ End Time: .................................

Location: ......................................................................

**Introductions and Consent:**
Greet participant and self-introduction.
Good morning my name is----------

I will be happy if you would help me in this study. I am talking to some of you carers in home based care activities. Can we talk and answer some of my questions?

Provide purpose of the study and the procedures to be followed during the interview (as stated in the consent form). Inform participant about note taking and audio recording during the interview. Participants will be allowed to ask for clarity of questions

**Section A: Socio-demographic information**

**A: General characteristics of the carer**

1. **Firstly I would like to ask you questions about yourself.**
   Would you please tell me more about yourself.

   *Prompt for* age? Tribe? Marital status? Number of children if any and the age range?

   *Probe:* whether carer is a member of the household.

   Circumstances leading to her/him providing care to the patient.

   Frequency of providing care to this patient?

2. **I now would like to know about this household**
   Can you please describe this household?

   *Prompt* for facilities available for provision of care?

   Size of the house/number of rooms, number of people living in the household, ages, sex, availability of individuals to help with care work, economic activities, source of water, sanitation arrangements, electricity supply or source of power, distance to the nearest health facility.

3. **I would now like to ask you questions about your patient.**
   Can you please tell me more about the patient you are caring for?

   *Prompt* for the age? Sex? marital status? your relationship with the patient? diagnosis if known? length of knowledge of the patient if not part of the household? length of illness of the patient especially the present state?

   *Follow up questions:* patient's economic status before becoming ill? if patient is usual member of the household? If patient is not a member of this household, where is the patient coming from and why did the patient choose to come to this household? Explain how it happened that you are the one taking care of the patient?

**B. Orientation to care functions questions**

**4. Can you tell me more about the care functions**:
Caring for chronically ill patient is sometimes a responsibility that is forced on you or one chooses to take it up: Can you give an account of what happened in your case, how did you find yourself providing care to this patient?

.

*Prompt for:* Type of care functions? When care starts and end? What are your thoughts about care work you are carrying out, in terms of your preparations and readiness for the work? Physical, emotional and spiritual readiness and feelings to carry on with the work
*Follow up question*: Explain the times when you felt you were carrying out care work that you had no clear understanding about? How did you address those times when you had doubts about care work? What were the resources around to help you deal with those situations?

5. **I would now like to ask you questions about your feelings about care work.**

Can you describe your life as a carer? What are your feelings about caring and how have you handled those feelings?
*Follow up questions*: How do you now feel about caring, how do others around perceive your care work? What are the circumstances in your care work that made you feel like talking about your experiences in caring?( prompt for feelings like venting out, angry, disappointed, discouraged, sharing experiences? And why?)
When you did or did not share, what was the result of those actions?
*Probe* for the kind of experiences and feelings at the time? What were the reaction of those listening to you?

**C: Addressing self during care situations**

6. **I would like to ask you questions about your emotions/feelings during care work**

Would you describe your day as a carer, How are your feelings about care work? What gives you the feeling of satisfaction and what does not? For the things that gave you the feeling of satisfaction can you explain what happened and what brought about the satisfaction? Explain the feeling of dissatisfaction in your care work? Prompt: Describe the circumstances, how did you cope, what did you do?)

7. **This is a follow up to the above question on your feelings about care work.**

Explain the times when you had feelings that you were faced with unfamiliar care demands, what were those demands and how did you deal with those demands and situations?

How familiar were you with those demands and situations? how have you dealt with those feelings and demands?
*Follow up question* What can you say about the actions that you took in addressing the demands and situations?
*Prompt* for positives and negatives. Explain actions that you had taken to address the feelings and demands and why you took or did not take action? What were the results of the actions(taken/not taken)? What were your feelings after?
The kind of environment within which care is provided- social, spiritual economical resources.

8. **I would now like to ask you about your feelings at the end of the care day**

Can you now describe your feelings at the end of each care day and why do you have those feelings. Can you please give an example of typical day that you remember most, what happened?
Prompt: describe the contribution care work was making to the health of the patient?
*Probe:* If the care interactions made sense to the carer and how? How were her/his interventions received by those around the patient? How was this expressed? By whom, What attributes the carer has to manage care work?

**D: Orientation of self during challenging times**

9. **I am now going to ask you questions about the challenging times you may have faced during care work**

Do you remember the early days of care work, what would you say about those times?
*Probe:* for any difficulties and challenges faced in meeting the needs of the patient,
How did you apply yourself to those challenges? Source of support? Form of support? value of support? Identification of support? When you compare the sources of assistance who in your feeling provided you more support and why?

10. ***Follow-up to the above questions***

Describe yourself when faced with stressful or difficulty situations. Did you have the understanding of the difficulty you were faced with? Why did you believe it was a difficulty you could deal with? Explain how and why you dealt with such challenges/difficulties? What are the factors that make you believe in yourself to deal with the situation?

11. **I will now ask you questions on your view about the challenges you faced during care work.**

There are times during care work that we are faced with challenging situations, Can you explain the type of challenges that you have faced?
*Prompt:* for nature and source of challenge, choice of action to address challenges, In your view why were you convinced it was a challenge and needed to be addressed? What was your understanding of the challenge? How did you view that challenge? How and why did you deal with the challenge?

**E: Information on access to resources**

12. **I will now ask you questions about your environment within which you provide care especially in relation to resources to meet the needs of the patient.**

How would you describe the environment within which you work in terms availability of resources to help meet the needs of the patient?
*Prompt* for the nature of resource in care work. Where the resources come from and why? How resources are identified and by whom? How the carer believes that the resource available would give meaning to care provision? What is the impact of the received resources on you as a

carer? What are your own resources (probe if physical, mental, social) and what are your views on your own resources?
*Prompt :* for the type of resources- human, financial, respite, material, spiritual and
*Probe* if the resources were coming from the household, community, church, friends, volunteers, health facility or other.

**13.** Describe what you would like to see done to help you deal with care work for chronically ill AIDS patients?
Prompt: by the government, families, community ( specify type of community)

**THANK YOU FOR YOUR PARTICIPATION**

APPENDIX C:

**Focus Group Discussion Guide for Family Carers FGD Tool No...........**

**Changing Family Roles: Coping Mechanisms of Family Carers in HBC in Zambia.**

Location of Focus Group Discussion....................................................................

Date...................................

Start Time.............................. End Time................................

Number of participants Males { } Women { }

List of attendees and where they are from

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

______________

**Introductions and Consent**:

- Greet participants and self-introduction.
- Provide purpose of the study and the procedures to be followed during the interview (as stated in the consent form). Inform participants about note taking and audio recording during the interview
- Allow participants to introduce themselves
- Participants will be allowed to ask for clarity of questions
- Seek consent ( by reading out the consent form)

**A: Information on HBC activities**

*1.* You have been identified by the community as one of those participating in the provision of care to chronically ill patients. *Probe:* Please explain how you were identified. How did they start providing care to chronically ill patients.

2. Are you aware of any home based care (HBC) activities going on in this community? *Probe* for type of patients receiving HBC, chronically or non-chronically ill, diagnosis if known, where the patient are found, who cares for them, what care they are receiving.

**B: Information on Carers**

3. Family members and others; whether the carers live in the household, relationship with patients; paid or not paid)

4. What/How is the selection of carers:( prompt if they are chosen, by whom, what is the criteria and why)

## C: General preparations for care functions

5. We will now talk about carers preparation for care work
   How do carers acquire knowledge on how to manage chronically ill patients
   *Probe for:* Information on training, who conducts training, duration, adequacy of training or explanation on how else care knowledge is acquired, appropriate or not and why the response)

## D: Challenges in care functions

We will now talk about challenges faced by informal carers during care work.

6. Can you describe the kind of challenges that you face as informal carers during care work:
   *Prompt for*: source of challenges, frequency of occurrence, ability of carers to address them. Why are carers facing these challenges? How they cope with the challenges

   Follow up question on why other carers are able to deal with challenges and others not.

## E: Identifying and harnessing resources to cope with care functions

7. We will now talk about resources that can and will help you as informal carers to adequately meet the needs of your patients.

In your view what are the available resources that you as carers can access and those that you cannot access?
*Probe*: How these resources are identified? Where these resources can be found? Identification of resources,(household, community, and the government: human, material, spiritual)? How do they deal with situations where they have no resources to help meet the needs of the patient and why? What kind of support exist in the community to help informal carers cope with care functions?

8. What would you like to see in place to help family carers meet the needs of patients and your own needs?

**THANK YOU FOR YOUR PARTICIPATION**

APPENDIX D: Focus Group Discussion Guide for Key Informants

**Focus Group Discussion Guide for Key Informants FGD Tool No...........**

**Changing Family Roles: Coping Mechanisms of Family Carers in HBC in Zambia.**

Location of Focus Group Discussion....................................................................

Date...................................

Start Time ............................ End Time................................

Number of participants Males { } Women { }

List of attendees and where they are from

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
_____________

**Introductions and Consent**:

- Greet participants and self-introduction.
- Provide purpose of the study and the procedures to be followed during the interview (as stated in the consent form). Inform participants about note taking and audio recording during the interview
- Allow participants to introduce themselves
- Participants will be allowed to ask for clarity of questions
- **Seek consent by reading( by reading out the consent form)**

**A: Information on HBC activities**

9. Are you aware of any home based care (HBC) activities going on in this community? *Probe* for type of patients receiving HBC, chronically or non-chronically ill, diagnosis if known, where the patient are found, who cares for them, what care they are receiving.

**B: Information on Carers**

10. In view of the response above in no. 1, if positive, (*Probe* whether those providing care are women, men, youths, volunteers, family members and others, ages of carers, whether the carers live in the household or not, relationship with patients; paid or not paid)

11. What/How is the selection of carers:( prompt if they are chosen, by whom, what is the criteria and why? Or how do carers become carers?)

## C: General preparations for care functions

12. How do carers obtain/acquire knowledge on how to manage chronically ill patients?

    *Probe for:* Information on acquisition of knowledge: How knowledge is acquired, who is responsible, duration, adequacy of training, or explanation on how else care knowledge is acquired, whether appropriate or not and why the response. )

## D: Challenges in care functions

We will now talk about challenges faced by informal carers during care work.

13. Can you describe the kind of challenges faced by family carers during care work:
    *Prompt for*: Type of challenge(s), source of challenges, frequency of occurrence of challenges, ability of carers to address challenges. Why are carers facing these challenges?
    Follow up question on why other carers are able to deal with challenges and others not.

## E: Identifying and harnessing resources to cope with care functions

14. We will now talk about resources that can and will help informal carers adequately meet the needs of their patients.

In your view what are the available resources that carers can access and those they cannot access?
*Probe*: How these resources are identified? Where these resources can be found? Identification of resources,(household, community and from the government: human, material, social, spiritual)? How do they deal with situations where they have no resources to help meet the needs of the patient and why? What kind of support exist in the community to help family carers cope with care functions?

15. What would you like to see in place to help family carers meet the needs of patients and their own needs?

**THANK YOU FOR YOUR PARTICIPATION**

# APPENDIX E: Checklist for Record Review

**Checklist for Record review** **Checklist Tool No............**

**Changing Family Roles: Coping Mechanisms of Family Carers in HBC in Zambia.**

**Location..........................................................................................**

**Date of Review............................**

| No. | VARIABLE | | | | | | |
|---|---|---|---|---|---|---|---|
| 1 | Name of organisation/Institution participating in the study | | | | | | |
| | | | | | | | |
| 2 | Date of establishment of the organisation/Institution | | | | | | |
| | | **Men** | **Women** | **Youths** | | **Total** | **Records reviewed and Comments** |
| | | **25-60** | **25-60** | **15-19** | **20-24** | | |
| 3 | **Number of trained carers** | | | | | | |
| 3.a | Volunteer | | | | | | |
| 3.b | Family members | | | | | | |
| 4 | **Number of untrained carers** | | | | | | |
| 4.a | Volunteer | | | | | | |
| 4.b | Family members | | | | | | |
| 5 | **Remuneration of carers** | | | | | | |
| 5.a | Number of Paid carers | | | | | | |
| 5.b | Number of Unpaid carers | | | | | | |
| 6 | Number of patients cared for in the last 2 years | | | | | | |
| 7 | Diagnosis of patients (if known) being cared for | | | | | | |
| 8 | Number of households currently under care | | | | | | |
| 9 | Frequency of visits to households | | | | | | |
| 10 | Type of support to households | | | | | | |
| 11 | Type of support to patients | | | | | | |
| 12 | Type of support to carers | | | | | | |

leeds metropolitan university

Faculty of Health

Civic Quarter
Leeds
LS1 3HE

Tel: 0113 812 0000
Main Switchboard
Web: www.leedsmet.ac.uk

[redacted]

14 January 2010

Dear Muriel

*Research Project 208: Who cares for carers: coping mechanisms of informal carers in home based care in Zambia*

Thank you for confirming that you have received a favourable ethical opinion for the above research given by The University of Zambia Biomedical Research Ethics Committee (their letter dated 4 January 2010).

I am happy now to confirm that Chair's Action has been taken to confirm a **favourable ethical opinion** for your research as detailed in the documentation. The Faculty Research Ethics Committee will be informed of this decision at its meeting in January 2010. Please notify the Faculty Research Ethics Committee if there are any significant changes in the study.

For your information, ethical approval is granted for a period of two years, after which point you will need to apply for an extension of approval. Please would you also note that we may, for the purposes of audit, contact you from time to time to ascertain the status of your research.

On behalf of the Committee I would like to express our good wishes and hope that there will be a successful outcome to your research.

Yours sincerely

[redacted]

Faculty Research Ethics Committee Chair
Faculty of Health
email l.j.norton@leedsmet.ac.uk

CC: Professor Rachael Dixey

*Faculty Research Ethics Committee administrator*
Sheila Casey, Faculty of Health, Room G28 Queen Square House
Leeds Metropolitan University, Civic Quarter, Leeds, LS1 3HE
email: s.a.casey@leedsmet.ac.uk, tel: 44 113 812 4312, fax: 44 113 283 1908

# THE UNIVERSITY OF ZAMBIA

## BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarec@unza.zm or unzarec@zamtel.zm
**Assurance No. FWA00000338**
**IRB00001131 of IORG0000774**

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

4 January, 2010
Ref.: 015-11-09

[redacted]

Dear [redacted]

RE: SUBMITTED RESEARCH PROPOSAL: **"WHO CARES FOR CARERS: COPING MECHANISMS OF INFORMAL CARERS IN HOME BASED CARE IN ZAMBIA"**

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee extra-ordinary meeting on 25 November, 2009 and was found to be well written. The proposal is approved.

**CONDITIONS:**

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).
- **Ensure that a copy of final results of the study is submitted to this Committee.**

Yours sincerely,

[redacted]

**Date of approval:** 4 January, 2010 **Date of expiry**: 3 January, 2011