EXPERIENCES OF CAREGIVERS IMPLEMENTING HIV AND AIDS SERVICES WITHIN COMMUNITY-BASED ORGANIZATIONS (CBOS) IN RURAL MASERU: LESOTHO

By

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DECLARATION

I declare that this mini-dissertation submitted for Master's Degree in Nursing at the University of the Free State is my personal work and has not been previously submitted for another academic qualification.

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MAMELLO G. MAKOAE

JULY 2014

DEDICATION

This research is dedicated to:

- My children: Diamond Lawson Lesaoana and Manehella Queenth Lesaoana. You have always been unconditionally there for Mom even at the most trying times during my studies.
- My late Mother: Masentebale Agnes Lineo Ramokepa – Makoae. I could have made you more proud.
- My dearly Sister: Sentebale Mamakoatsi Ratselane. You have been a shoulder to cry on.
- My lovely brothers: Lerotholi and Thato Makoae
- My precious late brother: Teboho Justice Makoae. You could have loved to witness my graduation. I will miss you as I celebrate my success.

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti- retroviral therapy
CBOs	Community Based Organizations
HIV	Human immune deficiency virus
LENASO	Lesotho Network of AIDS Service Organizations
NGO	Non-government Organization
OVC	Orphans and Vulnerable Children
PLWHIV	People Living With HIV
PMTCT	Prevention of Mother to Child Transmission of HIV
SADC	Southern African Development Community
UNAIDS	United Nations Programme on HIV and AIDS
UNFPA	United Nations Fund for Population Activities
UNICEF	United Nations International Children's Emergency Fund
WHO	World Health Organization

ABSTRACT

Prevalence of HIV in Lesotho has remained at the plateau of 23% for years, and this has increased the demands in care and support of the infected people (Akinkugbe and Mohanoe, 2009:132). With increased demand in care, the communities are forced to take charge and to voluntarily provide care and support to their relatives, friends and neighbours hence the establishment of the support groups and the Community Based Organizations (CBOs) which implemented HIV and AIDS activities in the communities at the grassroots (Kell and Walley, 2009:7-8).

A qualitative research was employed using focus group interviews to explore and describe the experiences of HIV and AIDS Caregivers within these CBOs. Tesch's (1990) method of data analysis as adopted and explained by Creswell (2009:185) was used to analyze data.

A purposive sample of HIV and AIDS caregivers was used and their experiences were categorized into activities, challenges, motivating factors and recommendations. The recommendations emanated from the discussions included the need to: design a standard guideline for community-based caregivers; include the caregivers in the budget for incentives, design the training guide for refresher courses and provide routine supervision and mentoring. The discussions also point to need for the local NGOs to involve the communities in their planning.

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CHAPTER 1
INTRODUCTIONS AND PROBLEM STATEMENT

1.1 INTRODUCTION

Human immune deficiency virus (HIV) has been reported by World Health Organization (WHO) to have caused the biggest epidemic worldwide whereby it is estimated that 34 million people in the world are HIV infected (UNAIDS World Aids Day Report, 2011). Approximately 22.9 million people are reported to have died from AIDS -related illnesses in Sub-Saharan Africa in 2005; while 22.4 million people are HIV positive (World Health Organizations, 2010: 11) This contributes to 68% of people living with HIV and AIDS in Sub-Saharan Africa (UNAIDS World Aids Day Report, 2011).

Lesotho as part of the Sub-Saharan Africa is among the countries with the highest HIV and AIDS prevalence at 23% for a population of 1.89 million (Lesotho Ministry of Health and Social Welfare Demographic Health Survey: 2009; Lesotho Ministry of Health and Social Welfare, 2010). Since 1986 when the first case of HIV and AIDS was identified in Lesotho, the statistical figures have been escalating from 4% in 1993 to 32% in 2003. However, there is a slight decrease that shows a plateau at around 23% from 2007 to 2009 (Lesotho Ministry of Health and Social Welfare Demographic Health Survey, 2009, Turkon, Hemmelgreen, Romero-Daza & Noble, 2009: 473). These figures are still high despite several interventions as per the report of the Lesotho National AIDS Commission, UNAIDS, (2009) that the annual mortality rate associated with HIV is 12,000. Even though the HIV prevalence rate is higher in the urban areas of Lesotho, the rural areas are still experiencing a big challenge as the prevalence rate is 21.1% (Hemmelgreen, Romero-Daza, Turkon, Watson, Okello-Uma, & Sellen, 2009: 405).

The key drivers of the HIV and AIDS epidemic in Lesotho are reported as: poverty, lack of resources, unemployment, food insecurity and multiple and concurrent partnerships

(Naidoo, Uys, Greeff, Hoizemer, Makoae, Dlamini, Phetlhu, Chirw & Kohi, 2007: 18-22; Ulick and Crush, 2007: 164).

While more people are infected with HIV, the Anti-Retroviral-Therapy (ART) is not accessible to all illegible clients as it is reported that about 26% of HIV positive clients were initiated on ART in 2009 in Lesotho (Lesotho Ministry of Health and Social Welfare, 2010: 10). There is high incidence of opportunistic infections that contribute to the increasing annual mortality rate due to AIDS-related illnesses (Makoae, 2009: 17). Palliative care is not technically practiced in Lesotho as there are no hospices. Chronically ill patients are admitted in hospitals, which are over-crowded with limited beds. As a result, most patients are cared for at their homes (Kell and Walley, 2009: 7-8).

Whereas the demands of HIV clients are increasing in Lesotho, the ratio is 1 health care worker to 8,000 patients (Akinkugbe and Mohanoe, 2009: 132). This situation has therefore increased the need for more support from volunteers and other community members including support groups and Community Based Organizations (CBOs) (Makoae, 2009: 19). Due to this task shifting, the volunteer caregivers within the CBOs are expected by the community to undertake duties of nurses without training (Kell and Walley, 2009: 7-8).

1.1.1 RESPONSE TO HIV AND AIDS PANDEMIC

In response to escalating HIV prevalence, the World Health Organizations (WHO) recommended multi-sectorial approach to address the increasing demands in HIV care, treatment and support. Lesotho adopted the multi-sectorial approach through establishment of many Community Based Organizations (CBOs) to implement HIV and AIDS interventions including palliative care for the chronically ill clients (Kell and Walley, 2009: 2-5).

These CBOs remain the key implementing partners at the grassroots to support the Lesotho government. They provide essential and comprehensive HIV and AIDS services in the community (Government of Lesotho National Strategic Plan, 2006-2011). According to the Lesotho partnership framework with the USA government, the civil society organizations including the CBOs are funded to implement HIV activities. The CBOs that are not funded still continue to support the HIV and AIDS patients at their homes.

The CBOs are composed of groups of volunteer caregivers who are mostly support groups. The care givers within these CBOs are the support system to the HIV and AIDS clients. They provide psycho-social support, Voluntary Testing and Counselling. They further support the people living with HIV (PLWHIV) and Orphans and Vulnerable Children (OVC) in the projects to strengthen their economic status. They support the PLWHIV and the OVC to establish home stead gardens for food security (Kabore, Bloem, Etheredge, Obbiero, Wanless, Doykos, Ntsekhe, Mtshali, Afrikaner, Sayed, Bostwelelo, Hani, Moshabesha, Kalaka, Mameja, Zwane, Shongwe, Mohr, Smuts & Tiam, 2010: 583-587).

1.1.1.1 Challenges encountered by the Caregivers implementing HIV and AIDS activities

It has been reported that the HIV and AIDS Caregivers continued to experience many challenges while implementing HIV and AIDS services in the community. These challenges include: capacity, resources in general, lack of technical skills, stress, food insecurity and lack of coordination of services (Turkon, *et al.*, 2009: 474-475, Government of Lesotho National Strategic Plan, 2006- 2011 published in 2009, Lesotho Ministry of Health and Social Welfare annual report, 2009).

1.1.1.1.1 Resources

Due to low economic status of Lesotho as a poor country, the HIV and AIDS caregivers experience challenges of unavailability of essential resources such as gloves and

aprons when handling the body fluids of chronically and terminally ill patients (Makoae, 2009: 18-24).

1.1.1.1.2 Food insecurity and increased workload

Whereas HIV and AIDS Caregivers are voluntarily taking care of the sick, they lack time to plough their own fields due to high workload. As a result, the nutritional status of both HIV and AIDS clients and that of their caregivers is hampered (Makoae, 2009: 25, Drimie, 2003: 651).

1.1.1.1.3 Stress and burnout

HIV and AIDS Caregivers are reported to often experience the stress and burn-out when caring for chronically-ill patients. These caregivers report that the level of stress increase when there is always high financial demand to ensure effective and comprehensive support emotionally, psychologically and socially (Makoae, 2009: 18-24).

1.2 THE PROBLEM STATEMENT

Regardless of the challenges mentioned above, the HIV and AIDS caregivers continue to provide voluntary services to their communities. Given these challenges and the responsibilities coupled with the general situation in Lesotho as a poor country, it became necessary to inquire into what actually motivates them to continue rendering the services. Over and above the prevailing challenges and how they cope with them, became the focus of the inquiry. The purpose of the study was therefore, to explore and describe the experiences of the HIV and AIDS caregivers within CBOs implementing HIV and AIDS activities in rural Maseru District in Lesotho. The value if the study is perceived to lie in the research-informed knowledge and it will inform the development of strategies aimed at supporting improving and motivating HIV and AIDS caregivers to further their services.

1.3 CONCEPT CLARIFICATION

The following concepts are used and discussed in this study**:**

1.3.1 EXPERIENCES

According to Oxford Free Dictionary (online: 2012), experience is defined as the practical contact with and observation of facts or events including knowledge and skill gained over time. In the context of this study experiences are thoughts and feelings of the HIV and AIDS Caregivers providing HIV and AIDS services in the communities of rural Maseru District in Lesotho.

1.3.2 HIV AND AIDS CAREGIVERS

The HIV and AIDS caregivers are the community members who provide voluntary services to HIV and AIDS patients (Kabore, *et al.,* 2010: 583-587). In this study the HIV and AIDS Caregivers are the volunteer caregivers in the Community Based Organisations (CBOs).

1.3.3 COMMUNITY BASED ORGANIZATIONS (CBOS)

According to Turkon, *et al*., (2009: 475) CBOs are groups of volunteers with a common goal to support the community-based activities. They may be formal and legally registered, while some are informal (Turkon, *et al*., 2009: 475, Akinkugbe, *et al*., 2009: 133-4). In this study CBOs refers to volunteer support groups that implement HIV and AIDS activities in the rural areas of Maseru Lesotho.

1.3.4 RURAL

According to Oxford Free Dictionary (online: 2012), rural means a remote area or a hard surface at the countryside. In this study, rural Maseru district means remote but places that are at the periphery of the town of Maseru.

1.4 RESEARCH METHODOLOGY

The research methodology will be discussed based on the following:

1.4.1 RESEARCH PARADIGM

According to Given (2008: 591), paradigm is described as “a set of assumptions and perceptual orientation shared by members of a research community that determine how members of the research community decide on the research methods that should be employed to study certain phenomena”. The phenomenon of interest in this study is the experience of the CBOs. Constructivism therefore, seemed the logical and suitable paradigm for adoption in this study. The paradigm was deemed suitable for at least two reasons. One, it enables the researcher to depict the reality, which exists within a context. Secondly, it has many constructions and interpretations (Polit and Beck, 2012: 12). According to Polit and Beck, (2008: 781), paradigm encompasses a set of philosophical assumptions and that guide one’s approach to an inquiry. These are the ontological, epistemological and methodological assumptions (Botma, Greeff, Mulaudzi, Wright, 2010: 40).

1.4.2 ONTOLOGY

The ontology is concerned with the nature of reality and its characteristics (Creswell, 2013: 20). It is believed that human beings create their own reality through the subjective meaning of their experiences, which are likely to be complex (Creswell, 2009: 8, Polit and Beck, 2012: 12-13). It is therefore reasonable to note in this inquiry that the knowledge, which the Caregivers construct, about their experiences will be based on among others, their subjective interpretations and will therefore be relative in nature.

1.4.3 EPISTEMOLOGY

Epistemology is concerned with what counts as knowledge and how these knowledge claims are justified, based on the relationship between the researcher and the researched (Creswell, 2013: 21). According to Botma, *et al.*, (2010: 40), epistemology puts more emphasis on the structure or format of knowledge rather than the content. It deals with how people can know and give explanation to something. In this study, the researcher will co-construct the subjective meanings from the reality and the perceptions as she will be interacting with the HIV and caregivers.

1.4.4 METHODOLOGY

Methodology is concerned with the manner in which the evidence will be best obtained (Polit and Beck, 2012: 13). In this study the researcher will be guided by the ontological and epistemological assumptions of the constructivism paradigm. Botma, *et al.,* (2010: 40) posit that the methodology for investigating the experiences of the HIV and AIDS caregivers must be inductive in nature. In obtaining the evidence in an inductive way, the study will therefore follow qualitative research designs and methods as explained by Creswell (2013: 22).

1.4.5 RESEARCH DESIGNS

The research design is defined as an architectural backbone of the study (Polit and Beck, 2012: 58). Since it describes the overall plan for obtaining answers to the research question, it must be clear and efficient (Babbie and Mouton, 2009: 72). This study will follow a qualitative, explorative descriptive contextual and phenomenological design.

1.4.5.1 Qualitative Research

Qualitative research is an inquiry that is based on distinct methodological traditions that explore the holistic picture, analyses words and gives a detailed view of informants and

their conduct in a natural setting (Creswell, 2013: 22). In this study the experiences of the Caregivers implementing HIV and AIDS activities will be explored.

1.4.5.2 Explorative Design

Explorative design is employed when little or no scientific knowledge in known about a group, process, activity or situation (Given, 2008: 327). The study will be explorative in nature, as the experiences of the HIV and AIDS Caregivers in Lesotho will be discovered for the first time in the proposed context. Marshall and Rossman (2011: 69) assert that such research has potential to generate new hypotheses. The new Caregivers' insights generated new hypotheses for further research as indicated in the section on recommendations in this research report.

1.4.5.3 Descriptive Design

Descriptive designs are aimed at providing an accurate portrayal of a particular event, for the purpose of finding a meaning, discovering what exists and the frequency of occurrence of such a phenomenon (Burns and Grove, 2009: 237). The study is aimed at gaining more insights into the HIV and AIDS Caregivers experiences regarding their activities in caring for HIV and AIDS clients. It was from this purpose that the study was therefore descriptive, as the reality of these individuals will be described within the principles of intuition and bracketing (Streubert and Carpenter, 2012: 81).

1.4.5.4 Contextual

Context implies the geographical, temporal cultural or aesthetic setting within which action took place (Patton, 2002: 63). It is from this intrinsic and immediate significance of the context that the qualitative researchers prefer to study the phenomenon of interest (Patton, 2002: 63). This study is contextual in nature, as the experiences of CBOs implementing HIV and AIDS activities in rural Maseru District in Lesotho, will be sought out where these experiences are discussed among the members. It is from this

contextual stance of the study, that the research will organize collection of data around the times of their meetings.

1.4.5.5 Phenomenological

The phenomenological design is aimed at capturing the essence of the lived experience of the participants for the purpose of understanding it's the meaning and its accurate description (Streubert and Carpenter, 2012: 78). The phenomenological approach in this study will be applied to explore the experiences of the caregivers implementing the HIV and AIDS services.

1.5 RESEARCH TECHNIQUES

The research technique that will be used for this study is focus groups. Focus groups are a form of interview that uses researcher-led group discussions to generate data (Given, 2008: 352, Polit and Beck, 2012: 537). The HIV and AIDS Caregivers within the CBOs implementing the HIV and AIDS services will be engaged in focus groups discussion by the researcher. The researcher will target the caregivers' regular meetings to recruit participants for focus group discussions. The scheduled meetings provided the participants with freedom of expression, feelings and behaviours. These are elements that signify homogeneity, which are required in focus group interviews (Burn and Grove, 2009: 513).

1.6 POPULATION

According to Given (2008: 644), population refers to "every individual who fits the criteria (broad or narrow) that the researcher has laid out for research participants". Polit and Beck (2012: 273-274) describe the population as the people who collectively behave in a similar manner or "characteristics". The Caregivers within the CBOs implementing HIV and AIDS services in communities of Lesotho are the population for this study. The HIV and AIDS Caregivers identified from the database of the Lesotho

Network of AIDS Service Organizations (LENASO) and the Lesotho Network of People Living with HIV and AIDS (LENEPHWA) will be the population in this study.

1.6.1 UNIT OF ANALYSIS

Polit and Beck (2012: 745) describe unit of analysis as "the basic unit that will yield data for analysis". There are 24 CBOs implementing HIV and AIDS services in the Maseru district with more than 15 members each registered with Lesotho network of AIDS service organizations (LENASO). Since Creswell (2013: 22) indicates that in-depth nature of qualitative research designs allow only few participants, not all the population of caregivers included in all the CBOs will be used. Thus, the units of analysis in this study will be CBOs who are implementing the HIV and AIDS services in the rural district of Maseru.

1.7 EXPLORATIVE INTERVIEW

Explorative interview is the mini study conducted preliminarily to the main study, so as to attest and identify gaps in the proposed study designs (Brink, van der Walt & van Rensburg *(*2012: 174-175). The purpose is for the refinement and improvement of the main study. Polit and Beck (2012: 195) assert that if the methods and the instruments of data collection are not appropriate, changes can therefore be applied.

Members of the HIV and AIDS Caregivers from one of the CBOs will be used for the purpose of explorative interview. As Brink, *et al.,* (2012: 174-175) advices, if data generated from the explorative interview require no change of methodology or questions this will form part of the major study.

1.8 DATA COLLECTION

According to Burns and Grove (2009: 42), data collection is the process of putting together relevant information gathered during the study. Before data collection,

gatekeepers are to give authorization (Polit and Beck, 2008: 70). The researcher went through to the following authority structures for approval of the study and data collection:

- Ethics committee of the Faculty of Health Sciences of the University of the Free State.
- Ethics committee of the Ministry of Health, Lesotho.
- Director General of the Ministry of Local Government
- District Administrator (DA) of Maseru District
- The principal chief of Maseru

The annexure at the end are given to prove the permission from the authorities.
The researcher compiled the list of CBOs in Maseru rural using the LENASO database. The researcher wrote the letters to CBOs chairpersons to request permission. The researcher introduced herself and the purpose of the study to the CBOs. When the Caregivers agreed, to participate in the study, they were requested to sign the consent form. The researcher negotiated for suitable times and places for interview appointments with the participants. As anticipated, the meeting times seemed to be appropriate time for data collection activities. The researcher made the participants aware that she would conduct the interviews in Sesotho language, as that is well understood by most participants.

Since the setting for the study was predominantly rural, the researcher complied with the acceptable and appreciated manner of dressing/attire, which was simple and casual and allowed for flexibility and interaction with the groups. The researcher requested permission to use the tape recorder to capture the interviews. This was so that data could later be analyzed and verified for documenting and reporting (Given, 2008: 190).

The researcher facilitated the focus-group discussions and took notes. Based on the experience and the nature of her work, the researcher has been engaged in several interviews for data collection of operational research in her field of work. The researcher

has under-gone the course on qualitative research for monitoring, evaluation and reporting of programs. This course enabled the researcher to gain skills in interviewing and facilitation of focus group discussions.

The researcher asked open-ended questions and used other techniques such as probing and paraphrasing to help in gathering more information (Brink, 2008: 152). The researcher affirmed confidentiality to groups of the CBOs.

The participants responded to the following questions:

- May you please tell me more about your activities as a HIV and AIDS Caregiver?
- May you please tell me more about your experiences in implementing activities?
- What motivates you to continue with your services?
- What do you think could be done to support you for the effectiveness and efficiency of your services?

At the end of discussions, the researcher thanked all participants for their time and contribution to the study. After the discussions, the researcher compiled the field notes while her memory was still fresh (Polit and Beck, 2012: 547-549). The field notes were based on a number of issues such as observation of actions of participants, their behaviors, and the experience of the researcher as well as feelings. The notes were therefore observational, theoretical, methodological and personal (Polit and Beck, 2012: 547-549). The researcher translated the field notes into English as soon as possible after each focus group interview.

1.9 DATA ANALYSIS

Data Analysis is re-arranging of information gathered during research to ensure that it can be interpreted to give clear meaning to the data (Burns and Grove: 2009: 43-44).

The transcribed tape-recorded interviews and the field notes were analysed using Tesch's method (1990) as cited by Creswell (2009: 185). This method provides the following steps that were used in the analyses:

- Get sense of the whole by reading through all of the transcriptions carefully, and write down the ideas as they come to mind;
- Pick one most interesting interview and go through it asking self: what is this interview about? Think of the underlying meaning. Write thoughts in the margin;
- Cluster similar topics together, and then form the topics into columns that might be arranged as major topics, unique topics and leftovers;
- The researcher revisited her data; abbreviate the topics as codes and write the codes next to the appropriate segment of the text;
- Turn topics into themes;
- Group together similar themes;
- Draw lines between the themes to show interrelationships;
- Make a final decision on the abbreviation for each category and arrange these codes alphabetically;
- The data materials belonging to each category were then assembled in one place, and a preliminary analysis was performed.

In line with Polit and Beck (2012: 569) open coding in which an independent coder and the researcher located the themes and assigned codes was used to convert data to smaller, more manageable and more manipulative units that could be easily retrieved. The researcher gave an independent coder who was experienced in qualitative research the raw data of the transcribed tape-recorded interviews and the field notes, as well as the Tesch (1990) method of data analysis as cited by Creswell (2009: 185). After analysing independently, the two met to discuss and reach consensus on the analysed data.

When it became necessary, re-coding of data was undertaken to capture the essence of what was being studied, and also identify other constituent parts of the needs (Tesch, 1990: 97; Creswell, 2009: 185). The results were then given to two of the research subjects to confirm whether the analysed data truly reflect their experiences.

1.10 MEASURES TO ENSURE TRUSTWORTHINESS OF THE RESULTS

In qualitative research, validity is measured through the accuracy and truthfulness of the findings (Brink, *et al.*, 2012: 172). Given (2008: 895) defines trustworthiness as "the way in which qualitative researchers ensure that credibility, dependability, transferability and conformability of the study are evident in their research".

Cuba's model, as referred to by Brink, *et al.,* (2012: 172) was used to ensure reliability of the results. The model identifies the criteria in assessing reliability.

1.10.1 CREDIBILITY

Credibility is mostly focusing on the reliability of the key findings during data collection in interviews whereby technicalities of the researcher in analyzing data looked into integrity to establish the truth of such findings (Brink, *et al., 2012: 172*). Babbie and Mutton (2009: 277) further emphasize that credibility is about the truth of the findings in the qualitative study. In this study the researcher engaged the co-coder with experience to assist in analysis of data. The researcher also checked with the participants to ensure that they agree with the findings (Patton, 2002: 220).

1.10.2 DEPENDABILITY

Dependability refers to stability of data and reliability, both of which denote credibility, and trustworthiness of the findings of the study (Polit and Beck, 2012: 585, Brink, *et al.* 2012:172-173). This was done to ensure that the information remained as original as was collected from the respondents. The researcher compared hand written notes to the recorded tapes during focus group discussions. Data was reviewed for consistency of study findings. Furthermore, the co-coder was engaged to review collected data for accuracy by comparing the transcribed notes with the research questions (Creswell, 2009:185).

1.10.3 TRANSFERABILITY

Transferability refers to the probability that the finding of the study may be sound and could be positively considered and applied for use by others in a similar situation (Brink, *et al.,* 2012: 173). Polit and Beck (2012: 585) denote that transferability means possibilities for application by others while on the same note, Babbie and Mutton (2009: 276) describes transferability as about when the findings of the study can be transferred and applied in other contexts; thus influencing change. The researcher compiled a dense description of the research methodology and findings to allow the reader to decide whether data can be used in another setting (Babbie and Mutton 2009: 276).

1.10.4 CONFORMABILITY

Conformability refers to neutrality and accuracy of data (Polit and Beck, 2008: 539). Brink, *et al.,* (2012: 173) reiterate that conformability is about information from the participants' views and the researcher should not be biased based on perceptions. Conformity was ensured by following the steps in qualitative research and by transparency in engaging participants. The documents that include unprocessed data from the focus groups discussions, scripts, and recorded tapes, produced material, processed notes as well as personal notes and the draft reports were handed over to the co-coder for audit (Creswell, 2009: 185).

1.11 ETHICAL ISSUES

The study followed the acceptable research ethics considerations such as informed consent, privacy and confidentiality (Burns and Grove, 2009: 61). How this was maintained is discussed in chapter 2.

1.12 LAYOUT OF THE STUDY

Chapter 1: Introduction and Problem
Chapter 2: Research Methodology
Chapter 3: Data Presentation and Literature Control
Chapter 4: Discussions, Conclusions, Recommendations and Limitations

1.13 CONCLUSION

The purpose of this first chapter was to provide a synopsis of this study. This chapter gave an overview of the HIV epidemic and the situation in Lesotho, whereby the volunteer caregivers within the community-based organizations implement HIV and AIDS services in the communities. The problem statement and the rationale for the research were described. The research question was identified and discussed. The definition of main concepts was given for clarification of the study. The research design and the research paradigm were explained. The population and the sample were identified and defined. Data collection methods and analysis were described. Measures to ensure trustworthiness were discussed with consideration of ethical issues. The research methodology is discussed in the next chapter.

CHAPTER 2
RESEARCH METHODOLOGY

2.1 INTRODUCTION

An overview of the study was discussed in chapter 1. This chapter discusses the research methodology that was followed to achieve the purpose of the study, which is to explore and describe experiences of the HIV and AIDS caregivers within CBOs implementing HIV and AIDS activities in rural Maseru District in Lesotho. The chapter first dwells on constructivism as the paradigm that the study proposed. As this worldview informs how a certain phenomenon is to be studied, this chapter will further deal with the research approach, research technique, description of data collection, analysis, as well as trustworthiness of the results and the ethical considerations that were followed in this inquiry.

2.2 RESEARCH PARADIGM

Paradigm is described as “a set of assumptions and perceptual orientation shared by members of a research community, that determine how members of research community decide on the research methods that should be employed to study certain phenomena (Given 2008: 591). The phenomenon of interest in this study is the experience of the HIV and AIDS Caregivers within the CBOs. Thus, a suitable paradigm is constructivism, as this paradigm depicts that reality exists within a context and has many constructions and interpretations (Polit and Beck 2012: 12). The constructivism paradigm influenced the exploration and description of the factors that incited the experiences of Caregivers within their social norms, beliefs, religious and political spheres of lives (Given, 2008: 118). As Botma, *et al.,* (2010: 288) advice, the researcher took into consideration the external environment, internal reality of subjective experience and social constructed reality and gave a descriptive meaning.

According to Polit and Beck, (2008: 781), paradigm encompasses a set of philosophical assumptions that guide one's approach to an inquiry. Botma, *et al.,* (2010: 40) identify these set of philosophical assumptions as the ontological, epistemological and methodological assumptions.

2.2.1 ONTOLOGY

Ontology explores the reality and nature of what is being studied (Brink, *et al.* 2012: 24). According to de Vos, Strydom, Fouche and Delport (2011: 309), ontology reflects on the reality of the social world. According to Polit and Beck (2012: 13), reality in constructivism paradigm is multiple, subjective and mentally constructed by individuals. In this study it was believed that the HIV and AIDS Caregivers within the CBOs had multiple realities regarding the activities, and as these are complex, they were allowed to create their own reality through the subjective meaning of their experiences (Creswell, 2009: 8, Burns and Groove, 2009: 51). In giving this latitude to the participants to construct their reality, it was imperative for the researcher to use research approaches that would allow and accommodate the complexity and subjectivity of the participants' reality (Creswell 2013: 36). As the participants constructed and co-constructed their realities through interaction with each other, it was necessary to use qualitative research approach, as this allows these multiple realities to be studied (Creswell 2013: 36).

2.2.2 EPISTEMOLOGY

Epistemology is concerned with what counts as knowledge and how these knowledge claims are justified, based on the relationship between the researcher and the researched (Creswell 2013: 21). In describing epistemological assumptions, Botma, *et al.,* (2010: 40), put more emphasis on the structure of knowledge rather than the content itself. In this manner, more value is placed on how the researcher knew and gave explanation to the knowledge claims (Creswell 2013: 21). In this study, the researcher became a co-constructor of evidence through description of the evidence (Creswell

2013: 36). Thus, the subjective meanings from the multiple and complex realities as given by the HIV and AIDS caregivers were interacted with and listened to for the purposes of interpreting the evidence (de Vos, *et al.,* 2011: 308-311).

In order to maintain trustworthiness of the study, the researcher avoided bias when she gave meanings to perceptions. In avoiding the biasness in the interpretation of the caregivers' perceptions, the researcher engaged the external co-coder who is a professional and expert in qualitative research studies. Based on how this knowledge was discovered, it was imperative for the research to employ qualitative research, as this approach does not present a definitive set of rules that may prevent the researcher from being a key instrument in data collection (Creswell 2013: 46).

2.2.3 METHODOLOGY

Methodological assumptions deal with the way in which information will be retrieved or obtained from the participants (Botma *et al.,* 2010: 288-289). Methodology explains how the researcher conducted investigations in the study (Botma, *et al.*,2012: 41). Botma, *et al.,* (2012: 41) indicate that the social world should be studied based on ontological assumptions. As ontology within constructivism paradigm is multiple, subjective and mentally constructed by individuals, the researcher had to align this with how the evidence was retrieved from the participants. The researcher's choice of method of how the truth should be known to the out-side world was also guided by the epistemology (Botma, *et al.,* 2012: 41). It is from this understanding of the subjectivity of epistemology and complexity of reality that the researcher decided on focus group interviews as method for collecting data.

Based on the philosophical assumptions of constructivism paradigm, the qualitative inquiry had to be employed for the collecting, analyzing and disseminating data in this study.

2.3 RESEARCH DESIGN

Research design is defined as the overall plan for addressing a research question to enhance the study integrity (Polit and Beck, 2012: 741). The purpose of this research is to understand the experiences of the HIV and AIDS Caregivers within the CBOs. The appropriate designs employed in this study were the explorative, descriptive, contextual and phenomenological designs within the qualitative inquiry.

2.3.1 QUALITATIVE RESEARCH

Qualitative research is an inquiry that is based on distinct methodological traditions that explore the holistic picture, analyses words and gives a detailed view of participants and their conduct in a natural setting (Creswell, 2013: 22). As Streubert and Carpenter (2012: 20) assert, the fundamental belief of qualitative research, is the idea that there is existence of multiple realities and that meaning has to be created for individuals participating in research. The researcher opted for qualitative research based on these characteristics as opposed to quantitative research. Table 1 below features the comparison of the quantitative and qualitative research and is followed by justification for adoption of the latter type of research in this study.

Table 1: Comparison of qualitative and quantitative research adopted from Streubert and Carpenter (2012: 20)

Qualitative Research	Quantitative Research
• It values the subjectivity of data	• Objective
• It focuses on multiple realities	• One reality
• While the aim is at discovery, this entails giving a description and understanding	• Reduction control and prediction
• It is geared towards Interpreting the data	• Measureable
• Whole is greater than the parts	• Parts equal the whole
• Report rich narrative	• Report statistical analyses
• Researcher part of the research process	• Researcher separate
• It is human in sense it call units of analysis participants	• Subjects
• Context dependent	• Context free

It is from these characteristics as listed in Table 1, that qualitative research strengths are being manifested (Streubert and Carpenter 2012: 20). It was because of these strengths that the researcher considered qualitative inquiry suitable to study the subjective, multiple and context-bound experiences of the Caregivers implementing HIV and AIDS services. According to Creswell 2013: 46) qualitative research involves the use of multiple designs rather than a tightly prefigured design. Thus, in this study the researcher executed explorative, descriptive contextual and phenomenological designs in reaching the purpose of the study.

2.3.2 EXPLORATIVE DESIGNS

Given (2008: 327) depicts that researchers use explorative design when they possess little or no scientific knowledge about a group, process, activity or situation they want to examine. In this study, explorative design was employed because there is neither data nor studies done in Lesotho regarding the experiences of the Caregivers in CBOs implementing HIV and AIDS services. This study is therefore one of the first research endeavors to qualitatively seek an experience-informed understanding of community-based experiences of Caregivers implementing HIV and AIDS activities in Lesotho and Maseru in particular. The formulation of strategies for the support, improvement and motivation of the caregivers implementing the HIV and AIDS activities in Lesotho had to be preceded by the exploration of their experiences from their view point. Marshall and Rossman (2011: 69) further posit that hypotheses generated by these discoveries are often a basis for further research. Interrogation of data for this inquiry led to discovery of one new hypothesis, which is mentioned and expounded on in Chapter four of this report.

2.3.3 DESCRIPTIVE DESIGNS

Polit and Beck (2012: 226), illustrate that descriptive research provides an accurate portrayal of a particular event or individuals for the purpose of discovering what exists as well as the frequency of those occurrences. It was considered necessary to conduct a descriptive design before drawing conclusions regarding strategies that will support and motivate the Caregivers implementing HIV and AIDS activities within CBOs. The purpose of descriptive research is to observe, describe and document the aspects of a situation as it occurs naturally (Polit and Beck 2012: 226). The description of the experiences of the HIV and AIDS Caregivers will constitutes combining the emic view of the participants and the etic view of the researcher as to form a final holistic product or conclusion for developing strategies that aimed at improving HIV and AIDS services through support and motivation (Streubert and Carpenter 2012: 172). As Streubert and

Carpenter (2012: 172) affirm, the strengths of etic view lies within the interpretation of emic view of the participants.

Descriptive designs are used to gain information about characteristics of a phenomenon of interest within a particular field of study (Burns and Grove, 2009: 237). This attribute of descriptive designs was found to be appropriate for the purpose of this study, as more information from the HIV and AIDS Caregivers' experiences regarding their activities was needed for funding purposes in Lesotho. As Brink, *et al.,* (2012: 112), advice, descriptive design was used to facilitate provision of relevant information that can be for the utilization of other professionals within the same field of HIV and AIDS. As descriptive designs are known to document the aspects of a situation as it occurs naturally it was found necessary in this study to preserve the natural context of the participants (Creswell 2013: 45). Hence the participants were not removed from the site where they normally hold their meetings.

2.3.4 CONTEXTUAL DESIGN

One of the aspects of qualitative research is the need to preserve the natural context (Patton 2002: 63). The context is seen as a framework, the reference point or an ecological sphere that is used to map people and their action (Patton 2002: 63). According to Babbie and Mouton (2009: 272), contextual designs are used to understand events, actions and process in their natural situation or context but not to generalize the findings to other situations.

The rural Maseru in which Caregivers implement the HIV and AIDS activities is the natural context of this study. These villages give context-based clues such as poverty, lack of health facilities and poor infrastructures such as roads. The context is necessary for the purpose of understanding and interpretation of the experiences of the caregivers implementing HIV and AIDS services therein. The phenomenon of interest in this study was studied because of its intrinsic relationship with the context, namely, the villages in which the Caregivers offer their services. The interviews were conducted at locations where the Caregivers hold their meetings and where the interaction and sharing of

experiences happen after their daily activities. To satisfy the principles of contextual designs in qualitative research, data was collected without disturbing the natural context (Babbie and Mouton 2009: 272). The context of the inquiry was taken as found, whereby the HIV and AIDS Caregivers were directly observed as they discussed issues and field notes were recorded in order to provide an accurate description of the phenomenon.

2.3.5 PHENOMENOLOGICAL

The phenomenological approach examines the lived experiences as explained by the people who experienced the phenomenon (Brink, *et al.,* 2012: 121-122). The phenomenological approach concentrates on the study of consciousness and objects of direct experience by individuals (Fouche and Deplort, 2005: 270). The approach deals with the reality as explained by the people who lived the experience and give their own meaning of the situation (Botma, *et al.,* 2010: 288). In this study, the HIV and AIDS Caregivers as people who lived the experience were asked to give meaning to their multiple realities as they cared for and support people with HIV and AIDS. The information was tape recorded as is, meaning the participants were allowed to use Sesotho, as to express themselves with the language they know very well. This is the mother tongue of the researcher.

In phenomenological approach, bracketing is very important as to avoid prejudices or biases (de Vos, *et al.,* 2011: 317). In this study, the researcher bracketed her own views and remained focused on and audio-recorded what was explained by the Caregivers as their own experience. The researcher probed more to allow HIV and AIDS Caregivers to share more experiences and narrate their own stories (de Vos, *et al.,* 2011: 317).

2.4 RESEARCH TECHNIQUES

Research technique provides a research method for a researcher to select the way in which information of interest can be obtained. The most appropriate technique for the

field researcher is questioning (de Vos, *et al.,* 2011: 360). In this study, focus group interviews were used as a method of data collection and the open-ended questions were used to allow participants to express themselves.

2.4.1 FOCUS GROUP INTERVIEWS

The Focus group interviews are a type of interview that uses researcher-led group discussions to generate data (Given, 2008: 352, Polit and Beck, 2012: 537). de Vos, *et al.,* (2011: 361) defines focus group as the well planned discussions that promote interaction and self-disclosure among participants, which is useful in generating information within a short space of time. The focus groups are groups of participants selected because they have something in common, in connection with the topic of the study (de Vos, *et al.,* 2011: 360). In this study, the researcher used convenience grouping as advocated by Polit and Beck (2012: 537) and Burns and Groove (2009: 514). It was convenient in that, those who lived in one community and worked together were selected to form a group. This was done as these caregivers share similar background and at times care for one another. The researcher took the opportunity of scheduling her appointments for the setting of appointments and facilitation of focus group interviews on the dates scheduled for the regular meetings of the CBOs. In collaboration with the chairpersons of the CBOs, the interviews were conducted in the environment that was relaxed to allow freedom of movement and speech (de Vos, *et al.* 2011: 361, Polit and Beck, 2012: 542).

2.4.1.1 Advantages of the Focus Group Interviews

The researcher used the focus group interviews because they allow the participants to express their views and learn from each other as much as possible (de Vos, *et al.,* 2011: 362). In this study learning from each other was seen when others encouraging information disclosure and empowering one another in a group (Burns and Groove, 2009: 514). In this inquiry, the researcher allowed the participants to talk freely as they expressed themselves in their local language. The technique was also perceived to be

more involving, respectful, friendly and supportive when people were in a group (de Vos, *et al.,* 2011: 362). The researcher in this study divided the HIV and AIDS caregivers into smaller groups of 8 people per focus group discussion to raise the level of participation (de Vos, *et al.*, 2011: 362).

According to Burns and Grove (2009: 513-14), the purpose of the study should be explained to participants prior to their involvement. In preparation for the focus groups' meetings, the researcher clearly defined the purpose of the study to the chairpersons of the CBOs and obtained permission to conduct focus-group interviews. The researcher recruited the participants for focus group discussions during the regular meetings of the HIV and AIDS caregivers. These elements signified homogeneity that is normally required in focus group interviews (Burns and Grove, 2009: 513).

2.4.1.2 Disadvantages of Focus Group Interviews

Some of the short limitations and shortcomings involved in the focus group interviews include more time spent in the discussions, as compared to questionnaires (Burns and Groove, 2009: 514). For purposes of this inquiry, the interviews took 45 minutes to an hour to be completed. Even though they seemed to be long, more useful data was obtained despite the lengthy time spent. The focus group interviews are further perceived to be more costly as the process may require more people to be engaged such as translators (Burns and Grove, 2009: 513). In this study, the researcher did not engage a translator, as she is fluent in Sesotho, which is the first language for the HIV and AIDS Caregivers.

The data-collection activity was not free of some challenges. For instance one of the challenges was that the participants wanted to discuss some issues that were not relevant to the purpose of the study (Burns and Groove, 2009: 513). For most participants the focus group discussion became an opportunity for them to air long-standing issues. So the participants took advantage of raising other issues such as problem of electricity installation. In such cases, the researcher referred the participants

to the relevant service-provider and redirected the participants to the purpose of the study without completely ignoring their other concerns.

Burns and Groove (2009: 514) caution that sometimes participants may be emotionally challenged as they give their personal accounts regarding the phenomenon of interest. Such was another of the challenges, which confronted the researcher. Some of the participants in this study got emotional as they shared their experiences. In cases of emotional feelings expressed the researcher allowed a period of silence for the participants to recover from these emotions (Burns and Groove 2009: 514). Besides sharing of their sentiments, some of the participants were confrontational as the discussions became engaging and robust. However, the researcher demonstrated the facilitation skills by reshaping and rephrasing the questions to avoid conflicts (de Vos, *et al.,* 2011: 373).

The researcher made use of her experience in facilitating the focus group discussions, as the researcher is used to conducting operational researches in Lesotho. The researcher had undergone training of short courses on qualitative research even before conducting this study.

Even though the researcher is experienced in facilitating the focus group discussions, it was essential to test whether the question intended for the study would yield the desired responses. Thus, an explorative interview was conducted in order to address and minimize the potential challenges before undertaking the main study (Polit and Beck, 2012: 195).

2.5 EXPLORATIVE INTERVIEW

Explorative interview is the mini study conducted preliminarily to the main study to attest and identify gaps in the proposed study designs (Brink, *at. al*. 2012: 174-175). The members of one of the CBOs in rural Maseru were interviewed for the purpose of explorative interview. Data generated from the explorative interview formed part of the major study because there were no changes required in the methodology and questions (Brink, *at. al*., 2012: 174-175)

2.6 POPULATION

According to Given (2008: 644), the population refers to “every individual who fits the criteria (broad or narrow) that the researcher has laid out for research participants”. Consistent with this assertion is Polit and Beck’s (2012: 273-274), description of population as the people who collectively behave in a similar manner or “characteristics”. The population for this study was the HIV & AIDS caregivers within the CBOs implementing HIV and AIDS services in communities of Lesotho. Since the researcher could not interview all the HIV and AIDS caregivers in Maseru, the selection criterion was based on the research topic which clearly indicates HIV and AIDS caregivers who provide services in Maseru rural. The total population was made up of 15 members per 10 CBOs, which is 150 HIV and AIDS caregivers in Maseru rural.

2.6.1 UNIT OF ANALYSIS

Polit and Beck, (2012: 745) describe unit of analysis as “the basic unit that will yield data for analysis”. According to Given (2008: 644), the unit of analysis is the smaller groups of people in sampling as opposed to the quantitative study whereby the whole population can be interviewed. In this study, units of analysis were the HIV and AIDS Caregivers from the CBOs implementing HIV and AIDS services in the district of Maseru, Lesotho.

2.6.2 SAMPLING

Qualitative researchers select their participants, based on the participants’ first-hand experience with phenomenon of interest (Streubert and Carpenter 2012: 20). Thus, purposive sampling was used as this facilitated a heterogeneous sample in this study (Creswell 2013: 155). The sample in this study was purposeful as the researcher purposefully recruited the male participants into the study, as few of them are HIV and AIDS Caregivers.

2.6.3 SAMPLE SIZE

According to Burns and Grove (2009: 711), in qualitative research, it is not everybody who is included in the study. The qualitative data provide a comprehensive description in an actual context that can reveal intricacy, which may have an effect on the phenomenon, and for this reason the number of subjects is often limited. In qualitative research, the sample size is determined by the saturation of data (Burns and Groove, 2009: 711). In this study, saturation of data was reached after 8 focus group interviews were conducted.

2.7 DATA COLLECTION

According to Burns and Grove (2009: 42), data collection is the process of putting together relevant information gathered during the study. Before data was collected by the researcher, the authorities and gatekeepers such as the chiefs, the District Administrators as well as the chairperson of the CBOs were consulted for authorization (Polit and Beck, 2012: 540).

Before the researcher collected the data, there was approval of the study and access to the participants was approved by the following authority structures that were conducted:

- Ethics committee of the Faculty of Health Sciences of the University of the Free State
- Ethics committee of the Ministry of Health, Lesotho
- Director General of the Ministry of Local Government
- District Administrator (DA) of Maseru District
- The principal chief of Maseru
- The chairpersons of the committees of the (CBOs).

After granting of permission by the authorities, the researcher compiled the list of CBOs in Maseru rural using the LENASO database. She then wrote the letters to the

chairpersons of the CBOs to request for permission to conduct the study and to secure the appointments. On the appointment date, which is the first visit to the field, the researcher met the chairpersons of the CBOs to give information about the study the purpose of study. The second visit was done to discuss the purpose of the study and how it will unfold with the Caregivers, and the Caregivers who agreed to participate in the study voluntarily, were informed that they will have to sign an informed consent. The researcher then arranged appointment with participants at their suitable times and convenient places. The researcher worked with the chairpersons to secure the date for the interviews.

2.7.1 CONDUCTING THE FOCUS GROUP INTERVIEWS

2.7.1.1 The Day of the Interviews

On the day of the discussion, the researcher again explained the purpose and the value of the study. The ethical considerations and informed consent were explained to the chairpersons of the CBOs and the caregivers. The benefits of the study were described to participants as freedom of speech through expression of their views, which may form the recommendations to the authorities in Lesotho.

During the visits to the villages, the dress coat was observed in accordance to the Basotho culture. The dress was acceptable smart-casual with the length below the knees to show respect to elders in the villages. This was done to allow flexibility and interaction with the groups in the villages so that the researcher could be seen as part of them (Burn and Groove, 2009: 511).

Before conducting the interviews, it was ensured that the number of the participants was not more than 8 to allow interaction with all the participants (de Vos, *et al.* 2011: 366). Those that arrived late were not selected to participate in the study as more than the number expected turned up for discussions.

The researcher used her facilitation skills to build rapport with the participants. The participants were made to feel at ease by starting with engaging them in an ice- breaker whereby she sang a song that is popularly known in village communities in Lesotho, namely – (seana-marena) i.e. Basotho blanket. A few more jokes were made to engage with the participants (Polit and Beck, 2012: 542-3). This type of icebreaker helped the researcher to build rapport with the participants. Snacks were served in order to allow interaction among participants and to further act as icebreaker so that the participants could feel at easy (de Vos, *et al.* 2011: 372*)*. As to avoid coercion to participate, the snacks were served before signing the informed consent.

To further relax the atmosphere the researcher greeted the participants and explained the process of the interviews. Open-ended questions were aksed in a relaxed, socializing but brief manner as to allow participants to express themselves (Burns and Groove, 2009: 510). During the interviews, the researcher requested for permission to use the tape recorder so that she could later analyze and verify data for documenting and reporting (Given, 2008: 190).

The researcher asked the following questions:

- May you please tell me more about your activities as a HIV and AIDS Caregiver?
- May you please tell me more about your experiences in implementing activities?
- What motivates you to continue with your services?
- What do you think could be done to support you for the effectiveness and efficiency of your services?

As indicated by Polit and Beck (2012: 543), where the researcher needed clarification, she used the communication techniques such as listening, probing and paraphrasing explained below.

2.7.2 COMMUNICATION TECHNIQUES

The researcher used the following communication techniques to gather information and to facilitate expression of views by the participants: listening, probing, and paraphrasing

- **Listening**

  The researcher listened carefully to the participants as they were sharing their experiences and kept nodding head to show attentive listening (Burns and Groove, 2009: 510, Polit and Beck, 2012: 543). To encourage the participants to continue talking the researcher either used clues and hints such as; *mmm*…., or allowed silence so that the participants could think and add more on what they had said.

- **Probing and paraphrasing**

  As advised by Burns and Groove (2009: 510), the researcher used probing to seek for clarity of some incomplete sentences or too short sentences. Therefore the researcher asked questions such as *"and then?" "What more happened?" "Did you say…", "I understood you well when you said…..," "Can you say more on that?"* This facilitated generation of more information from the participants.

  At the end of discussions, the researcher made sure that all has been discussed and there was no information closed out as she asked questions such *as: Do you have anything more to say? "* (Polit and Beck, 2012: 543). The researcher thanked all participants for their time and contribution to the study and re-affirmed confidentiality as it was stated at the beginning of the interviews. The interviews took 45-60 minutes.

  Polit and Beck, (2012: 543) exit procedures had to be observed. On exit, the researcher gave her telephone contacts to the participants and told them to call her in case they needed to provide her with more information or ask questions

that would benefit the study. The participants were reminded that they were free to withdraw from the study when they felt the need to anytime. The researcher also promised to share the study findings with the participant so that they can confirm if that is the true reflection of their experiences. The researcher left the community with a traditional Basotho song.

2.8 FIELD NOTES

Field notes are described as compiling of all occurrences that the researcher comes across during the study through listening, observing, thinking and experiencing during data collection (de Vos, *et al.,* 2011: 372). Having completed the focus group interviews, the researcher immediately compiled the field notes while the memory was still fresh (de Vos, *et al.,* 2011: 372). The observational, theoretical, methodological and personal notes were compiled based on the number of issues such as; observation of actions of participants, their behaviors, their experience and the feelings of the researcher (Polit and Beck, 2012: 547-549).

- **Observational Notes**

  Observation notes are descriptive notes of activities and communication that the researcher observed while engaging with the participants during the course of the study (Polit and Beck, 2012: 548).

  In this study the researcher took note of the surroundings or the area, the land, the distance to services such as health facilities, the roads that were gravel the gender combination of the groups, the way the participants interact with each other, as well as how they express themselves both verbally and non-verbally. The researcher also took note of participants that were too emotional at times when they expressed themselves. In order to address this situation, the researcher allowed silence for the participants to recover (Burns and Groove, 2009: 514). Some participants looked upset when the discussions were too

confrontational and the researcher had to intervene and rephrase the questions to avoid sensitivity (de Vos, *et al.* 2011: 373).

- **Theoretical Notes/ Analytical Notes**

  Theoretical notes prepare the researcher for analysis of information gathered during the study while building on the thoughts to make a good meaning (Polit and Beck, 2012: 549).

  In this study, the researcher took note of the passion the participants expressed while explaining their activities, their expression of anger as they talk about those who fail to adhere to treatment and their excitement as they talk about what actually motivates them in the work they do.

- **Methodological Notes**

  Methodological notes are useful to provide guidance and remind the researcher of her role as she conducts the study so that she is always on track (Polit and Beck, 2012: 549). The researcher took note of the misleading concerns and views by the participants as they raised issues that were not connected to the topic under investigation. The researcher had to apply facilitation and interviewing skills to redirect the participants to the research topic. In this study the researcher controlled her emotions and remained the researcher and stuck to the study design.

- **Personal Notes**

  The personal notes explain the feelings, emotions, ethics and assumptions of the researcher at the field of the study (Polit and Beck, 2012: 549). The researcher noted her discomfort as she listened to participants who talked for longer time and repeated what was already said. The researcher regarded these repetitions as emphasis of the magnitude of the problem and was therefore considered

significant. The researcher took note of her anxiety while exposed to challenges of the community settings and arrangements for the focus group interviews. Most of the interviews were held outside the house, under the tree or in the sun. In one of the interviews, there was lot of smoke from the fireplace, as some of the Caregivers were preparing lunch for the orphans under their care. The researcher subtly took note of her uneasiness and how she managed to cope with the situation by sitting in the opposite direction of the smoke. As stated earlier the researcher observed an acceptable dress code for purposes of being socially accepted in the research setting.

2.9 DATA ANALYSIS

After each interview, the tape-recorded were transcribed and translated into English. The study supervisor who is experienced in qualitative research listened to the tapes to verify if the transcribed notes reflected the audio-tapes as she knows the Sesotho language. Data Analysis is re-arranging of information gathered during research as to enable interpretation and clear meaning of the data (Burns and Grove: 2009: 43-44). The transcribed tape-recorded interviews and the field notes were translated into English and were then analyzed using Tesch's method (1990) as adopted by Creswell (2009: 185). The steps involved are given in chapter 1. The data analysis techniques used by the researcher included reading transcriptions thoroughly and carefully as well as noting ideas; coding, reflecting on and writing thoughts in the margins next to the transcribed interviews (Burns and Groove, 2009: 522).

The mastication of similar topics was inevitable in a study of this nature. It involved clustering of similar topics together, and forming proportions; while arranging major topics together to form themes that were grouped together to form categories (Creswell, 2009:185). At the end, the researcher drew lines between the themes to show interrelationships (Creswell, 2009:185).The data materials belonging to each category were assembled in one place, and preliminary analysis was performed (Creswell, 2009:185).

Identification and connection of common themes was followed by the process of open coding which was carried out by an independent coder for purposes of ensuring reliability (Creswell, 2009:185). The themes were then assigned codes in an attempt to convert data to a smaller, more manageable and more manipulative units that were easily retrieved (Polit and Beck, 2012: 569**).**

The researcher gave an independent coder based on the experience in qualitative research, the raw data of the transcribed tape-recorded interviews and the field notes, as well as the Tesch (1990) method of data analysis (Creswell, 2009: 185). The researcher used the feedback from the study supervisor to further analyse data independently. She also met with co-coder to discuss and reach consensus on the analysed data. The results were then given to the research subjects to confirm whether the analysed data truly reflected their experiences.

2.10 MEASURES TO ENSURE TRUSTWORTHINESS OF THE RESULTS

In qualitative research, validity is measured through the accuracy and truthfulness of the findings (Brink, *et al.,* (2012: 172). Given (2008: 895) defines trustworthiness as "the way in which qualitative researchers ensure that credibility, dependability, transferability and conformability of the study are evident in their research". Cuba's model, as pointed out by Brink, *et al.,* (2012: 172) was used to ensure reliability of the results. The model identifies the criteria in assessing reliability. In this study, credibility, triangulation, transferability, dependability and conformability or neutrality were observed as discussed below.

- **Credibility**

  Credibility is mostly focusing on the reliability of the key findings during data collection in interviews whereby technicalities of the researcher in analyzing data looked into integrity to establish the truth of such findings (Brink, *et al.,* 2012:

172). Babbie and Mutton (2009: 277) further emphasizes that the credibility is about the truth of the findings in the qualitative study. In this study the researcher engaged the co-coder with experience to assist in analysis of data. The study supervisor was also used to listen to the audiotapes, as she knows the language. The researcher further checked with the participants to ensure that they agreed with the findings.

- **Triangulation**

  According to Guion, Diehl, and McDonald (2011: online), triangulation is a method used to ensure validity of the study to confirm consistency on data collection approaches and sources in order to support the evidence that is generated. Triangulation that was employed in this study was the collection of data from various sources in the same study (Guion, Diehl, and McDonald (2011: online). The researcher conducted focus group discussions with different participants in different locations. The participants were of different ages and sex and some were old while some were young. Some of the participants were from the groups of people living with HIV while some were just caregivers not knowing their status or those who are HIV negative. Some of the participants had long experience in caring for the patients while some were not. In this regard, data triangulation was beneficial in that it increased assurance in data, informative and diverse while providing more understanding of the problem (Guion, *et al.*, 2011: online).

- **Dependability**

  Dependability refers to stability of data and reliability that denotes credibility and trustworthiness of the findings of the study (Polit and Beck, 2012: 585, Brink, *et al.,* 2012: 172-173). This was done to ensure that the information stays the same as collected from the respondents. The researcher compared hand written notes to the recorded tapes that were done during focus group discussions. Furthermore, the researcher made use of the supervisor to compare the transcribed discussions with tape recorded discussions. Data was reviewed for

consistency of study findings. Furthermore, the Co-coder was engaged to review collected data for accuracy by comparing the transcribed notes with the research questions.

- **Transferability**

  Transferability refers to the probability that the finding of the study may be sound and could be positively considered and applied for use by others in a similar situation (Brink, *et al.,* 2012: 173). Polit and Beck (2012: 585) denotes that transferability means possibilities for application by others while on the same note, Babbie and Muton (2009: 276) describes transferability as to when the findings of the study can be transferred and applied in other context hence influencing change in another context. The researcher compiled a dense description of the methodology and findings to allow other researcher to replicate the study in another setting (Patton 2002). This was to ensure that the criteria allow transferability of the study, as results in qualitative research are context bound (Brink, *et al.,* 2012: 173).

- **Conformability/ Neutrality**

  Conformability refers to verification and assurances that the findings, conclusions and recommendations are true reflection of data based on the researchers interpretations and or neutrality of data and its interpretation (Polit and Beck 2012: 723). Brink, *et al.,* (2012:173) reiterate that conformability should focus on ensuring that information from the participants' views and the researcher should not be biased based on perceptions of the latter. In this study the researcher satisfied this by being transparent in engaging participants while also avoiding to be judgmental in their views (de Vos, *et al.,* 2011: 317). The research further applied the strategy of bracketing to ensure neutrality.

- **Bracketing**

  According to Given, (2008: 555), understanding and description of human views is of utmost importance, neutrality is not very easy to maintain, Hence bias is

major threat to the validity of the findings (Streubert and Carpenter, 2012: 20). However, in this study, researcher's various interpretations of the phenomenon, feelings, thoughts and perceptions were bracketed before the beginning of data collection and analysis so that the validity of the study results may be maintained to the end (Polit and Beck, 2004: 14). The researcher allowed participants to express themselves on all aspects even when she realized that she was more familiar of certain phenomenon, she did not stop the participants from voicing their views.

2.11 ETHICAL CONSIDERATIONS

According to Burns and Grove (2009: 61), ethics refers to standards or principles that should be taken into consideration to protect the rights of participants. The researcher requested for permission from ethical committees such as; Faculty of Health Sciences of the University of the Free State and Ministry of Health in Lesotho to conduct the study that was professionally monitored.

The morality issues were applied in this study as indicated by Joubert and Ehrlich (2007: 32) as autonomy, beneficence and non-maleficence, justice, voluntary participation, informed consent and confidentiality. Brink, *et al.* (2012: 39-40), further indicate the importance of respect, information and choice. The following ethical issues discussed below, were observed by the researcher:

- **Confidentiality**

  Confidentially is treating information in privacy whereby it can only be shared through obtaining permission from the participants (Joubert and Ehrlich, 2007: 32, Burns and Grove, 2009: 196). Therefore, in this study, the researcher respected the human rights of the participants by adhering to the principles of maintaining privacy and confidentiality (Burns and Grove, 2009: 194-197). The researcher did not disclose any information discussed by the participants without their consent. The collected data was not linked to any participant and the names

were not revealed in any publication. The villages where participants are staying were not identified as this may link them to data; instead, the focus group from each village was given a particular number.

- **Beneficence and non-maleficence**

  Beneficence means doing good, while non-maleficence is protection from all sorts of harm that may be exposed to participants during the course of study (Polit and Beck, 2012: 152-153). For purposes of this inquiry, the researcher professionally treated all personal information in a very confidential manner to protect the participants' exposure from any harm that may be unforeseen (Burns and Grove, 2009: 188). The participants in this study were protected from environmental harm as the focus group discussions were held at their normal meeting places where they are free and relaxed. The participants did not incur any costs to participate in the study hence protection from any financial harm. They did not pay for travel to the meeting place because the focus groups discussions were held during their normal meetings. There were no unforeseen risks associated with the study.

- **Justice**

  Justice refers to non-judgmental and equal treatment of participants (Joubert and Ehrlich, 2007: 33, Polit and Beck, and 2012: 155). The researcher treated participants fairly from selection. They were well informed of the purpose of the study before they sign the consent form. The researcher kept to the promise of confidentiality and did not take advantage of the participants' weaknesses (Polit and Beck, 2012: 155-156). The researcher did not interfere with the participants' views at all.

- **Voluntary participation**

  The participants were not forced to participate in the study but their participation was voluntary. The participants, who volunteered to take part in the study, were

informed that they were free to decline at any time if they so wish (Babbie and Mouton, 2009: 521).

- **Informed Consent**

  Informed consent deals with provision of full information about the study to the participants and seeking for their permission in an agreement form, to participate in the study (de Vos, *et al.,* 2011: 115-6). To ensure this, the researcher provided full information about the study to all participants in their preferred language (Sesotho). The consent form was written in the local language, namely – Sesotho. It was read together with the participants before signing. Before signing, the researcher took cognizance of the rights of participants and provided information based on the following:

  - The participants were made aware that there are no incentives for participating in the study.
  - The researcher made the participants aware that their participation is voluntary and they are free to decline at any time without losing any incentives.
  - The researcher informed the participants that there is no risk involved, as the interviews will be held at their normal meeting place. This was to emphasis protection from harm and discomfort.
  - The researcher further explained to the participants that confidentiality would be maintained at all levels hence the right to privacy.

2.12 CONCLUSION

In this chapter, the research paradigm was discussed. Qualitative research was used based on the constructivist paradigm based ontological, epistemological and methodological assumptions. The research designs used in this study were explorative, descriptive, contextual and phenomenological in nature. The focus-group interview technique was the main data collection strategy in this inquiry. The communication

techniques such as probing and paraphrasing were applied where there was a need for more clarification during focus-group interviews. The ethical considerations and the measures to ensure trustworthiness of the results were followed and discussed in this chapter. In the next chapter, the data presentation and literature control will be discussed.

CHAPTER 3
DATA PRESENTATION AND LITERATURE CONTROL

3.1 INTRODUCTION

The previous chapter discussed the research method and the design followed in this study. This chapter features data presentation and literature control. The discussion is based on the experiences of the Caregivers within Community-Based Organizations (CBOs) implementing HIV and AIDS services. Literature control is illustrated and weaved into the collected data to make meaning (Creswell, 2009: 185).

3.2 DESCRIPTION OF THE SAMPLE

The sample in this study was the HIV and AIDS caregivers from the Community Based Organizations in the rural areas of Maseru district. Eight focus group interviews consisting of eight participants in each group were conducted. The participants comprised of fifty-five women and nine men of different ages.

3.3 DATA ANALYSIS

As stated in section 2.9 of the previous chapter, data analysis means the process of identifying themes so as to formulate an idea that is derived from the collected data, and an endeavor to support these ideas (Burns and Grove, 2012: 94). In qualitative research, data analysis is described as a process of scientifically organizing the interview transcripts and the filed notes until they are understood in order to address the research question (Polit and Beck, 2012: 569). The researcher read the transcripts and compared the noted through listening to the audiotape several times for the analysis of data, and then formulated the categories, sub-themes and themes.

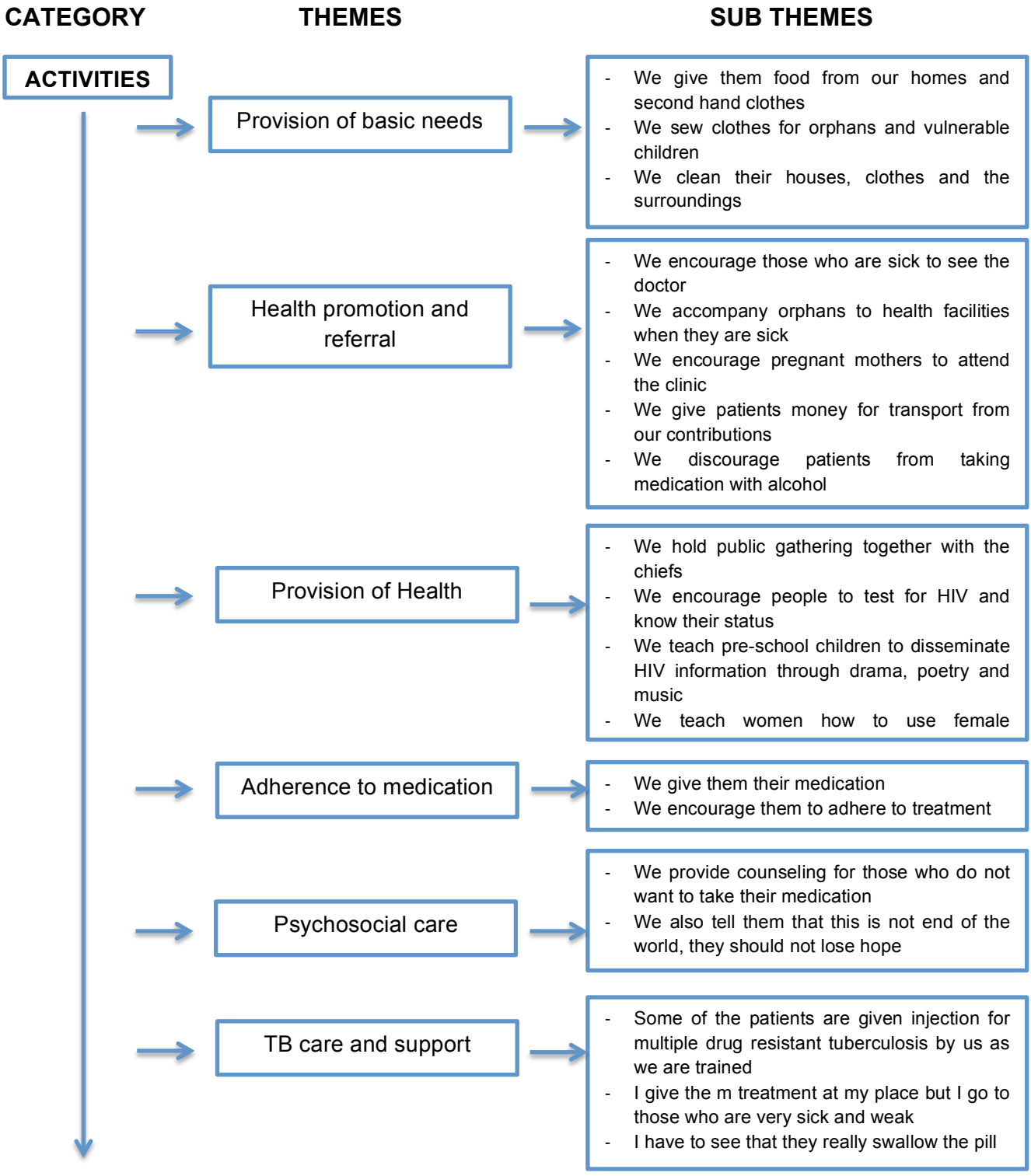
The independent co-coder was provided with transcripts, field notes and the tape-recorder as well as the protocol for data analysis. Having gone through all the

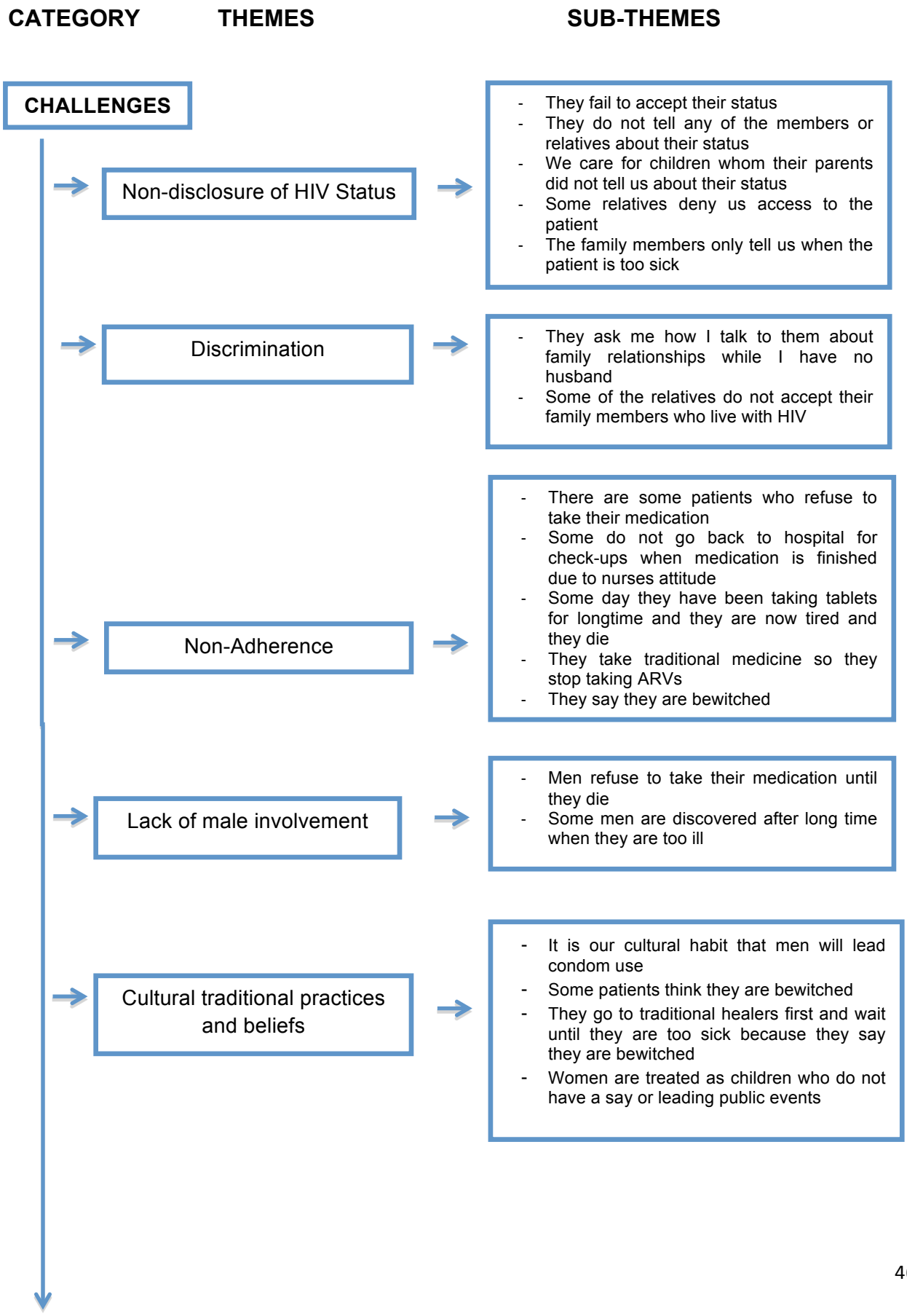
documents, the meeting was held between the researcher and the co-coder to discuss and reach consensus on the categories, sub- themes and themes as identified in the transcripts.

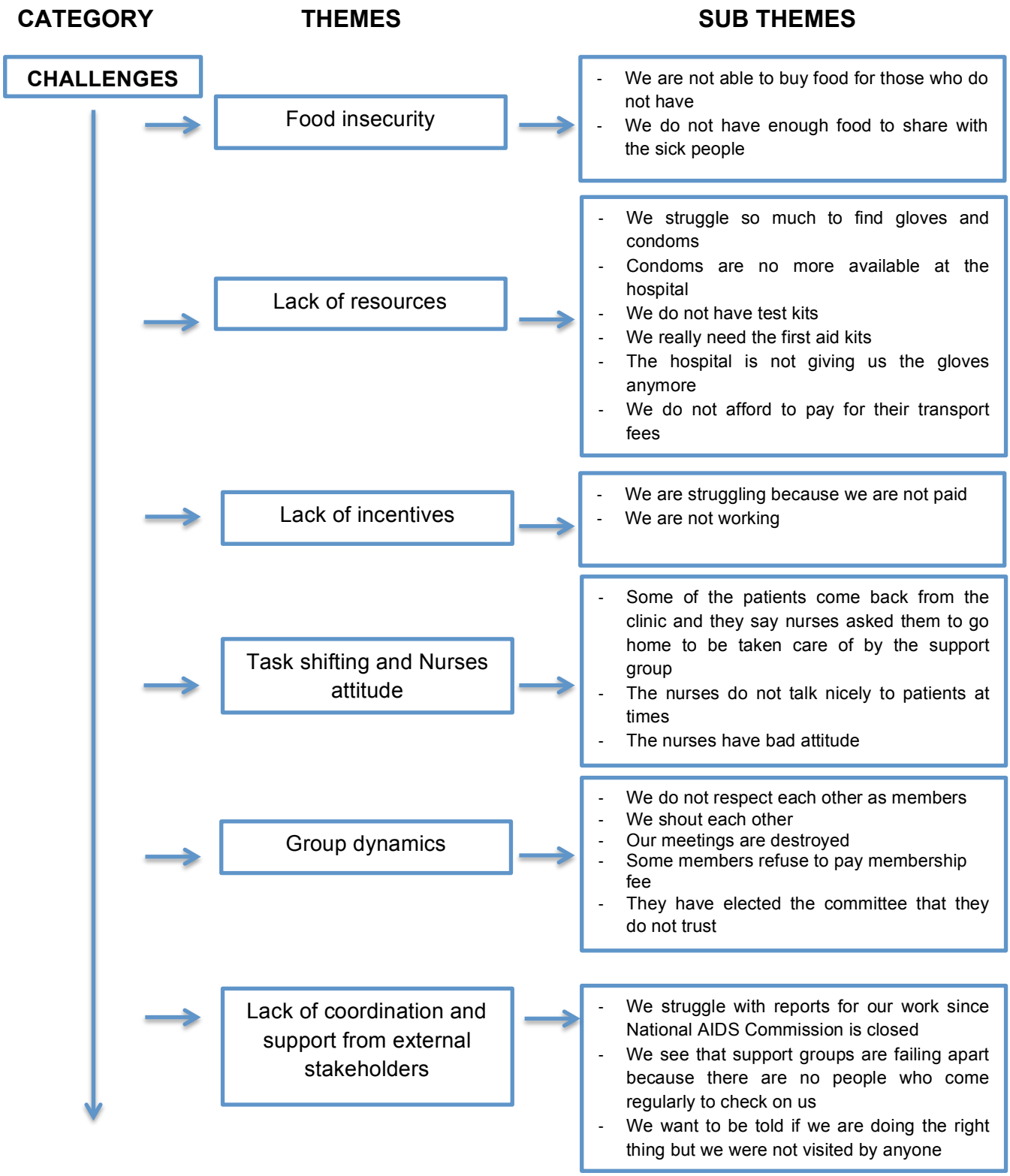
Four main categories of data were identified from the data and sub-themes and themes under each category were developed. The themes were derived from the transcripts as said by the participants while the sub-themes were informed by these themes to make the meaning/idea as interpreted by the researcher (Creswell, 2009: 183). These themes explained the experiences of the Caregivers within the CBOs implementing HIV and AIDS Services in Maseru. The main four categories according to the four questions asked were:

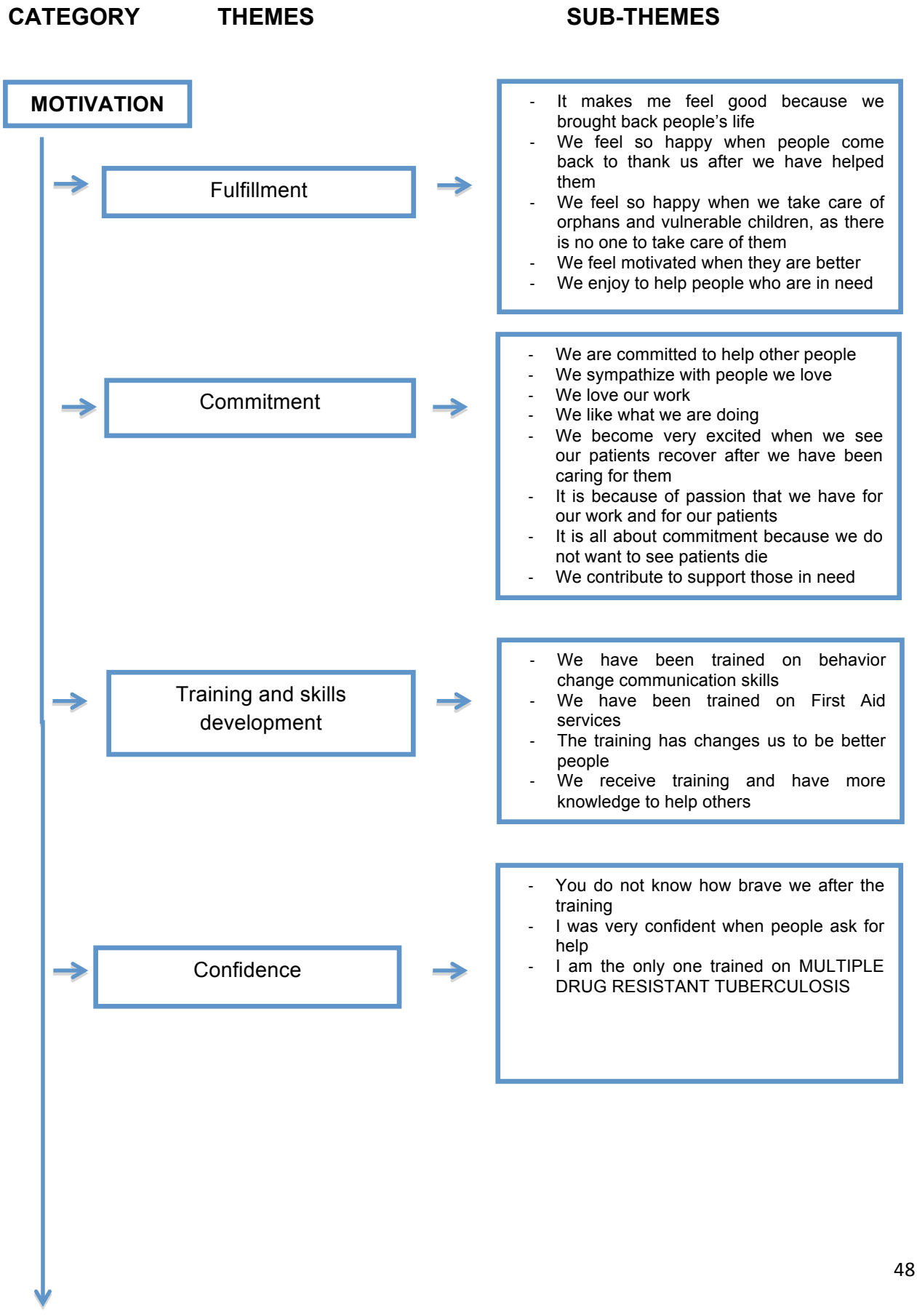
- Activities
- Challenges
- Motivating factors
- Recommendations

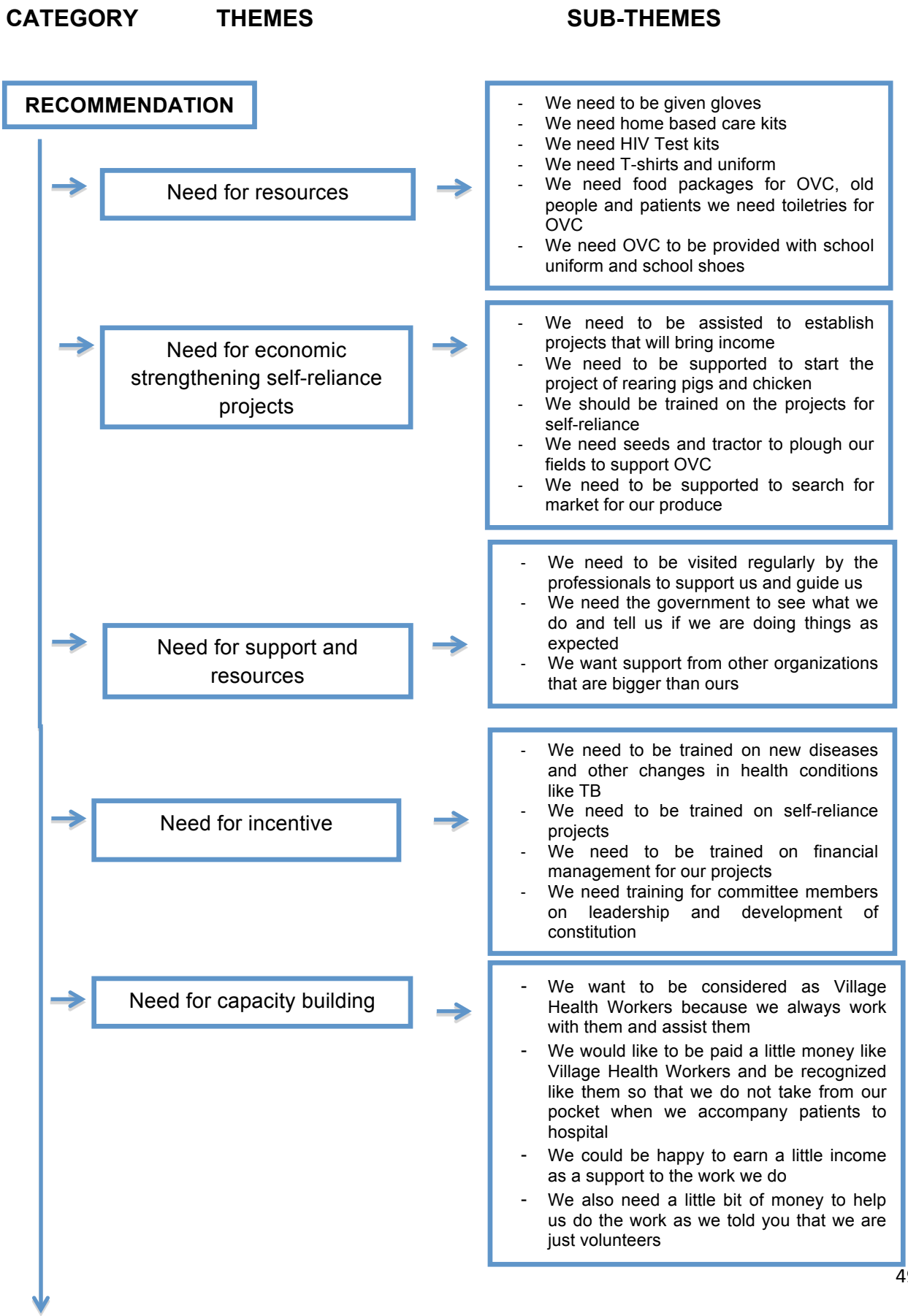
3.4 FIGURE 1: A FRAMEWORK OR DATA ANALYSIS




CATEGORY
THEMES
SUB-THEMES
CHALLENGES
Non-disclosure of HIV Status
- They fail to accept their status
- They do not tell any of the members or relatives about their status
- We care for children whom their parents did not tell us about their status
- Some relatives deny us access to the patient
- The family members only tell us when the patient is too sick
Discrimination
- They ask me how I talk to them about family relationships while I have no husband
- Some of the relatives do not accept their family members who live with HIV
Non-Adherence
- There are some patients who refuse to take their medication
- Some do not go back to hospital for check-ups when medication is finished due to nurses attitude
- Some day they have been taking tablets for longtime and they are now tired and they die
- They take traditional medicine so they stop taking ARVs
- They say they are bewitched
Lack of male involvement
- Men refuse to take their medication until they die
- Some men are discovered after long time when they are too ill
Cultural traditional practices and beliefs
- It is our cultural habit that men will lead condom use
- Some patients think they are bewitched
- They go to traditional healers first and wait until they are too sick because they say they are bewitched
- Women are treated as children who do not have a say or leading public events


CATEGORY
THEMES
SUB THEMES
CHALLENGES
Food insecurity
- We are not able to buy food for those who do not have
- We do not have enough food to share with the sick people
Lack of resources
- We struggle so much to find gloves and condoms
- Condoms are no more available at the hospital
- We do not have test kits
- We really need the first aid kits
- The hospital is not giving us the gloves anymore
- We do not afford to pay for their transport fees
Lack of incentives
- We are struggling because we are not paid
- We are not working
Task shifting and Nurses attitude
- Some of the patients come back from the clinic and they say nurses asked them to go home to be taken care of by the support group
- The nurses do not talk nicely to patients at times
- The nurses have bad attitude
Group dynamics
- We do not respect each other as members
- We shout each other
- Our meetings are destroyed
- Some members refuse to pay membership fee
- They have elected the committee that they do not trust
Lack of coordination and support from external stakeholders
- We struggle with reports for our work since National AIDS Commission is closed
- We see that support groups are failing apart because there are no people who come regularly to check on us
- We want to be told if we are doing the right thing but we were not visited by anyone


CATEGORY
THEMES
SUB-THEMES
MOTIVATION
Fulfillment
- It makes me feel good because we brought back people's life
- We feel so happy when people come back to thank us after we have helped them
- We feel so happy when we take care of orphans and vulnerable children, as there is no one to take care of them
- We feel motivated when they are better
- We enjoy to help people who are in need
Commitment
- We are committed to help other people
- We sympathize with people we love
- We love our work
- We like what we are doing
- We become very excited when we see our patients recover after we have been caring for them
- It is because of passion that we have for our work and for our patients
- It is all about commitment because we do not want to see patients die
- We contribute to support those in need
Training and skills development
- We have been trained on behavior change communication skills
- We have been trained on First Aid services
- The training has changes us to be better people
- We receive training and have more knowledge to help others
Confidence
- You do not know how brave we after the training
- I was very confident when people ask for help
- I am the only one trained on MULTIPLE DRUG RESISTANT TUBERCULOSIS


CATEGORY
THEMES
SUB-THEMES
RECOMMENDATION
Need for resources
- We need to be given gloves
- We need home based care kits
- We need HIV Test kits
- We need T-shirts and uniform
- We need food packages for OVC, old people and patients we need toiletries for OVC
- We need OVC to be provided with school uniform and school shoes
Need for economic strengthening self-reliance projects
- We need to be assisted to establish projects that will bring income
- We need to be supported to start the project of rearing pigs and chicken
- We should be trained on the projects for self-reliance
- We need seeds and tractor to plough our fields to support OVC
- We need to be supported to search for market for our produce
Need for support and resources
- We need to be visited regularly by the professionals to support us and guide us
- We need the government to see what we do and tell us if we are doing things as expected
- We want support from other organizations that are bigger than ours
Need for incentive
- We need to be trained on new diseases and other changes in health conditions like TB
- We need to be trained on self-reliance projects
- We need to be trained on financial management for our projects
- We need training for committee members on leadership and development of constitution
Need for capacity building
- We want to be considered as Village Health Workers because we always work with them and assist them
- We would like to be paid a little money like Village Health Workers and be recognized like them so that we do not take from our pocket when we accompany patients to hospital
- We could be happy to earn a little income as a support to the work we do
- We also need a little bit of money to help us do the work as we told you that we are just volunteers

3.5 FINDINGS AND LITERATURE CONTROL

3.5.1 ACTIVITIES

Activities refer to actions or state of being actively involved (Oxford free dictionary: online: 2012). According to the Lesotho Partnership Framework (2010), the Civil Society Organizations through their caregivers have a meaningful participation and involvement in HIV and AIDS interventions. These activities are reported on presented in the study.

3.5.1.1 Provision of Basic care

According to Moetlo, Pengpid & Peltzer (2011: 139) Community Homes-based Care (CHBC) activities that Caregivers have confidence in implementing include among others: health education, bathing, giving prescribed medication and counseling in provision of psychosocial. The participants in this study shared the same sentiments and further added the following: provision of basic needs, promotion of health care referral, prevention of child abuse, promotion of HIV prevention and team member support. This finding is in line with what Stjernsward (2005: 111-117) describes as effective community participation. According to Stjernsward (2005: 111-117), effective community participation in the care of chronically ill clients is prioritized to focus more at attaining good nutrition, reducing social isolation, reassuring family support while at the same time maintaining basic hygiene. The participants in this study described their activities as follows:

"We clean their houses and the surroundings"
"We sew clothes for orphans and vulnerable children"
"We wash clothes for patients"
"We give them food from our homes."

These activities represent the activities that are provided to patients who are unable to accomplish these basic needs. The findings in this study were consistent with what was

reported by Kabore, *et al.,* (2010: 583-587), that the Caregivers in their report also provided basic care that includes psychosocial support, food security through establishment of homestead gardens and provision of care and support for orphans and vulnerable children. Kell and Walley (2009: 2-5) further reported similar findings in in that their study describes Community Caregivers as the ones implementing palliative care, who ensure cleanliness of the patient and their surroundings, as well as giving their patients food.

3.5.1.2 Health Promotion

Among the activities mentioned by the participants in this study, health promotion was the most cited. According to the assertion by of O'Donnell (2009: 1), Health Promotion activities by the Caregivers are seen as "the art and science of those helping people discover the synergies between their core passions and optimal health, enhancing their motivation to strive for optimal health, and supporting them in changing their lifestyle to move toward a state of optimal health". O' Donnell's assertion point to health promotion as motivation that not only builds skills, but also creates opportunities for access to an environment that makes positive health practices the easiest choice. Lifestyle change is further facilitated through learning and enhancing awareness (O'Donnell, 2009: 1). The participants in this study expressed the same sentiments of health promotion, by mentioning health promotion activities that they were implementing. the following statements emphasized their activities:

"*We hold public gatherings with the chiefs"*
"We provide education on behavior change"
"We encourage those who are sick to see the doctor"
"We provide HIV Testing and counseling in the community"
"We accompany orphans to health facilities when they are sick"
"We discourage patients from taking medicine with alcohol"
"We encourage patients to adhere to their treatment"

The participants' responses in promoting health appeared to have invested in social mobilisation strategies as described by Marsh, Schroeder, Dearden, Sternin & Sternin (2004). According to Marsh, *et al.* (2004) partnering with the communities is the positive power of producing change. The participants in this study seem to have invested in this, as there was also involvement of the chiefs. Having the mandate of the authorities within the communities, the participants further implemented referral activities as some of health promotion interventions were intended to create demand and access to health services. The activities were given like this by the participants:

> *"We encourage those who are sick to see the doctor"*
> *"We accompany orphans to health facilities when they are sick"*
> *"We encourage pregnant mothers to attend the clinic"*
> *"We give patients money for transport to health facility from our contributions"*

The findings are consistent with O'Donnell's (2009) definition of health promotion through social mobilization in the communities, whereby patients were identified and referred for early diagnosis. This was made possible by the fact that the community-based organizations in Lesotho provide HIV testing and screening for TB (Government of Lesotho National Strategic Plan (2011).

3.5.1.3 Provision of health education and HIV prevention activities

The Government of Lesotho National Strategic Plan (2011), proposes the following activities for HIV prevention activities:

- HIV testing and counseling,
- Information dissemination,
- Promotion of consistent and correct use of condom,
- Promotion of social behavior change,
- Prevention of mother to child transmission of HIV,

- Promotion of voluntary medical male circumcision and
- Reduction of multiple current partnerships.

The participants in this study indorse these activities in line with the Government of Lesotho National Strategic Plan. Their excerpts are as follows:

> *"We encourage people to test for HIV"*
> *"We teach pre-school children to disseminate HIV information though drama, poetry and music"*
> *"We teach woman on the use female condoms"*
> *"We encourage them to use condom, and provide condoms to those who want them"*
> *"We provide HIV testing and counseling, as well as counseling on behavior change."*

The findings demonstrate that the Government of Lesotho National Strategic Plan is effective in the sense that their strategies are already being implemented by the caregivers. Thus, the findings give a positive evaluation in this regard. The findings in this study are in accordance with what is reported by Kabore, *et al.,* (2010: 583-87) regarding the community based organizations activities in resource-limited settings in Sub-Saharan Africa. The report indicates that the Caregivers within the community based organizations provide HIV preventative services such as HIV counseling and testing, defaulter tracking, and promoting positive living. It is further suggest that the National Behavior Change Strategies that advocates information dissemination through interpersonal communication, social mobilizations and advocacy, is being implemented (Medical care development international: 2008). The participants mentioned their interventions in health education thus:

> *"We hold public gathering together with the chiefs"*
> *"We teach women how to use female condoms"*
> *"We encourage people to test for HIV and know their status"*

"We teach pre-school children to disseminate HIV information through drama, poetry and music"

These activities portray the multifaceted roles of these Caregivers with the affirmation to accomplish and support government sectors such as health, education and social welfare departments.

These findings are therefore echoing a leadership role as stipulated by the Lesotho National AIDS Commission report (2009), that community support groups as Non-Governmental Organizations (NGOs) should play the lead-role in the health education activities in their communities.

3.5.1.4 Provision of psychosocial support

Psychosocial support is defined as a continuum of care that takes into consideration the state of mind, thoughts, emotions, feelings and behaviors in relation to the social interaction, relationships with others, environment, cultures and traditions as well as the roles and tasks of individuals (Smith, Saslow and Sawyer, 2003: 141-143). Forouzan, Shushtari, Sajjadi, Salimi, and Dejman's (2013: 5), report indicate that psychosocial support is not only an important intervention for people living with HIV, but also empowers the clients to manage the condition and adhere to their medication. Evidence of this lies in participants' indication that they support the clients through counselling to adhere to their medications. About this one of the participants said:

"We provide counseling for those who don't want to take their medication".

The findings of this study confirm Forouzan, *et al.'s.,* (2013: online) observation that HIV and AIDS clients suffer depression and distress that may lead to loss of hope; hence need for psychosocial-support to empower them to have no fear of stigma, rejection or discrimination, as they feel that they are accepted and supported by the society. The finding is depicted in participants' report that they provide counseling to instill hope in

their clients so that they are not depressed. The statement below substantiates this:

> *"We also tell them that this is not the end of the world, they should not loss hope in life."*

Findings also relate to psychological support among the participants as one participant said:

> *"We counsel each other in a group within the Community Based Organization."*

This demonstrates that the activities of these Caregivers are stressful and emotionally strenuous.

3.1.5.5 Adherence to medication

According to Osterberg and Blaschke (2005: 487) "adherence is generally defined as the extent to which patients take medications as prescribed by their health care providers". Osterberg and Blaschke (2005: 487) further indicate that the word "adherence" is preferred by many health care providers, because "compliance" suggests that the patient is passively following the doctor's orders. With regard to adherence, the Government of Lesotho Health Services Decentralization Strategic Plan, (2009: 56-57) indicates the important role played by the caregivers in the community is their support to continuity and adherence to medication, which actually prolongs lives. This is reiterated by the Kingdom of Lesotho HIV Epidemiology and National Response Situation Analysis Report, (2011: 16), which asserts the need for follow-up of patient on ART. This follow-up is necessitated by the fact that these patients often fail to attend to their appointments and fail to be retained in care hence increased defaulter rates (the Kingdom of Lesotho HIV Epidemiology and National Response Situation Analysis Report, 2011: 16). The participants in this study demonstrate how they contribute towards adherence by statements as such:

"*We give them their medication"*
"We encourage them to adhere to treatment, and
"We even discourage them from taking their treatment with alcohol."

The findings of this study portray the important role played by the Caregiver in ensuring that daily treatment is taken with continued support. These findings are consistent with the report by Kabore, *et al.,* (2010: 583-587), that the HIV and TB clients adhere to their medication if there is support at home, from the family members and the community in general.

3.5.1.6 Tuberculosis (TB) care and support

The World Health Organizations treatment guidelines for TB (2003) emphasize the involvement of the Community Based Organizations in the treatment, care, support, monitoring and evaluation of TB programmes. These guidelines are consistent with the Community System Strengthening Framework of the Global Fund to fight AIDS, TB and Malaria (2014), which indicates that the community interventions to stop TB should focus on the direct observation of treatment by the home-based Caregivers to ensure adherence. The participants in this study cited the following statements to indicate their activities in TB care and support:

"Some of the patients are given injection for multiple drug resistant tuberculosis by us as we are trained"
"I give them treatment at my place but I go to those who are very sick and weak"
"I take care of other TB clients beside those having multiple drug resistant tuberculosis"
"I have to see that they really swallow the pill"

The findings of this study prove that the participants are in line with the Kingdom of Lesotho National Tuberculosis Programme Policy and Manual (2007), which stipulates

that the community TB program should recognize the involvement of the CBOs as they play an integral role in the care and support of TB clients at home. Their role is seen as vital, as they provide the direct observation of treatment (DOTs) and further support the treatment of patients of multiple drug resistant tuberculosis at their homes (the Kingdom of Lesotho National Tuberculosis Programme Policy and Manual, 2007).

3.5.2 CHALLENGES

The concept challenge means “something that puts someone’s ability to test” Oxford free dictionary (online: 2012). The challenges that Pertain to the implementation of HIV activities have been described by the Kingdom of Lesotho HIV Epidemiology and National Response Situation Analysis Report (2011) as relating to inadequate capacity to manage HIV and AIDS at the community level, slow uptake of ART, low levels of condom use, fragmentation of intervention and inadequate coordination. The same challenges are being expressed by the Southern African Development Community **(**SADC) HIV and AIDS Strategic Framework, 2010-2015 (2009). This framework identifies gaps and challenges such as lack of access to services, cultural issues, religion, as well as stigma and discrimination that lead to non-disclosure of HIV status (the Southern African Development Community **(**SADC) HIV and AIDS Strategic Framework, 2010-2015, 2009).

The responses by the participants included issues associated with the following:

- The Non-disclosure of HIV status that leads to late referrals hence non-adherence and high defaulter rate,
- Discrimination,
- Lack of male involvement,
- Lack of coordination,
- Lack of resources,
- Cultural issues,
- Task shifting and group dynamics,
- Food insecurity, and

- Dependency syndrome that goes with lack of participation by the community.

3.5.2.1 Non-disclosure of HIV Status

According to the Government of Lesotho Policy Frame-work on HIV Prevention, Control and Management (2000), there is a strong call for multi-sectorial team approach to involving CBOs in the fight against HIV and AIDS. However, the policy indicates that the HIV status of a person should be treated confidential whereby, the caregiver may not be aware of the patient status. The participants in this study uttered statements such as:

> *"They fail to accept their status"*
> *"They hide their sickness"*
> *"We care for children whose parents do not tell us about their status"*
> *"Some relatives deny access to the patient"*
> *"The relatives do not want us to know that they have patients"*
> *"The family members only tell us when the patient is very sick"*
> *"Some relatives hide their patients from us"*
> *"Some patients do not tell any of the members or relatives about their status."*

These findings demonstrate that the participants adhere to the principle of confidentiality, but they were however concerned about the extent of confidentiality, as it was to some preventing patients point from accessing the needed services. This is demonstrated by some of the relatives that were hiding their patients.

The findings of this study confirm the findings of Peacock, Redpath, Weston, Evans, Daub & Greig's (2008: 17) regarding confidentiality, as some of the HIV infected women in their study, did not disclose their status to their partners because of fear, stigma and discrimination.

3.5.2.2 Discrimination

According to Goffman (1963), stigma is an attribute that is discrediting, which within the realm of a society serves to reduce one who possesses it. While Reis, Heisier, Amowitz, Moreland, Moferi, Anyamele & Lacopino, (2005), comment about the HIV patients suffering discrimination and stigmatization by family members, community and at the workplace, the response of the participants depict that they were experiencing stigma and discrimination. Insight from an analysis of responses in this inquiry points to the statements such as:

> "*They ask me how I talk to them about family relationships while I have no husband"*
> *"Some people asked me how I tell them about condoms while I have no husband"*
> *"Some of the relatives do not accept their family members who lives with HIV"*

The descriptions like these challenged some of the participants, as this voluntary work did not stipulate who can be allowed to participate. Thus, it became a challenge for them**.**

3.5.2.3 Non-adherence

The concerned for non-adherence, has been stated in the Government of Lesotho National Guidelines for the Prevention of Mother-to-Child Transmission of HIV (PMCT) (2013), in which some patients on ART have been found to miss appointments and therefore fail to adhere to their treatment. The challenge is that the community is further expected to support them to adhere to treatment. In this study this challenge is evidenced in the following statements:

> *"There are some patients who refuse to take their medication"*
> *"Some say they have been taking tablets for long time and they are now tired and they die"*

"Some do not go back to hospital for check-up when medication is finished, meaning these patients stop taking their medication"

"Some patients who are on treatment also drink lot of alcohol and some of them even take traditional medicine or other herbal drugs"

"Some stop taking them because they were asked to stop by their traditional healers"

"Some patients refuse to go back to the clinic because they say they fear nurses"

"Some of them refuse to take TB treatment and say they are bewitched."

The responses of the participants reveal limited knowledge on the side of their clients, which is expressed by their damning deeds The findings are consistent with the observation in the Annual report by the Lesotho Network of AIDS Service Organizations and Elizabeth Glaser Paediatric AIDS Foundation Report (2013), that there are several patients who default their HIV and TB treatment because they take other drugs from their traditional healers and stop taking ARVs.

3.5.2.4 Lack of Male of Involvement

Some cultural norms, expectations and beliefs on gender roles dictate that male persons be regarded as more knowledgeable and experienced on issues of sex and sexuality (UNAIDS, 1999). These norms may contribute to inability of some men to seek information or admit to their lack of knowledge regarding sex matters. Findings from this inquiry indicate how this unfounded pro-male assumption can reasonably be associated with men's delay to seek services, resulting in unnecessary loss of life. The following are some of the responses to this effect:

"Men refuse to take their medication"

"Some men refuse until they die"

"Some are discovered after long time when they are too ill"

"Men refuse to do everything but they prefer to die."

The findings confirm the conclusion by WHO (2008) that men's misconceptions about masculinity and bravery can reasonably be associated with failure to seek and access health services.

3.5.2.5 Cultural issues

Cultural and gender issues remain the biggest challenge in many African countries in general whereby men are the decision makers in nearly all family issues including sexual matters and health issues for their wives (WHO report, 2008). For communities in countries such as Lesotho evidence of this situation is embraced in responses such as the following:

"Women have to listen to what men say as in our culture women are treated as children who does not have a say"
"Women cannot use condom when their men don't allow them"

The findings are consistent with Gupta's (2000) finding, in which cultural norms and gender expose women to vulnerability, as they are always inferior and expected by men to have no role in decisions on sexual issues such as use of condoms.

Besides decision in sexual issues, some of the participants cited the issues of witchcraft. The participants in this study mentioned statements such as:

"Some patients think they are bewitched"
"They go to traditional healers first and wait until they are too sick because they say they are bewitched"
"Some of the patients just refuse to take HIV and TB treatment because they think they are bewitched and they die."

The participants expressed these cultural issues as challenges, as the clients themselves and their relatives were not eager to disclose the HIV status. Thus, their provision of information regarding HIV and cultural issues were based on speculations.

The findings are in accordance with Ashforth (2001) report, that patients who suffer opportunistic infections of HIV and AIDS claim to have been bewitched. Bewitchment was also reported in a study by Kwena, Manyasa, Byarugaba & Mwanzo (2009) in which people infected with HIV delay to seek medical attention, as they first consult their traditional healers on grounds of witchcraft. These were revealed in this current study.

3.5.2.6 Food insecurity

According to Barrett (2010: 825) food security represents "a situation that exists when all people, at all times, have physical, social and economic access to sufficient, safe and nutritious food that meets their dietary needs and food preferences for an active and healthy life." In many African countries the situation has that of food insecurity. This kind of situation is mostly associated with improper allocation of land that has related to gender biasness (Drimie: 2003). The following statements from participants in this study evidenced that Lesotho is no exception in this regard.

"We are not able to buy food for the patients"
"We do not have enough food to share with the sick people"

Though the participants put emphasis on sharing, their definition of not enough food does not tally with definition of food security, which states access of food to all people.

These findings are in accordance with Makoae (2009) report, which indicates that caregivers are compelled to share their food with the HIV patients whereas they don't even have enough time to go to plough and harvest the food. This due to the fact that most of their time is spend providing care and support to the sick, than tilting their fields (Makoae: 2009).

3.5.2.7 Lack of Resources

Resources are supplies needed for the accomplishment of the essential activities (Oxford free dictionary, online: 2012). Stuart, Harkins & Wigley (2005) indicate that often communities lack resources to implement HIV activities effectively and efficiently. This inquiry reveals that caregivers at community level are similarly challenged due to limited resources such as gloves, test kits and first aid kits. Some of their responses to this effect include:

> "We struggle so much to find gloves and condoms"
> "Condoms are no more available at the hospital"
> "We do not have test kits"
> "We really need the first aid kits"
> "The hospital is not giving us the gloves anymore"
> "We do not afford to pay for their transport fees"

The descriptions above reiterate the findings by Makoae, (2009: 18-24) as she reports that there are no resources such as gloves and home-based care kits with the result that caregivers end up improvising by using ordinary plastic.

3.5.2.8 Lack of incentives

Incentive is an encouragement or motivation for caregivers as volunteers who support implementation of HIV activities remuneration or stipend may be expected (Schneider, Hlophe & van Rensburg: 2008). However, the responses below indicate that participants are not paid anything:

> *"We are struggling because we are not paid"*
> *We are not working"*
> *We don't have money to transport the patients of to feed them because we are not paid."*

The findings echo those from Kangthe's (2009) study in which it is reported that caregivers of HIV clients are volunteers who are expected by the community to feed the sick, provide them with transport and to spend their time providing care and support to these patient without any pay.

3.5.2.9 Task Shifting and Nurses Attitude

Barnighausen, Bloom, & Dehumair, (2007) indicate that due to workload of nurses in the care for HIV and AIDS, the responsibilities are now shifted to community caregivers. This is confirmed by the findings from this study wherein the participants indicated below, that patients are taken care of by the volunteers, support groups and the CBOs.

> *"Some of the patients come back from the clinic and they say nurses asked them to go home to be taken care of by support group."*

On the same note, WHO Report (2008) shows that there is a shortage of health personnel especially nurses. As a result, the community health-workers assume the role of nurses in HIV care and support. The present study reveals the findings consistent with the statement in the WHO report.

Furthermore, these findings confirm those by Deetlefs, Greeff & Koen (2003: 29), who report that nurses have a negative attitude towards HIV positive patients because they (nurses) lack knowledge on HIV. The same attitude as embodied in the following responses suggests that nursing care in some communities in Lesotho may not be any different.

> *"The patients refuse to go back to health facility for checkup because they fear nurses"*
> *"These nurse don't talk properly to patients at times"*
> *"The nurses have bad attitude towards patients"*

"The nurses scold them if they missed appointment or did not come on time to collect medication"

The findings in this study confirm Rebab and Zadeh's (2011) findings that demonstrate the inability of nurses to understand and sympathize with other social issues affecting the HIV patient. Such incapacity can be associated with their failure to radiate a positive attitude to the HIV-positive patients (Rebab and Zadeh's (2011).

Though their challenges were similar to those mentioned by the Southern African Development Community (SADC) HIV and AIDS Strategic Framework, 2010-2015 (2009), the participants in this study further indicate that there are challenges that were related to the Caregivers within the Community Based Organizations. These included group dynamics and lack of coordination and supervision from the government, as this may monitor and evaluate their activities.

3.5.2.10 Group dynamics

Forsyth (2006) regards group dynamics as the way people interact and react in a group. The responses below depict the notion of interaction as a group dynamic in the activities of caregivers:

"*We do not respect each other as members"*
"We shout at each other"
"Our meetings are destroyed and work is not as we would want it to be"
"Some members refuse to pay membership fee"
"They have elected the committee that they do not trust."

The findings in this study indicate that lack of respect for each other among service providers may result in lack of direction and guidance during meetings and discussions around issues of membership. In describing issues around group dynamics, the WHO

(2008) states that group limitations may be associated with the literacy level, professionalism, and different cultures of the members. Accordingly this lack trust, respect and leadership skills may lead to problem in providing guidance. This insight may be gleaned from the excerpts of the current study findings.

3.5.2.11 Lack of coordination and supervision

The Government of Lesotho National Strategic Plan on HIV and AIDS (2011: 16) expresses the need for coordination among civil society organizations as their services are too fragmented to be effective. Evidence of this lies in the following responses:

> *"We struggle with reports when we have done the work we do not know where to send them since National AIDS Commission is closed"*
> *"We see that support groups are falling apart because there are no people who come regularly to check on us"*
> *"We want to be told that we are doing the right thing bit we are never called by anyone or even visited by anyone who can tell us how to do things right"*

The findings confirm an observation in the Kingdom of Lesotho HIV Epidemiology and National Response Situation Analysis Report, (2011) which points to lack of coordination of services for NGOs, CBOs and FBOs. These civil society organizations were used to reporting to the Lesotho National AIDS Commission that was resolved in 2011 (The Government of Lesotho National Strategic Plan on HIV and AIDS, 2011: 16). Since the termination of the Lesotho National AIDS Commission, the CBOs were no longer monitored nor supervised. This dissolution resulted in CBOs not knowing where to report hence lack of coordination as reported by participants in this study.

3.5.3 MOTIVATION

According to Burton (2012), motivation is the action that keeps one encouraged and interested to continue with the performance. Motivation can be financial or non-financial,

whereby if people work for a specific goal as a team they remain motivated; or if they are recognized and praised for their efforts, commitment, or even when they know they can gain something (Burton: 2012).

Motivation is associated with achievement to meet the basic needs according to Maslow hierarchy of needs (Burton: 2012). The statements sourced from focus-group interviews in this inquiry render reasonable a conclusion that motivation can be associated with self-actualization, fulfillment and commitment to one's work, therefore, achievement.

3.5.3.1 Fulfillment

According to Longman dictionary (online: 2011), fulfillment is being satisfied and filled with happiness due to one's actions that are valuable, important and interesting. The Oxford Free Dictionary, (online: 2012), further defines fulfillment as "*a feeling of satisfaction at having achieved your desires*". The findings from this study point to a sense of fulfillment at work and satisfaction with the interventions that the caregivers offer to communities. This feeling is embodied in the statements as displayed below:

> *"It makes me feel good because we brought back people's life"*
> *"We feel so happy when people come back to thank us after we have helped them"*
> *"We feel so happy when we take care of orphans and vulnerable children, as there is no one to take care of them"*
> *"We feel motivated when they are better"*
> *"We enjoy helping people who are in need"*

The findings in this study concur with those of Banks and Bailey (2010: 1496-1497) which points to a sense of self-fulfillment and satisfaction in nurses when they watch their patients recuperate because of their care and watch them leave the hospital.

3.5.3.2 Commitment

Commitment means obligation or dedication according to Oxford Free Dictionary, (online: 2012). According to UNAIDS, (2008), commitment to care, treatment and support for the HIV-infected is done by all stakeholders including governments, civil society organizations, Community Based Organizations, families and individuals. In line with above statement, the participants in this study declared their commitment in their testimonies as indicated below.

> *"We are committed to help other people"*
> *"We sympathize with people we love"*
> *"We love our work"*
> *"We like what we are doing"*
> *"We become very excited when we see our patients recover after we have been caring for them"*
> *"It is because of passion that we have for our work and patients"*
> *"It is all about commitment because we do not want to see patients die"*
> *"We contribute to support those in need"*

There is a relationship between these findings and those by Orbach (2007), who indicates that the older women who cared for HIV infected clients tend to develop commitment because they want to see their family members recover. So the participants in this inquiry are volunteers who care for their neighbors and their family members. Most of these Caregivers were older women.

3.5.3.3 Training and skills development

According to WHO report, (2010), training and development means the practice of providing training, workshops, coaching, and mentoring, as to inspire, challenge, and motivate trainees to perform the functions of their position to the best of their ability and

within the set standards and set by local, state, guidelines. Thus, training and development provides trainees with necessary skills and tools needed for professional development, knowledge increase and capacity building for robust contribution in the health care and support systems (WHO report, 2010). The report further indicates that training and development help to initiate change and assertiveness in decision-making. Analysis of focus-group interview data seems to suggest that there is possibility of a positive relationship between training and improved skills for effective provision of care for the patients. Evidence of this lies in the following responses:

"We have been trained on behavior change communication skills"
"We have been trained on First Aid services"
"The training has change us to be better people"
"We receive training and have more knowledge to help others."

These descriptions correlate with the findings by Roper and Msimang, (2011) who states that training inspires caregivers to continue their work in the community, deal with difficult people and relationships, and improve services as well as sharing of skills among the community members.

3.5.3.4 Confidence

Confidence means belief in oneself, one's powers and abilities and self-reliance, (Oxford Free Dictionary, online: 2012). Participants in this study indicated that they are now brave in their work, hence thus the statements below:

"You do not know how brave we feel after the training"
"I was very confident when people ask for help"
"I am the only one trained on multiple drug resistant tuberculosis."

Commitment to clients' needs and their satisfaction is documented as one of the aspirations of Caregivers because this improves their confidence (Roper and Msimang

2011). This inquiry reveals the same findings as posited by Roper and Msimang.

3.5.4 RECOMMENDATIONS

Below are the recommendations by the participants:

3.5.4.1 Need for Resources

The need for resources for community caregivers who implement HIV activities cannot be over-emphasized (Makoae: 2009). Participants in this study recommended that they should be supported with necessary resources such as; home-based care kits, gloves, food packages, hygiene kits and uniforms as stated in the statements below:

"We need to be given gloves"
"We need home-based care kits"
"We need HIV Test kits"
"We need T-shirts and uniform"
"We need food packages for OVC, old people and patients"
"We need toiletries for OVC"
"We need OVC to be provided with school uniform and school shoes."

It has been reported that Caregivers often use their own resources to provide services and food for their clients and children and also to provide money where necessary as it is indicated by the participants in this study (de Saxe Zerden, Zerden & Billinghurst, 2006). This is in line with the findings of this study which further supports the findings by Waterman, Griffiths, Gellard, Olang, O'Keeffe (2006) as they reported that the Caregivers in the communities are the key pillars in provision of home-based care wherein they take the responsibility to provide the professional care and support to the sick with very limited resources that they have to struggle by themselves hence the need to be supported with relevant resources for effective service delivery.

3.5.4.2 Need for supervision and guidance

Kebalepile (2001), states that supervision is needed to improve on the skills in identified areas whereby the in service training may be provided along as gaps are identified. The need is emphasized in the form of the following excerpts, which are indicative of a recommendation for provision of supervision and guidance:

> *"We need to be visited regularly by the professionals to support us and guide us"*
> *"We need the government to see what we do and tell us if we are doing things as expected"*
> *"We want support from other organizations that are bigger than our own"*

The findings from this study reiterate the findings by MacGregor and van Pletzen (2013) who reported that it is essential to ensure that the caregivers are well guided and supervised to ensure that they perform according to required standard and nurses at times provide necessary supervision in the community as may be required.

3.5.4.3 Need for capacity building

According to Kebalepile (2001), capacity building in health-care is needed by all carders due to lots of changes in the HIV and health-care that need updates and frequent refresher training to keep care-providers and health professionals upraised with new information and new insights. The need for capacitating community nurses for assumption of the role of community level care-givers and other volunteers is essential (Schneider, *et. al*., 2008). Emphasis of this need is confirmed in this study through responses which included the following:

> *"We need to be trained on new diseases and other changes in health conditions like TB"*
> *"We need to be trained on self-reliance projects"*

"We need to be trained on financial management for our projects"
"We need training for committee members on leadership and development of constitution"

3.5.4.4 Need for Incentive

Uys (2002) emphasizes that for effective and successful community program, there is a need for an incentive as community care-givers are just volunteers. Based on findings from this study in the form of the recommendations given below by participants it seems that the need for incentives for care-givers cannot be over-emphasised:

"We want to be considered as Village Health Workers because we always work with them and assist them"
"We would like to be paid a little money like Village Health Workers and be recognized like them so that we do not take from our pocket when we accompany patients to hospital"
"We would like to be paid a little money like Village Health Workers and be recognized like them so that we do not take from our pocket when we accompany patients to hospital"
"We could be happy to earn a little income as a support to the work we do"
"We also need a little bit of money to help us do the work as we told you that we are just volunteers"

The findings from this inquiry show similarities with those in a study by Waterman, *et. al*., (2006); O'Grady, *et. al.,* (2008) which indicate that lack of incentives often forces care-givers to use their own money to provide services to HIV-stricken people in the communities. However, de Saxe Zerden, *et al.'s* (2006) and Schneider, *et. al*.'s, (2008) studies indicate that constraining as it is, the gesture of using their own resources to provide care, gives care-givers a high-level role. According to these authors, this calls

for need for caregivers to be recognized by giving some incentives as these will actually make them feel motivated to perform better.

3.6 CONCLUSION

The literature review has demonstrated that the Caregivers implementing HIV and AIDS activities have courage to do their work. They are committed and motivated to support the sick. The literature has informed the findings of this study that the Caregivers within the CBOs implement various interventions in HIV and AIDS that ranges from HIV prevention, treatment, support, impact mitigation, management and coordination. From the literature it has been demonstrated that there are several factors that motivate the caregivers to continue to do their job voluntarily as they find it to be fulfilling even though they face various challenges. The literature further support Caregivers' recommendations whereby the mentioned the need for more support, the need for recognition and the need for incentive.

CHAPTER 4
DISCUSSIONS, CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

4.1 INTRODUCTION

In the previous chapter data was presented and then substantiated with relevant literature. The discussion of findings, conclusions, recommendations and limitations of the study will be presented in this chapter.

4.2 DISCUSSION OF FINDINGS FOR INSIGHTS

The findings of this study confirm that due to task shifting, the HIV and AIDS Caregivers as volunteers in the communities play a fundamentally integral role in saving lives as they provide basic nursing care of patients at home (Kell and Walley, 2009: 2-5). This implies that the HIV and AIDS Caregivers are the strong pillars of the basic care at the grassroots as they provide palliative care services for the chronically ill.

The study reveals that Caregivers adopt a holistic approach to ensuring fresh food security, easy accessibility and improved nutritional status of their community level chronically sick. They for instance, maintain good nutrition for their clients through establishment of fresh vegetable homestead gardens for their HIV/AIDS clients. Furthermore, care-givers not only provide support on improved hygienic ways for patients to ensure cleanliness against infections, but also provide psychosocial care and support for orphans and vulnerable children in such communities. Such an approach is in line with Kell and Walley's (2009: 2-5) reasoning and position regarding destitute victims of HIV and AIDS.

One of the key insights from this research is therefore that HIV and AIDS care-givers are not only supporting patients on HIV and AIDS issues but their approach is in a

comprehensive manner to holistically address the well-being of the HIV infected patients. This further denotes that the Caregivers play an integral role in primary health care as evidenced in the respondents' report that they not only facilitate for health promotion linkages and referral to health services, but also provide awareness and education on prevention of child abuse and HIV prevention in general (Stjernsward, 2005: 111-117).

The study indicates that there is a somewhat positive relationship between effectiveness of the knowledge which Caregivers disseminate, and their involvement, commitment and motivation. Evidence of this lies in their (Caregivers) active involvement in dissemination of awareness-raising information on HIV testing and counseling; promotion of consistent and correct use of condom; promotion of social behavior change; prevention of mother-to-child transmission and promotion of voluntary medical male circumcision as well as reduction of multiple current partnerships.

Findings from the study seem to suggest also that existence of a clear national strategic plan has a role in guiding the activities and commitment of health providers at community level. It is evident from the findings that the CBOs are supporting the Government of Lesotho National Strategic Plan (2011). According to this plan, the Caregivers are supposed to be key implementers of HIV prevention interventions down to grass-root levels of society. The essence of the findings in this regard seems to be as understood and emphasized by Kabore, *et al.,* (2010: 583-587) that, care-givers play a supportive role in the governments' endeavors to curb the spread of HIV.
According to the Lesotho National AIDS Commission Report (2009), multiple concurrent sexual partnerships have been found to be among the key drivers of epidemic. In response, the behaviour change communication strategies illustrates the methods of information dissemination as health education through multimedia; entertainment and recreational events; interpersonal communication and social mobilizations through advocacy. The findings illustrate that the participants have been fully engaged in the implementation of the strategy and were contributing to the national response. Thus, they were taking lead role in the health education activities of their communities as Non-

Governmental Organizations (NGOs) (Lesotho National AIDS Commission report, 2009). The findings further highlight the commitment by these HIV and AIDS Caregivers in influencing healthy lifestyles and promoting effective community participation in order to ensure individual and family support.

The study has brought to surface and in congruence with Kabore, *et al.,* (2010: 583-587) finding, that it is possible for HIV and AIDS care-givers to proactively assume the role of nurses by providing general and holistic health promotion activities, which contribute effectively in the early diagnosis, counseling and referral of patients from the community to health facilities and to further enhance adherence to treatment". The respondents in this study mentioned that they have been providing services to promote positive living behaviors through psychosocial support for the people living with HIV. Their interventions have been envisioned to ensure that they are empowered towards stable state of mind, thoughts, emotions, feelings and behaviors, social interaction, relationships with others, environment, cultures and traditions as well as the roles and tasks of individuals. This emphasizes the holistic approach in the care and support by these non-professionals.

Furthermore, the respondents stated that they support the clients through counseling to enhance adherence to their medication and to create support by the society to reduce stigma and to promote hope. The health professionals rarely provide these interventions, as they are limited in number based on the demands at the community level (The Kingdom of Lesotho HIV Epidemiology and National Response Situation Analysis Report, 2011: 16), (Forouzan, *et al.,* 2013: online). While the psychosocial support is needed at all times, even at home by family members, the community and others, the respondents in this study mentioned that caregivers are better placed to provide these services as they leave in the community with patients. They help to retain patients in care and reduce the defaulter rate for both ART and TB through direct observation of treatment (DOTS) (Kabore, *et al.,* 2010: 583-587). This therefore implies that the Caregivers play a nursing role due to lack of health personnel.

The respondents in this study indicated" that the HIV and AIDS Caregivers are challenged as they are not professionals in this field, but they are forced by circumstances to perform the nurses' duties due to limited health personnel who are expected to provide the quality care services (Makoae, 2009: 18-24). It is implicit from the findings that lack of professional knowledge acquired from training could be a factor in some of the challenges which Caregivers encounter in their implementation of community level anti-HIV interventions.

It has been evidenced from the respondents of this study that due to workload of nurses in the care for HIV and AIDS, there is task shifting to the volunteers, support groups and the CBOs. However, the support is also limited as stated by the respondents that the nurses have negative attitude towards HIV positive patients. It is further stated that most of the nurses lack knowledge on HIV and AIDS issues which makes it even more difficult to provide technical support and supervision to the volunteer caregivers. It is worse because the respondents had further indicated that the nurse also have negative attitude toward HIV positive clients (Rebab and Zadeh, 2011, Deetlefs, Greeff & Koen, 2003:29). The findings of this study has indicated that there is general inadequate capacity to manage HIV and AIDS interventions at the community level as there are no clear coordination structures to enhance supervision and mentoring for the implementers (The Government of the Kingdom of Lesotho HIV Epidemiology and National Response Situation Analysis Report, 2011). Therefore, the respondents of this study stated that the CBOs remain uncoordinated, as their activities are not standard and fragmented since the closure of Lesotho National AIDS Commission in 2011. Despite lack of guidance, coordination and supervision of the Caregivers implementing HIV and AIDS activities in the communities, the findings of this study confirm that these Caregivers lack skills, because they were not trained in the work they were doing to support the ministry of health (de Saxe Zerden *et al.,* 2006).

It seems reasonable to conclude from the findings in this study illustrate that there is lack of mechanisms or structures for coordinating activities for the implementation of anti-HIV interventions, and this may be a factor in government's failure to curb the

challenges which care-givers reportedly continue to experience in their efforts. Participants mentioned for instance, that they encounter challenges such as access to services, cultural issues that includes gender and norms, religion, as well as stigma and discrimination that leads to non-disclosure of HIV status. Could there have been a strong coordinating body some of these challenges could have been given a clear direction and strategies that guide implementation. Therefore, the nation fails to capture and include the effort of CBOs into the national response because there is no effective coordination.

Failure to disclose one's HIV status can make it difficult for the caregivers to intervene from outside. It emerges from interrogation of findings that the situation may get aggravated by not only failure by the client to disclose their status even to the family members; but also by family members' display of unwelcoming attitude towards care-givers. The respondents in this study for instance, emphasize that some of the patients fail to disclose their status even to their family. In worse case scenarios the family members themselves are negative towards Caregivers. The study reveals as did that by Peacock *et al.,* (2008: 17) that non-disclosure is a grave challenge to those who provide care since it in turn leads to delay in provision of appropriate support and receipt of treatment. On the other hand findings from the study nail clients' failure to disclose their status on fear of stigmatization and discrimination.

Furthermore, non-disclosure will always remain a challenge as it is supported by the HIV policy that the status of individual should be treated in a confidential manner. This does not enable other service providers such as the CBOs to participate effectively because they may not know the status of such individuals. On the same note, it is true that there is element of discrimination even by the people who are very close to this HIV positive individual as indicated by the respondents in this study. Women are even at more risk of discrimination and stigma as their in-laws often treat them like outcasts (Reis *et al.,* 2005). It is obvious in this study that, the caregivers experienced lot of challenges related to cultural issues that perpetuate stigma, discrimination and non-disclosure of HIV status. A further reasonable insight regarding reluctance to disclose

one's HIV status seems to be associated with the HIV policy provision which legitimises privacy of one's status.

These challenges on cultural issues become more complicated when the patients believe that they were bewitched and they fail to adhere to their treatment hence high defaulter rate (Peacock, *et al.,* 2008: 17). The respondent of this study further indicated that due to these attitudes and believes in witchcraft, patients delay to seek for western medical attention; but rather continue to use traditional medicine and consequently get further exposed to more opportunistic infections (Ashforth, 2001).

Though on different grounds for men and women, the study points to cultural issues as a factor in men's and women's failure to seek health services". Men for instance refrain from seeking health services because it is culturally believed to be weak and womanish of them to fail to resist pain. The findings therefore, suggest that men will always hide their illnesses because they want to show their strength as men. So cases of death among men may, as stated in the UNAIDS (1999) and WHO (2008) reports, be reasonably associated with some gender-related cultural expectations regarding the reaction of male persons to illness.

It emerges from analysis of findings that cultural and gender norms affect the extent to which women clients can access health services for safety of their life. In their female capacity women culturally have no decision-making status in sexual relationships. Evidence of this was in participants' statements about men's refusal to use condoms (Hlalele and Letsie, 2011: 159-161). This implies that men never consider the interests of women as their sexual partners. Therefore women, as indicated by Gupta (2000), cannot decide that they need to use condom; while their male partners might even be sick and hiding their status.

The focus-group interviews revealed that one of the key challenges is lack of resources such as gloves, test kits and first aid kits. This means that the HIV and AIDS care-givers struggle to provide quality services as they often have to improvise and put their lives at risk of getting infection while they want to save lives of others (Makoae, 2009: 18-24).

The findings show that the HIV and AIDS Caregivers are not given incentives for the good work they do. However, the community demands as well as the expectations are high. Most often, people tend to forget that these Caregivers are volunteers who just want to make change in other people's lives, yet sadly, they are often expected to even provide material goods such as food packages and or transport to the health facilities (Kangthe: 2009).

Even though the findings of this study confirmed that the Care-givers had several challenges, the respondents indicated that HIV and AIDS Caregivers remained committed and motivated to care for the HIV and AIDS patients out of good will because they are their relatives, neighbours and friends (Orbach: 2007).The respondents mentioned that they have a feeling of satisfaction as they see the patients recover because they would have achieved their goal. It has been indicated that some patients take care of themselves; while some were orphans and vulnerable children with no one to look after them. As such, they are supporting the government by so doing since it is the role of the Ministry of Social Development to cater for the needs of destitute children.

It was specified by the respondents in this study that they were committed in what they were doing. Therefore this implies that the Caregivers felt that they are compelled to provide care and support to the HIV positive clients. They (Caregivers) had courage and motivation because they are fulfilled when they see them recover as it is stated above (UNAIDS Report: 2008). The commitment further made the Caregivers gain skills and experience as they continue to care for HIV positive clients. Caregivers mentioned that they were at times trained and attended several workshops even though this was when the Lesotho National AIDS Commission was still active. It seems that these trainings have empowered them to deal with difficult situations and to remain assertive and confident as they perform their duties (Roper and Msimang, 2011).

The findings of this study confirmed that the HIV and AIDS Caregivers are not given an

incentive as token for appreciation or even to help them with transport. However, these Caregivers are not given any incentives to motivate them despite their continued commitment in the form of voluntary and free support to HIV-positive and affected orphans and other vulnerable children. The study reveals, as did that by Waterman, *et al.* (2006) that these care-givers' generosity and commitment go to an extent of spending their own monetary and other resources for the health welfare of the clients. The study further indicted there is high demand and a lot of expectations from the donors and the government yet there is no indication of any commitment of a budget to cover for their stipends, remuneration, support and recognition for their efforts (Schneider: 2008).

4.3 SUMMARY OF CONCLUSIONS

The analysis of the focus-group interviews as the main data collection tool for this study has brought to surface the following main conclusions:

- Caregivers in the communities of Lesotho remain the key pillars of community level home-based care for chronically ill patients. They are therefore a health support structure that needs to be recognized and empowered as a dependable, always available and sustainable, mechanism to deliver basic home-based nursing care.

- Lack of a structure for coordination of the anti-HIV intervention activities is cause for concern. Whereas the caregivers seem to be very active and committed in implementing the interventions that are not even coordinated, the need for motivation, guidance and supervision by the Government and its partners to ensure quality of the services cannot be over emphasized as stated in the (Government of Lesotho National Strategic Plan on HIV and AIDS, 2011: 16).

- Good quality provision of proper care seems to depend on availability of monetary and other resources. The quality services by the volunteer Caregivers can further

be realized if there are sufficient financial, technical and material resources provided to Caregivers in the communities by the Government. Since these caregivers are volunteers with no pay they need to be motivated to perform better through incentives that will allow them to effectively address the demands of the patients in the community.

- Task and role shifting wherein the caregivers assume the role of health professionals seem unavoidable for Caregivers operating at community level. There is therefore, a need to capacitate them with relevant professional skills to as a way of empowering them to better perform these duties.

4.4 RECOMMENDATIONS

The recommendations are presented such that they address the main findings and conclusions from the study as discussed in chapter 3 of this report.
Specifically, these recommendations are presented around resources, capacity building and incentives as key areas, which seemed to underpin the bulk of the responses from focus-group interviews.

4.4.1 RESOURCES

The Caregivers implementing HIV and AIDS activities continued to provide various services that even put their lives at risk due to limited resources. From the respondents, it is deduced that there is a need for the government, donors and relevant implementing partners to budget for resources such as home based care kits, gloves, test kits and toiletries and food packages for those patient who are economically challenged. These resources could be managed through the health facilities and the district health management teams as well as the NGOs and CBOs so that all can make a proper follow-up and support on the use of the resources. Clear and detailed tools for reporting should be developed and all resources accounted for.

4.4.2 CAPACITY BUILDING

It emerges from the inquiry that the Caregivers lack knowledge and skills required to better perform their duties. It seems imperative put in place structures and training mechanisms that will empower Caregivers with requisite understanding, knowledge and skills for their work. The respondents themselves recommended that they need training and refresher courses on various topics due to new changes in treatment guidelines and the new discoveries as well as priorities in the national response. For instance, they point out that currently the country is implementing Prevention of Mother to Child Transmission – Option B+. These pregnant mothers need to be identified and referred from the community by these caregivers. Developments such as these dictate need for Caregivers to be capacitated with skills and strategies for convincing pregnant women to attend anti-natal services at the first trimester for uptake of the recommended services. Moreover, these Caregivers need to be provided with the guiding tools that are written in simple language so that they can use it as reference when doing their work.

The study reveals that some of the developments in health care include changes in the guidelines for treatment of TB and HIV.As the people who support patients to adhere to their treatment, Caregivers need to be updated when such changes are introduced. There is therefore, need for the Ministry of Health to develop a purpose-built training curriculum that is meant for community Caregivers.

Besides the trainings on patient care and support, the respondents in this study recommended that they need to be trained on self- reliance projects so that they do not just depend of donors but they can be able to produce and generate income for their sustainable projects. It is reasonable therefore, to recommend that the NGOs and other community implementers take cognizance of capacity building for sustainable community projects that help to generate income for volunteers.

4.4.3 SUPERVISION AND GUIDANCE

The Caregivers in the communities are just volunteers with good will to support and take care of the sick people. Having been trained to build on their capacity, they need a close follow-up, mentoring, guidance and supervision to ensure safe and efficient delivery of health services. Caregivers may be dangerous to the patients due to limited understanding and knowledge of this work as they are not technical experts or professionals in this field hence need for close supervision.

The Ministry of Health in collaboration with the CBOs and NGOs implementing HIV and AIDS services should develop standard guidelines which define the scope of work for the Caregivers at the grassroots. So the Ministry of Health should organize strategic orientation workshops for the caregivers on the standard guidelines to avoid fragmentation of services. Furthermore, the Ministry through its organs such as public health nursing structure needs to provide supervision and mentorship to ensure quality of services by the Caregivers.

4.4.4 INCENTIVE

It is recommended that the Caregivers be given an incentive as a form of recognition and appreciation of their efforts. However, the incentive in their case is not only for recognition, but also a token in the form of a minimum stipend to supplement the costs they incur their support of the chronically sick community members. It is further recommended that the Ministry of Health should consider including monetary incentives for community Caregivers in their planning and budgeting. This will facilitate effective referral of patients to services as the Caregivers will be in a position to among others, provide these patients with transport fees during referral.

The recommendation is that the programmers should be proactive in the planning to address all the basic needs of the Caregivers. Inclusion of food packages and toiletries as part of incentive for the Caregivers would seem reasonable in some cases. Moreover, as these Caregivers travel from one house to another and from one village to

the next, they need incentives such as rain suits, walking shoes, umbrellas and they mentioned further that they are more recognized, identified and respected when they are in uniform. Therefore, the recommendation is that T-shirts and caps that bear the names of the support groups be provided to the Caregivers as an incentive. This could be achieved if they are supported with start-up capital to establish some income generating projects. Therefore, it implies that the community's structures need to be empowered to prescribe terms and conditions that suit and benefit them when they implement the project. Furthermore, the community implementers have to consult with the community members when they design a community project to ensure that they are involved and capacitated to build ownership and sustainable interventions.

4.5 RECOMMENDATIONS FOR FURTHER RESEARCH

The current study was conducted in Maseru rural, which is the small portion of the country that does not represent the whole. The Caregivers implementing HIV and AIDS activities are scattered throughout the country in CBOs and support groups that are formed in different ways. The findings of this study may not be considered to signify the situation in the country or in the very remote areas. The experiences of caregivers may differ from the other site of the country to another. Moreover, there are various types of CBOs that have caregivers who implement HIV and AIDS interventions in the country.

The recommendation is that further researches may:

- Include all the CBOs in the country building on the findings of this study to explore more on their experiences in caring.
- Explore on the strategies that can be used to empower the CBOs and caregivers implementing HIV and AIDS interventions.
- Explore how CBOs and caregivers overcome challenges in experienced while implementing HIV and AIDS activities in the communities.
- Inquire into the support rendered by the health professionals/nurse to the interventions of the community care-givers implementing HIV and AIDS.

4.6 LIMITATIONS OF THE STUDY

The limitations of the study are discussed as follows:

- The recruitment of participants into the focus groups interviews was not inclusive as some members of the support group were left out due to purposive sampling and the number that had to be in the interviews. So, some people who were left out may have been more vocal than those who in selected to participate.
- Some of the caregivers were busy working at the community projects during the data collection; so only those who were available could participate.
- The interviews were conducted in local language, which is Sesotho. So, translation into English might have failed to pick some words that could not be better expressed in another language.

4.7 VALUE OF THE STUDY

It is anticipated that the study will have the following impact on the diverse organizations:

- The results of the study will help the Ministry of Health in Lesotho to improve on coordination and supervision the Caregivers within the CBOs implementing HIV and AIDS interventions in the country.
- The government will use the findings and the recommendations of the study to standardize services in that are currently implemented in a fragmented manner.
- The NGOs and other partners implementing community-based activities with volunteers Caregivers will use the findings and recommendations of the study in their programming.
- The study findings and recommendations will help the networks of CBOs such as the Lesotho Network of AIDS service Organizations (LENASO) in planning for capacity building of the CBOs.

4.8 CONCLUSION

The purpose of the study was to explore the experiences of the Caregivers within CBOs implementing HIV and AIDS activities in the communities of rural Maseru. The explorative, descriptive, contextual and phenomenological designs were applied in the qualitative paradigm. The focus group interviews were conducted to generate information on the experiences of Caregivers hence the recommendations were created based on the findings of the study. In conclusion this study has successfully met its purpose.

REFERENCES

Akinkugbe, M. and Mohanoe, M. 2009. *Public health expenditure as determinant of health status in Lesotho.* South Africa: Grahams Town. http://www.tandfonline.com/doi/abs/10.1080/19371910802569716#.VMNwbVqXI1g. Accessed May 2013.

Ashforth, A. 2001. Aids, witchcraft, and the problem of power in Post-Apartheid South Africa. https://www.sss.ias.edu/files/papers/paperten.pdf. Accessed January 2014.

Babbie, E. and Mouton, J. 2009. *The practice of social research*. 1st edition. Oxford. University Press South Africa (Pty) Ltd: Cape Town.

Banks, Z.M. and Bailey, J.H. 2010 Career motivation in newly licensed registered nurses: What makes them remain? *The qualitative report* 15 (6):1489-1503 http://www.nova.edu/ssss/QR/QR15- Accessed Jul 2013.

Barnighausen, T.I., Bloom, D.E., Humair, S. 2007. Human resources for treating HIV/AIDS: needs, capacities, and gaps. *Journal of Aids patient care and stds* 21(11): 799-812. http://www.liebertonline.com/doi/pdfplus/10.1089/apc.2007.0193?cookieSet=1 Accessed March 2014.

Barrett, C.B. 2010. Measuring food insecurity. *Science:* American association for the advancement of science: York Avenue NW, Washington, DC 20005 http://www.sciencemag.org/cgi/content/full/327/5967/825. Accessed March 2014.

Botma, Y., Greeff, M., Mulaudzi, F.M. & Wrigth, S.C.D. 2010. *Research in health sciences*. 1st Edition. Forest Drive: Cape Town.

Brink, H., Van der Walt, C. and Van Rensburg, G. 2012. *Fundamentals of research for healthcare professionals*. Juta & Co. Ltd: Cape town.

Brink, H.I. 2008. *Fundamentals of research methodology for health care professionals.* Juta & Co. Ltd: Cape Town.

Burns, N. and Grove, S.K. 2009. *The Practice of nursing research: Appraisal, synthesis, and generation of evidence.* 6th Edition. Saunders Elsevier: St. Louis.

Burns, N. and Grove, S.K. 2012. *The practice of nursing research*: *Appraisal, synthesis and Generation of Evidence*. 7th Edition. Saunders Elsevier: St. Louis.

Burton, K. 2012. A study of motivation: How to get your employees moving. SPEA Honors Thesis Spring. Indian University Management.

Creswell, J.W. 2009. *Research design qualitative, quantitative and mixed methods approaches*. University of Nebraska, Sage Publications Inc: London.

Creswell, J.W. 2013. *Qualitative inquiry and research design. Choosing among five approaches*. 3rd Edition. Sage Publications Inc: London.

De Saxe Zerden, L., Zerden, M. & Billinghurst, K. 2006. Caring for home-based care workers: understanding the needs, fears and motivations of front-line care workers in South Africa. *Southern African Journal of HIV Medicine* 38: 40-43

De Vos, A.D., Strydom, H., Fouche, C.B. & Delport, C.S.L. 2011. *Research at Grass roots*. 3rd Edition. Van Schaik: Pretoria.

Deetlefs, E., Greeff, M. & Koen, M.P. 2003. The attitudes of nurses towards HIV positive patients *Health SA Gesondheid*, 8(2): 23-33.

Drimie, S. 2003. HIV/Aids and land: Case Studies from Kenya, Lesotho and South Africa. *Development Southern Africa* 20(5): 650-660.

Forouzan, A.S., Shushtari, Z.J., Stajjadi, H., Salimi, Y. & Dejman, M. 2013. Social support network among people living with HIV/AIDS in Iran: Hindawi publishing corporation Journal of AIDS research & treatment. Article ID 715381: 1-7 http://dx.doi.org/10.1155/2013/715381. Accessed May 2013.

Forsyth, D.R. 2006. *Group dynamics*. 4th Edition. Thomson Wadsworth: Australia. https://www.cengagebrain.com.mx/content/forsyth68220_0534368220_02.01_chapter01.pdf. Accessed January 2014.

Fouche, S.H., and Deplort C.S. 2005. *Research at grass roots*. Van Schaik Publisher: Pretoria.

Freedictionary. (online) 2011. http://www.thefreedictionary.com/impeding. Accessed 25 July 2014.

Given, L.M. 2008. *The Sage Encyclopedia of Qualitative Research Methods*. University of Alberta. Volumes 1 & 2. Sage Publications: Los Angeles.

Global Fund to Fight Aids, tuberculosis and Malaria. 2014. Community system strengthening framework http://www.theglobalfund.org/en/fundingmodel/support/infonotes/. Accessed October 2014.

Goffman, E. 1963. *Stigma: Notes on the management of a spoiled identity*. 1st Touchstone Edition. Simon and Schuster: New York.

Government of Lesotho. 2000. Policy framework on HIV prevention, control and Management. http://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---ilo_aids/documents/legaldocument/wcms_173185.pdf. Accessed Dec 2013.

Government of Lesotho. 2009. Lesotho Health Service Decentralization Strategic Plan. Lesotho Government printing: Maseru.

Government of Lesotho. 2011. Lesotho National HIV & AIDS Strategic Plan 2011-2016 Lesotho Government printing: Maseru.

Government of Lesotho. 2013. Lesotho National Guidelines For the Prevention of Mother to Child Transmission of HIV. Lesotho Government printing: Maseru.

Guion, L.A., Diehl, D.C. & McDonald, D. 2011.Triangulation: Establishing the validity of qualitative studies. http://edis.ifas.ufl.edu> accessed August. 2011.

Gupta, G.R. 2000. Gender, Sexuality, and HIV/AIDS: The What, the why, and the how. Presented at XIIIth International AIDS Conference Durban, South Africa. http://www.icrw.org/docs/Durban_HIVAIDS_speech700.pdf. Accessed May 2013.

Hemmelgreen, D.A., Romero-Daza, N., Turkon, D., Watson, S., Okello-Uma, I. & Sellen, D. 2009. Addressing the HIV/AIDS food insecurity syndemic in Sub-Saharan Africa. *African Journal of AIDS Research, 8(4):401-412*.

Hlalele, D. and Letsie, P.R. 2011. Gender Inequality and HIV/AIDS in Lesotho: A human disease ecological perspective. *Journal Human Ecology*, 36(3):159-165.

Joubert, G. & Ehrlich, R. 2007. *Epidemiology: A research manual for South Africa*. 2nd Edition. Oxford University Press Southern Africa (PTY) Ltd: Cape Town.

Kabore, I., Bloem, J., Etheredge, G., Obbiero, W., Wanless, S., Doykos, P., Ntsekhe, P., Mtshali, N., Afrikaner, E., Sayed, R., Bostwelelo, J., Hani, A., Moshabesha, T., Kalaka, A., Mameja, J., Zwane, N., Shongwe, N., Mttshali, P., Mohr, B., Smuts, A. & Tiam, A. 2010. The Effects of community-based support services on clinical efficacy and health-related quality of life in HIV/AIDS patients in resource-limited settings in Sub-Saharan Africa. *Journal of Aids patient Care and STDs,* 24(9):583-587.

Kangthe, S. 2009. Critical coping challenges facing caregivers of persons living with HIV/AIDS and other terminally ill persons: *The Case of Kanye care program, Botswana*. Jul-Dec; 15(2): 115-21.

Kebalepile, T.M. 2001. An evaluation of the quality of care midwives provide during the postpartum period in northern Botswana. Unpublished Thesis submitted at the Faculty of Medicine, University of Oslo.

Kell, M.E. and Walley, D.W. 2009. Palliative Care for HIV in the era of antiretroviral therapy availability: perspectives of nurses in Lesotho. *Bio Medical Central, Palliative Care.* 8 (11): 1-9. *http://www.biomedcentral.com/1472-684X/8/11.* Accessed June 2013.

Kwena, Z.A., Manyasa, E., Byarugaba & Mwanzo, I. 2009. *5th International Aids Society Conference on HIV Pathogenesis and Treatment:* The possible impact of witchcraft beliefs on HIV care seeking in the general population of Lambwe, Division in Suba District, Kenya. Cape Town, South Africa. July 19-22 2009.

Lesotho Government. 2007. Kingdom of Lesotho National Tuberculosis Programme Policy and Manual. Lesotho Government printing: Maseru.

Lesotho Government. 2011. Kingdom of Lesotho HIV Epidemiology & National Response Situation Analysis Report. Lesotho Government printing: Maseru.

Lesotho Ministry of Health and Social Welfare. 2009. *Demographic and health survey report. Lesotho* Government Printing: Maseru.

Lesotho Ministry of Health and Social Welfare. 2010. Annual joint review report. Lesotho Government printing: Maseru.

Lesotho Ministry of Health and Social Welfare. 2010. *Annual Report*. Ministry of Health. Lesotho Government printing: Maseru.

Lesotho National AIDS Commission. 2009. Annual report. National Aids commission. Maseru. Lesotho Government printing: Maseru.

Lesotho National AIDS Commission. 2009. National strategic plan.2006-2011. National Aids commission. Lesotho Government printing: Maseru.

Lesotho Network of AIDS Service Organizations and Elizabeth Glaser Pediatric AIDS Foundation. 2013. Report. Lesotho Network of AIDS Service Organizations and Elizabeth Glaser Pediatric AIDS Foundation.

Lesotho Partnership Framework to Support Implementation of the Lesotho

National HIV and AIDS. 2010. Response between the government of United State and the Kingdom of Lesotho. Lesotho Government printing: Maseru.

Longman Dictionary. (Online), Available from: www.longmandictionriesonline. Accessed 2011

MacGregor, H. and van Pletzen, E. 2013. The backbone for accessible care and support**,** multi-country research, South Africa Report. Caregiver action network South Africa, Cape Town.

Makoae, M. G. 2009. The phenomenology of bodily care: caregivers' experience with

Marsh, D.R., Schroeder, D.G., Dearden, K.A., Sternin, J. & Sternin, M. 2004. The power of positive deviance. *Biomedical journal* 2004, 329:1177-1179.

Marshall, C. & Rossman, G.B. 2011. *Designing qualitative research.* 5th edition. Thousand Oaks: Sage Publications: London.

Medical care development international. 2008. Behaviour Change Communication in Lesotho: National Behaviour Change Strategy 2008-2013. Government of Lesotho. Healthclearinghouse.unesco.org/sites/default/files/resources/iiep_lesotho_bccstrategy2008_2013.pdf. Accessed June 2014.

Moetlo, G.J., Pengpid, S. & Peltzer, K. 2011. An evaluation the implementation of integrated community home-based care services in Vhembe District, South Africa. *Indian Journal of Palliative Care*. 17(2): 137.

Naidoo, J.R., Uys, L.R., Greeff, M., Hoizemer, W.L., Makoae, L., Dlamini, P., Phetlhu, R.D., Chirwa, M. & Kohi, T. 2007. Urban and rural differences in HIV/AIDS Stigma in five African countries. *African Journal of AIDS Research,* 6(1):17-23.

O'Donnell, M.P. 2009. Defination of Health Promotion 2.0: Embracing passion, enhancing motivation, recognizing dynamic balance and creating opportunities. *American Journal of Health Promotion*: 24 (1) 1-10.

O'Grady, N.P.,' Barie, P.S., Bartlett, J.G., Bleck, T., Carroll, K., Kalil, A.C., Linden, P, Maki, D.G., Nierman, D., Pasculle, W., Masur, H. 2008. Guidelines for evaluation of new fever in critically ill adult patients. *American College of Critical Care Medicine; Infectious Diseases Society of America*. 36(4): 1330-1349.

Orbach, D. 2007. Committed to caring- older women and HIV and AIDS in Cambodia, Thailand and Vietnam –Help Age International. http://www.helpage.org/. Accessed June 2013.

Osterberg, and Blaschke, T. 2005 *Drugs don't work in patients who don't take them.* drug therapy**.** Adherence to Medication. Medical Society: Massachusetts. www.nejm.org. Accessed June 2013.

Oxford Free Dictionary. (Online). www.oxforddictionaries.com. Accessed July 2012.

Patton, M.Q. 2002. *Qualitative research and evaluation methods*. 3rd Edition. Thousand Oaks, CA. Sage Publications: London

Peacock, D., Rededpath, J., Weston, M., Evans, K., Daub, A. & Greig, A. 2008. *Literature Review on Men, Gender, Health and HIV and AIDS in South Africa.* Sonke Gender Justice Network: Johannesburg www.**genderj**ustice.org.za. Accessed May 2012.

Polit, D.F. & Beck, C.T. 2004. Nursing research: Generating and assessing evidence for Nursing Practice. 2nd Edition. Lippincot Williams and Wilkins: Philadelphia.

Polit, D.F. & Beck, C.T. 2008. Nursing research: Generating and assessing evidence for Nursing Practice. 7th Edition. Lippincot Williams and Wilkins: Philadelphia.

Polit, D.F. & Beck, C.T. 2012. Nursing research: Generating and assessing evidence for Nursing Practice. 9th Edition. Lippincott Williams and Wilkins: Philadelphia.

Rebab, S. & Zadeh, E. 2011. Knowledge and attitude of nurses towards care of HIV/AIDS patients. Journal of Academic and Applied Studies.1 (1): (Online) www.academians.org. Accessed July 2012.

Reis, C., Heisler, M., Amowitz, L.L., Moreland, L.S., Mafeni, J.O., Anyamele, C. & Lacopino, V. 2005. Discriminatory attitudes and practices by health workers toward patients with HIV/AIDS in Nigeria. *PLoS Medicine*. www.plosmedicine.org. Accessed January 2013.

Roper, M. & Msimang, C. 2011. Can skills development programmes for community caregivers enhance their capacity to respond to vulnerable children? The Thogomelo Project: HWSETA Conference: Human Resource needs opportunities and challenges facing service delivery in the health and welfare sector. Durban, South Africa. Sept 2011.

Schneider, H., Hlophe, H., Van Rensburg, D. 2008 Community health workers and the response to HIV/AIDS in South Africa: tensions and prospects. Centre for Health Policy, School of Public Health: University of Witwatersrand.

Smith, R.A., Saslow, D., Sawyer, K.A. 2003. American Cancer Society guidelines for breast cancer screening. CA: *Cancer Journal for Clinicians,* 53(3):141–169.

Southern African Development Community [SADC]. Towards Common Future. 2009. SADC HIV and AIDS Strategic Framework: 2010-2015 final draft. http://www.sadc.int/files/4213/5435/8109/SADCHIVandAIDSStrategyFramework2010-2015.pdf. Accessed June 2013.

Stjernsward, J. 2005. Community participation in palliative care. Indian Journal of Palliative care. http://www.jpalliativecare.com/text.asp?2005/11/2/111/19190 Accessed June 2014.

Streubert, H.J. and Carpenter, D.R. 2012. Qualitative research in nursing: Advancing the Humanistic Imperative. 5th Edition. Lippincott Williams and Wilkins: Philadelphia.

Stuart, L., Harkins, and J., Wigley, M. 2005. Establishing referral networks for comprehensive HIV care in low-resource settings. Arlington, VA: Family Health International. http://www.popline.org/node/263454. Accessed June 2014.

Tesch, R. 1990. Qualitative Research: Analysis Types and Soft method tools. Falmer Press: New York.

The Joint United Nations Programme on HIV and AID [UNAIDS] and World Health Organization [WHO]. 2009. Report on the global AIDS epidemic update. UNAIDS: Geneva.

The Joint United Nations Programme on HIV and AID [UNAIDS]. 1999. Gender and HIV/AIDS: Taking Stock of Research and Programs. UNAIDS: Geneva.

The Joint United Nations Programme on HIV and AID [UNAIDS]. 2008. The Report on the Global AIDS epidemic. UNAIDS: Geneva.

The Joint United Nations Programme on HIV and AID [UNAIDS]. 2009. Lesotho HIV prevention response and modes of transmission analysis. Lesotho National AIDS Commission. World Bank Global HIV/AIDS Program and Global AIDS monotoring and evaluation team. UNAIDS: Geneva.

The Joint United Nations Programme on HIV and AID [UNAIDS]. 2010. Report on the global AIDS epidemic. UNAIDS: Geneva.

The Joint United Nations Programme on HIV and AID [UNAIDS]. 2011. World Aids Day Report. UNAIDS: Geneva.

Turkon, D., Hemmelgreen, D., Romero-Daza, N. & Noble, C. 2009. Anthropological perspectives on the challenges to monitoring and evaluating HIV and AIDS programming in Lesotho. *African Journal of AIDS Research,* 8(4): 473-480.

Ulick, T. and Crush, T. 2007. Poverty, Gender and Migrancy: Lesotho's migrant farmworkers in South Africa. *Development South Africa,* 24(1): 155-172.

United Nations General Assembly Special Session on HIV/AIDS. 2001. Keeping the promise: Summary of the declaration of commitment on HIV/AIDS. 25-27 June. UNAIDS: New York.

Uys, L.R. 2002. The practice of community caregivers in a home-based HIV/AIDS project in South Africa. *Journal of clinical nursing* 11:99-108.

Waterman, H., Griffiths, J., Gellard, L., Olang, G. & O'Keeffe, C. 2006. Action research project: home-based care for people living with HIV/AIDS. MildMay International: Manchester.

World Health Organization [WHO]. 2003. Treatment of tuberculosis, guidelines for National programmes. whqlibdoc.who.int/hq/2003/who_cds_tb_2003.313_eng.pdf Accessed May 2014.

World Health Organization [WHO]. 2008. WHO report: Primary Health Care: Now More Than Ever. www.int/whr/2008/whr08_en.pdf. Accessed July 2014.

World Health Organization [WHO]. United Nations International Children's Emergency Fund [UNICEF], United Nations Fund for Population Activity [UNFPA] and the World Bank. 2010. *Trends in maternal mortality: 1990 to 2008: Estimates developed by WHO, UNICEF, UNFPA and The World Bank*. Geneva, World Health Organization.
(http://www.who.int/reproductivehealth/publications/monitoring/9789241500265/en/index.html. Accessed September 2013).

ANNEXURE A

APPROVAL LETTER FROM ETHICS COMMITTEE:

UNIVERSITY OF THE FREE STATE

UNIVERSITY OF THE FREE STATE
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YUNIVESITHI YA FREISTATA
UFS UV

Research Division
Internal Post Box G40
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E-mail address: StraussHS@ufs.ac.za

Ms H Strauss/hv

2013-04-10

REC Reference nr 230408-011
IRB nr 00006240

MS MG MAKOAE
C/O MRS MR MPELI
SCHOOL OF NURSING
UFS

Dear Ms Makoae

ECUFS NR 38/2013
MS MG MAKOAE **SCHOOL OF NURSING**
PROJECT TITLE: EXPERIENCES OF HIV AND AIDS CAREGIVERS WITHIN COMMUNITY BASED ORGANIZATIONS (CBOS) IMPLEMENTING SERVICES IN RURAL MASERU DISTRICT IN LESOTHO.

- You are hereby kindly informed that the Ethics Committee approved the above project at the meeting held on 9 April 2013.
- Committee guidance documents: Declaration of Helsinki, ICH, GCP and MRC Guidelines on Bio Medical Research. Clinical Trial Guidelines 2000 Department of Health RSA; Ethics in Health Research: Principles Structure and Processes Department of Health RSA 2004; Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa, Second Edition (2006); the Constitution of the Ethics Committee of the Faculty of Health Sciences and the Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines.
- Any amendment, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.
- The Committee must be informed of any serious adverse event and/or termination of the study.
- A progress report should be submitted within one year of approval of long term studies and a final report at completion of both short term and long term studies.
- Kindly refer to the ETOVS/ECUFS reference number in correspondence to the Ethics Committee secretariat.

Yours faithfully

.....
PROF WH KRUGER
CHAIR: ETHICS COMMITTEE

Cc **Ms MR Mpeli**

ANNEXURE B

APPROVAL LETTER:

LESOTHO NATIONAL HEALTH RESEARCH ETHICS COMMITTEE

LESOTHO

National Health Research Ethics
Committee (NH-REC) via
Research Coordination Unit (RCU)
Ministry of Health
PO Box 514
Maseru 100

May 13, 2013

Mamello G. Makoae
Student number 2002005953
Masters degree student
University of Free State

Dear M. G. Makoae,

Re: Experiences of HIV and AIDS Caregivers within Community Based Organizations (CBOs) Implementing Services in Rural Maseru District in Lesotho (ID 61-2013)

Thank you for submitting the above mentioned proposal. The Ministry of Health Research and Ethics Committee having reviewed your protocol hereby authorizes you to conduct this study among the specified population. The study is authorized with the understanding that the protocol will be followed as stated. Departure from the stipulated protocol will constitute a breach of the permission.

We are looking forward to have a progress report and final report at the end of your study.

Sincerely,

Dr. Jill Sanders
Co-Chairperson of the NH-REC

ANNEXURE C

APPROVAL LETTER FROM:

THE DISTRICT ADMINISTRATOR

FOR THE PRINCIPAL CHIEF OF MATSIENG, ROTHE

AND THABA-BOSIU

TEL: +266-22322988
FAX: +266-22310905

DISTRICT ADMINISTATION
P.O. Box 28
MASERU 100

DALA/HLT/8 **22ND July, 2013**

Morena oa Sehlooho
MATSIENG
ROTHE
THABA-BOSIU

Morena,

TABA: BOIPHIHLELO BA BAHLOKOMELI HOLIMA HIV LE AIDS METSENG

Ho latela sehlooho se hlahang mona ka holimo, ke hlahisa ho uena Mofumahali Makoae, ea lakatsang ho etsa boithuto ka boiphihlelo ba bahlokomeli holima HIV le AIDS, mekhatlong e hlahang lethathamong le qhoaeletsoeng.

Ka hona Morena, ke mo kopela kamohelo le tšebelisano 'moho e mofuthu libakeng tseo a tla li etela.

Kea leboha Morena.

Oa hau Mohlanka,

'MUSI OA SETEREKE
DISTRICT ADMINISTRATOR
2013 -07- 22
MASERU, LESOTHO

A. S. K. Makoro

MAJ. GEN. (ret) S.M. MAKORO
'MUSI OA SETEREKE – MASERU

Kopi: Mof. Mamello Makoae

ANNEXURE D

APPROVAL LETTER FROM THE:

DISTRICT ADMINISTRATOR OF MASERU

TEL: +266-22322988
FAX: +266-22310905

DISTRICTADMINISTRATION
P.O. Box 28
MASERU 100

DALA/HLT/8 **29th April, 2013**

Ms. Mamello G. Makoae

Dear Madam,

RE: PERMISSION TO CONDUCT RESEARCH

With reference to your letter dated 25th April, 2013, permission is, therefore, granted to you for this noble endeavour, however, you are advised to liaise with the Ministry of Health for approval.

Yours in service,

"MUSI GA SETEREKE
DISTRICT ADMINISTRATOR
2013 -04- 30
LESOTHO

MAJ. GEN. (ret) MAKORO S. MAKORO
DISTRICT ADMINISTRATOR - MASERU

ANNEXURE E

LETTER FROM EDITOR

LIFELILE MPHO MATSOSO (PH.D)

Box 1881, Maseru 100, LESOTHO, Southern Africa

January 26, 2015

The supervisor

Faculty of Health Sciences

University of the Free State

Bloemfontein 930

RSA

Dear Madam/Sir,

REF: MAMELLO G. MAKOAE

Language Editing of a Masters Mini Dissertation: *Experiences of Caregivers Implementing HIV and AIDS Services within Community-based Organisations in Rural Maseru: Lesotho*

The above-captioned subject has reference. By this letter I confirm that I have language edited the script. I submit that in my opinion the candidate has implemented the comments I had made. I recommend the script for onward submission to the External Examiner.

Sincerely,

Lifelile Mpho Matsoso (Ph.D)

Senior Lecturer: Language Education – National University of Lesotho

ANNEXURE F

APPROVAL LETTER FROM THE:

PRINCIPAL CHIEF

MATS/HCTH/10-10
SBS. TEMA

MORENA OA SEHLOOHO
MATSIENG
2013 -07- 26
P.O. BOX 1
MATSIENG, MASERU

Morena,

TABA: BOIPHIHLELO BA BAHLOKOMELI HOLIMA HIV LE AIDS MATSIENG

Ke hlahisa ho lona Mofumahali Mamello Makoae, eo lekeatsang ho etsa boithuto ka boiphihlelo ba bahlokomeli holima HIV le AIDS. Mekhatlong e ka hara libaka tsa lona.

Ka hona, tsebisang Sechaba sa lona taba ena le hore le mo amohele le Sebetse le eena hantle.

Ka litumeliso.
Ng.
Adj. Morena oa Sehlooho Matsieng.

ANNEXURE G

CONSENT TO PARTICIPATE IN RESEARCH

CONSENT TO PARTICIPATE IN RESEARCH

Study tittle: Experiences Of Caregivers Implementing HIV And AIDS Services Within Community-Based Organizations (CBOS) In Rural Maseru: Lesotho

I ……. have been asked to voluntarily participate in this study. I have been informed about this study by the Ministry Of Health of Lesotho, Ministry of Local Government of Lesotho, District Administrator of Maseru District in Lesotho, the Principal Chief of Maseru and by the researcher Ms. Mamello G. Makoae, a Masters student in the School of Nursing, University of the Free State.

I have been informed that there are no incentives for my participation, and that the study has no possible risks.

My participation in this study is voluntary, and I can decline at any time during the course of the study.

I am aware of the research study, including the above information. Therefore I voluntary agree to participate.

_____ _____

Participant Signature Date

If you have any questions and comments about rights as a research participant you can contact the following offices: The secretariat of the Ethics committee of the faculty of health sciences, UFS at telephone number (002751)4052812 and Ministry of Health Lesotho at telephone number (00266 223122).

ANNEXURE H

CONSENT FORM TRANSLATED TO SESOTHO:

TUMELLO EA HO KENYA LETSOHO LIPATLISISONG

TUMELLO EA HO KENYA LETSOHO LIPATLISISONG

‘Na …… ke kopuoe ke moithiti ho nkakarolo lipatlisisong tsena ka boithaopo.

Ke tsebisitsoe kalipatlisiso tsena ke Lekala la Bophelo Lesotho, Lekala la Puso ea Libaka Lesotho, Mobusi oa setereke Maseru, Morena oa Sehloho oa Maseru, le Moithuti e leng Mamello G. Makoaeeai ea thutelang Masters sekolong sa booki Universithing ea Foreisetata.

Kea tseba hore lipatlisiso tsena hali fane ka litsiane ho mang kapa mang

Ke kena karolo boithutong bona ka boithaopo ke sa qobelloa me ha ke se ke sa thabele ho tsoelapele, kea tseba hore kena le bolokolohiba ho emisa kapa ho tsoa.

Bakeng sa lipotso, lithlakisetso kappa maikutlo mabapi le lipatlisiso tsena,kappa litokelo tsa hau,u ka letsetsa ntlo-kholo ea lekala la tsa bophelo Maseru linomorong tsena: (00266 223122) le Universithingea Foreisetata Bloemfontein linomorong tse latelang: (002751)4052812.

_____ _____

Motekeno oa ea kenyang Letsoho Letsatsi

ANNEXURE I

INFORMATION DOCUMENT

INFORMATION DOCUMENT

Study title: Experiences Of Caregivers Implementing HIV And AIDS Services Within Community-Based Organizations (CBOS) In Rural Maseru: Lesotho

Introduction:
My name is Mamello G. Makoae, a Masters' Degree Student at University of the Free State. I am conducting research on the experiences of Community Based organizations (CBOS) implementing HIV&AIDS activities in the communities of Maseru districts in Lesotho

Invitation to participant:
I am requesting you as members of the CBOs to participate in this study because you are implementing HIV & AIDS interventions in the communities you serve in Maseru district.

What is involved in the study:
In this study the researcher will conduct focus group discussions with different support groups or CBOs in their areas of work.

Benefits:
The purpose of the study is to explore and describe experiences of Community Based Organizations (CBOs) implementing HIV and AIDS activities in the communities of Maseru district, Lesotho. By participating in this study, the CBOs will be able to express their feelings, provide information and recommendations that will be shared with the relevant institutions such as Ministry of Health and other NGOs.

Risks: There are no associated risks.

Confidentiality: Confidentiality will be highly maintained to at all times.

Costs: Participation in this study is free from any costs.

Results: The results of this study may be published.

Time: The interviews will take approximately 40 minutes to 1 hour

Participation in the study:
Participation is voluntary. Participants have the right to refuse to participate and they have the right to decline at any time.

Researcher contact details: +266 22316067 (W) +266 63372280
(Mobile) +266 62710000

Secretariat Ethics Committee UFS: (051)4052812

_____ _____

Signature of Participant Date

ANNEXURE J

INFORMATION DOCUMENT TRANSLATED TO SESOTHO: TOKOMANE EA BOITSEBISO

TOKOMANE EA BOITSEBISO

Sehloho sa Lipatlisiso: Lintho tseo Mekhatlo e sebetsanang le litaba tsa HIV le AIDS metseng ea Maseru Lesotho e kopanang le tsona ha ba ntse ba tsoela-pele ho sebetsa litaba tsa HIV le AIDS.

Selelekela:
Lebitso la ka ke Mamello G. Makoae. Ke moithuti oa Masters' Degree Universithing ea Foreisetata Bloemfontein.Boithuto ba ka ke ho etsa lipatlisiso ho Mekhatlo e sebetsanang le litaba tsa HIV le AIDS ka hare ho metse ea Maseru Lesotho ele ho fumana lintho tseo ba kopanang le tsona ha ba ntse ba sebetsa.

Memo ea ho nka karolo lipatlisisong tsa boithuto:
Ke kopa ho mema Mekhatlo e sebetsanang le litaba tsa HIV le AIDS ho nka karolo lipatlisisong tsa boithuto ka lintho tseo Mekhatlo ena e kopanang le tsona ha be le tsebetsong ka hare ho metse ea Maseru Lesotho.

Tse ka hare ho Lipatlisiso tsa boithuto:
Boithutong bona ke moo moithuti atla etela mekhatlo ea setereke sa Maseru ka bongoe moo a tlang ho etsa lihlopha tse tla tsohla litaba kamokha o bulehileng me batataisoa ka lipotso ke moithuti.

Melemo ea boithuto:
Sepheo sa boithuto bona ke ho fuputsa le ho hlalosa tseo Mekhatlo e sebetsang le litaba tsa HIV le AIDS e kopanang le tsona tsebetsong ea bona ka hara metse ea Maseru Lesotho. Maikutlo le likhothatso tsa litho li tla fitisetsoa le ho aroleloana le ba amehang le ho bamuso esita le mekhatlo e meng e meholo.

Kotsi: kotsi ha e eo ho hang ho banking karolo boithutong bona

Lekunutu: Lekunutu le tla bolokoa ka linako tsohle

Litjeo: boithuto bona ke ba mahala. Ha ho patalo ae letho ke ba nkang karolo lipatlisisong

Sephetho: Sephetho sa boithuto bona se ka phatlalatsoa ha ho lumelleha.

Nako ea lipuisano: Lipuisano li tla nka metsotso e mashome a mane ho isa horeng.

Ho nka karolo boithong bona:
Ke ka boithaopo, setho se nkang karolo se na le litokelo tsa ho hana kapa ho ikhula ha li se li qalile

Linomoro tsa Moithuti: +266 22316067 (W) +266 63372280
(Mobile) +266 62710000

Ntlo-kholo ea komiti e sebetsanang le tsamaiso ea Lipatlisiso UFSS: (051)4052812

_____ _____

Motekeno oa ea nkang karolo: Letsatsi:

ANNEXURE K

PARTICIPANTS INTERVIEW

Focus Group interview

Date: 23rd July 2013

Number of participants in the interview: 8

The researcher started the interviews with some jokes as the icebreaker.
The researcher then asked the chairperson of the support group; "Could you please tell me more about your activities as HIV and AIDS Caregivers?"

The Chairperson said: "we are the support group that takes care of people who are ill in the village. We wash their clothes; we clean their houses; *rea lila fatse;* we support the children who have lost their parents and also those who are abandoned by their parents and become vulnerable. We give them food, school uniform, clothes and we also accompany then to the hospital when they are sick. We work with chiefs to support us with our work. I know my status and we encourage all the people to test for HIV so that they don't infect others. "

Researcher said: "mmm…that is good what could others say on the activities that you do as HIV and AIDS caregivers?"

Participant 1 responded: "We work with one of the organizations and support groups where we support the patients and orphans. We give them second hand clothes."

Participant 2 interjects: "We are actually doing a lot as HIV infection is a problem in our communities. Most people are now sick in the village and they fail to accept their status. So we help them to take their medication all the time."

Researcher said: "mmm… is there anything more on the activities?"

Participant 3 said: "Yes we can say a lot because as the name of our support group say, we also care for children under five years in a pre-school. We have taught them to disseminate HIV information through drama, poetry and music."

Participant 4 added: "We also have the sewing machine for the support group that we use to sew clothes for the orphans and vulnerable children."

Researcher said: "ok! I can see that you are passionate about children. What more do you do?"

Participant 5 said: "There are some patients who refuse to take their medication as one of my colleagues mentioned earlier. Some don't go back to the hospital for check-up when their medication is finished. We provide counseling and support for such patients so that they take their medication."

Participant 6 intruding: "these patients don't accept their status and they don't even tell anyone of the family members and relatives about their status. They hide their status. Our work is again to make sure that they take medication because they keep infecting their partners when they keep it as a secret. They also fail to go to the hospital because they do not have support of the family, because they do not tell them so they do not know."

Participant 7 adding: "these patients need counseling because some of them even take their medication with alcohol and we educate them on the problems of taking their medication with alcohol."

Participant 1 adding: "yes! We are really doing a lot. We have realized that we also need to be empowered. We sometimes meet as the support group to counsel each other as a group. But we want that support to be provided to us by someone else also. We sometimes bring something's like soap from our homes and share among the group and for the patients and orphans. We do this because we like sharing with others."

Silence……..

Researcher said: "mmm…. I can hear that you are doing a lot as the support group to support HIV and AIDS activities. Could you please tell me more about your experiences in implementing activities? Can you share some of the challenges you encounter when doing the work?"

Participant 5 responded: "people still fail to accept their status and some of the relatives don't accept their family members when they live with the HIV disease."

Participant 1 added: "Yes! So we have to take care of these ones that are neglected but we struggle so much to find gloves and condoms. They are no more available at the hospital most of the time."

Participant 4 added by saying: "as we have mentioned before, these patients then stop taking their medication because they are not supported by the family as they have not told them of their status and they hide their sickness."

Participant 6 said: "we even have children in the pre-school who are on medication for HIV but their parents did not tell us. So, we are not able to support the children in giving medication especially when we have travelled in school trips. We are also trained in HIV Testing and Counseling but we do not have test kits."

Researcher said: "I am aware that you have many challenges but you still continue with services. How do you deal with some of these challenges?"

Participants 8 responded: "oh… we try to overcome our challenges but we are not safe. We use plastics for gloves but these plastics have holes so they are not safe. At times children fall and sustain injuries, so we quickly take plastics to touch their wounds. But we really need the First Aid kit."

Researcher said: "you mean the plastic bags are used as gloves?

Participant 1 answered: "oh yes! At least we know that we have to protect ourselves but we are always scared that these plastics may be torn".

Silence……

Researcher said: "ok! I am still listening….. is there anything more you want to say on your activities?....."

Silence….

Researcher said: "when you are still thinking, could you tell me what motivates you to continue with your services despite all the challenges you mentioned?"

Participant 7 responded: "hei! We are motivated because we do what we love."

Researcher: "which is……"

Participant 2 interjects: "yes! We like what we are doing which is taking care of those who need our support who are patients and vulnerable children. We become very excited when we see our patients recover after we have been caring for them. It is makes us feel good because we feel that we have brought back peoples' life."

Researcher said "mmm…."

Participant 8 adding: "Yes! I also agree with my colleagues that there are some things that we gain in our work. We have been trained on behavior change and reduction of multiple concurrent partnerships. This is changing our lives in the families. We know

how to make our family happy without going outside to seek for satisfaction form other partners."

Participant 4 adding: "ehhshh……" standing and emphasizing with hands " you do not know how brave we feel after the trainings. I even managed to lead the program for funeral services as the master of ceremony. Being a woman, I never thought I could be doing that, as it is culturally a habit that men will lead the funeral services. This time men were also scared to deliver their speech because I was very confident. The trainings have really changed us to be better people."

Researcher said: "mmm…. You seem to be enjoying what you do. Did you say women are now brave?"

Participant 4 responded: "Oh yes! We are proud of our work! We are so happy indeed because women were never recognized to lead big public events in our culture such as funeral. I have started and I never stop and I will even lead the public gatherings."

All participants nodding with heads.

Researcher said: "what else do other say motivates them as individuals or as a group?"

Participant 3 said: "when we are together as the group, we share experiences and support each other. So this makes us feel motivated to do more work as we learn from others on how they come across some of the challenges."

Participant 6 adding; "and the sharing of what we have such as soap, makes us feel that we are one thing."

Participant 7 also said: "oh I really think that this is all about love we have for the people near us. We are not paid to do this work but we are much happy to do it for our people, our relatives, our neighbors and everybody in the village."

Researcher: "mmm….. so, what do you think could be done to support you for the effectiveness and efficiency of your services? What could be your recommendations?"

Participant 6 said: "we need to be given gloves so that we protect ourselves as we care for the sick and the children in pre-school if they bleed. We also want to be considered as village health workers because we always work with them and assist them in their work."

Researcher: "you mean you want to be village health workers?"

Participant 1: "yes! We would like to paid a little money like the village health workers and be recognized like them so that we don't take from our pocket when we accompany patients to the hospital."

Participant 8 added; "yes! Yes! That is right, we feel we are doing good work. We need to be assisted to establish projects that will bring income so that we don't depend from our families to take care of children."

Participant 2 added; "I think we also need trainings on management of income that we will get from those projects."

Silence…

Researcher: "mmm… proceed I am listening….."

Participant 5 said: "we need to be supported as we care for children. We need to be supported to provide them with school uniform as some of them are orphans and they

need support, as their caregivers cannot afford. We also want the T-shirts so that they all have the same clothes during the events."

Participant 6 adding: "yes! We can sew the clothes and uniform for orphans as we have the machine but we need the cloth."

Researcher: "mmm... Anything thing more…."

Silence……

Researcher: "it seems we have come to end of our discussions. I would like to thank you all for participating. I will share the results with you at the later stage. Please feel free to call me if you still want to say more."

The researcher served snacks and left the place.

ANNEXURE L

PROTOCOL FOR DATA ANALYSIS

PROTOCOL FOR DATA ANALYSIS ACCORDING TO TESCH METHOD (1990)

- Get sense of the whole by reading through all of the transcriptions carefully, and write down the ideas as they come to mind;

- Pick one most interesting interview and go through it asking self: what is this interview about? Think of the underlying meaning. Write thoughts in the margin;

- Cluster similar topics together, and then form the topics into columns that might be arranged as major topics, unique topics and leftovers;

- The researcher revisited her data; abbreviate the topics as codes and write the codes next to the appropriate segment of the text;

- Turn topics into themes;

- Group together similar themes;

- Draw lines between the themes to show interrelationships;

- Make a final decision on the abbreviation for each category and arrange these codes alphabetically;

- The data materials belonging to each category were then assembled in one place, and a preliminary analysis was performed.