

PRIMARY CAREGIVERS' EXPERIENCES OF CARING FOR HIV INFECTED ADOLESCENTS

BY

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Submitted in partial fulfilment of the requirements for the degree

**MAGISTER ARTIUM in Social Work (Social Development
and Planning) in the Faculty of Health Sciences**

at the

NELSON MANDELA METROPOLITAN UNIVERSITY

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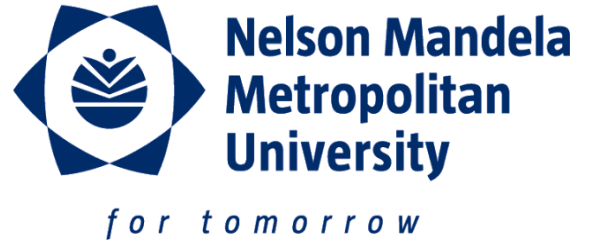
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December 2014

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DECLARATION

In accordance with Rule G4.6.3, I hereby declare that the above-mentioned treatise is my own work and that it has not previously been submitted for assessment to another University or for another qualification.

Signature_____

DATE_____

ACKNOWLEDGEMENTS

I wish to acknowledge and express my appreciation to the following people who have contributed to the successful completion of this study.

- To **GOD** Almighty, for giving me the strength, courage and good health. “Your name is above all names”... Also to the Ethiopian Episcopal Church for the spiritual upliftment.
- I wish to express my heartfelt thanks to my family who are my pillar of strength: my Mom (who played a role of being a mother to my daughter and a mentor for my studies), my brother Ngenge (for support and the academic bag gift that eased the load of the heavy academic books), my sister Anda (without your support I am nothing), my sunshine, Lathitha (for pressurising me to finish studying so that you can have quality time with me) and Fundiswa my sister from my other mother. Lastly my late father who always encouraged me to study hard and pass.
- A sincere thanks to my friends who supported, advised and guided me whenever I needed them: Lulama Makana, Antoinette Cannon, Busi Daniels, Maj. A.P. Malgas and Hlombe Mfono – your ears were never too far whenever I needed to share my achievements and frustrations with you.
- Thanks to Department of Health. Eastern Cape for affording me the opportunity to study and their support. A special thank you goes to Settlers Hospital former Hospital Manager, Mrs Moyakhe and the primary Health Care Clinics under the leadership of Mrs. Mtoba who is the Makana sub-district Manager, my former Supervisor Mrs. Mariejie Bezuidenhoud, and Settlers Hospital Skills Development Officer, Ms Ndileka Manyati.
- Thanks to late **Prof. Mashologu-Kuse** for her last telephonic words with me when she was leaving NMMU. “I have confidence in you...the present you can give me is to get these Masters.” May her soul rest in peace!
- Finally, I would like to express a special thanks to my supervisors, **Dr. Soji and Prof. Terblanche**. You were so amazing; you made me to believe in myself. I always looked forward to the consultation sessions because you always inspired me and gave me the light. I can never ask for other supervisors, you are the best.

DEDICATION

This study is dedicated to the Primary Caregivers of Children who are living with HIV/AIDS. They are often forgotten or taken for granted for their role. They are the “unsung heroes” and “heroines.” One of the researchers named them, the “hidden patients” or “unseen victims” of HIV/AIDS.

In this study I am saluting them! They are the agents of change. The statement that says “we support people who are living with HIV/AIDS” has become a common saying which has no meaning to many, but the “agents of change” are living their words.

I am recalling the speech that I made in Ethiopian Episcopal Church in 2010 Synod while presenting the status quo of our church with regards to HIV/AIDS. I quote my statement “to say that we support people who are living with HIV/AIDS is easier said than done, we need to be more practical about that.”

ABSTRACT

HIV/AIDS has affected families in a profound and tragic way. Children whose parents have succumbed due to HIV/AIDS related infections have to be cared for by their relatives. This study focused on the experiences of primary caregivers of adolescents who are living with HIV in a semi-rural area of Eastern Cape Province, Grahamstown. There is a dearth of literature that is addressing the well-being, experiences and challenges of primary caregivers of adolescents living with HIV. Adolescence is a complex life stage during which adolescents usually present challenging behaviours and are grappling with moral issues. Caregiving to these youngsters who are burdened with HIV infection places additional demands on caregivers, especially so when they are experiencing poverty and poor social and welfare support.

A qualitative study was most appropriate to explore and describe the experiences of adolescents infected with HIV. The population of this study was the primary caregivers of adolescents caring for adolescents with HIV in the area of Grahamstown, who are between 11 to 19 years old. A purposive sample of nine primary caregivers of adolescents living with HIV was selected. Data was collected by conducting individual interviews, using a semi-structured interview schedule. Data was analysed thematically according to prescribed theoretical guidelines. Data was verified by means of guidelines for the truth value, applicability, consistency, and neutrality of the study. The findings of the study indicated that primary caregivers experience that caring for adolescents who are living with HIV places a huge burden due to adolescents' negative behaviour, HIV stigma and discrimination, poor support from their families, being confronted with adolescents' emotional issues that they are not capacitated to deal with, and no adequate community resources to assist them. The challenges primary caregivers experience lead to negative effects on their health status. The findings of the study could be useful for informing intervention programmes that are targeting this group and policy development, and implementation of programmes benefiting both infected adolescents and their primary caregivers.

Keywords: Adolescents living with HIV, primary caregivers, children living with HIV, challenges, HIV/AIDS support services

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CHAPTER 1

OVERVIEW OF THE RESEARCH STUDY

1.1 Introduction and Contextual Information

In South Africa alone, 2.5 million children were orphaned and 1.4 million are orphaned due to Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS) related illnesses. After the introduction of the antiretroviral treatment (ARV), perinatally infected children live a longer lifespan. Treatment leads to growing numbers of HIV infected children entering adolescence with a chronic infectious and highly stigmatized disease (Petersen, Bhana, Myeza, Alicea, John, Holst, McKay & Mellinse 2010: 970). Naswa & Marfatia (2010: 10) concur with the latter as they noted that the most common mode of transmission for adolescents who have HIV is heterosexual; and yet there is an increasing number of children who are infected perinatally entering adolescence. Their study estimated that the prevalence of HIV infection among adolescents between 15-19 years of age is about 5.9%.

Adolescence is a tremendously trying period for any young person, and having to cope with the added burden of being infected with HIV at this critical stage of development can have devastating effects on a young person's psychological development. Adolescents face many challenges as they are growing up and the psycho-social challenges of HIV infected adolescents include dealing with the loss of parents, disclosure difficulties which are as a result of stigma attached to living with HIV, health problems at a young age, and treatment compliance problem (Petersen *et al.*, 2010: 974).

Studies indicate that adolescents are an emerging group in the global HIV/AIDS epidemic. Adolescence is a complex life stage during which children attempt to find their own identity, struggle with social interaction, present experimental behavior and grapple with moral issues (Harder, 2002: 1). The challenges of adolescents who are infected with HIV are aggravated by the burden of a life threatening and a highly stigmatized disease. Consequently primary caregivers of these adolescents are

facing their own challenges to support and guide them (as mentioned in the above paragraph).

The results of a study by Udjo (2011: 1) suggests that the number of orphans due to HIV/AIDS related illnesses in South Africa may increase to about 1.9 million by 2015 if current trends continue, and these figures are lower than estimated by some previous researchers. Nyirenda, McGrath and Newell (2010: 10) in their study cited that in South African societies, caring for children of extended family members is a commonplace. Caregiving may start even before the death of the child's parents, particularly if they had a life threatening chronic illness that is making them too ill to take care of their children and as a result of that, another family member or significant other takes over the responsibility of looking after the child(ren) of a sick relative or person.

According to Orner (2006: 236) "caregiving in the context of HIV/AIDS places a considerable demand on caregivers which is exacerbated by insufficient support, dire poverty and an added responsibility of caring for other family members." A great deal of scientific evidence is indicating that family care-giving can have negative impact on caregivers' health, psycho-social well-being and labour force participation due to work absenteeism due to taking care of a sick family member (Toseland, 2004: 1). Evans and Thomas (2009: 111) are also of the view that "caregivers play a crucial role in providing emotional support and re-assurance for people with HIV, which in turn often affects caregivers' emotional and physical well-being." The findings by Petersen *et al.* (2010: 276) indicate that the challenges of caregiving in the context of HIV/AIDS include poverty, stigma, and minimum supported foster care arrangement which refers to the informal foster care arrangement that families organize themselves or maybe arranged by an official without following foster care procedure. Within the environment that HIV is heavily stigmatized, caregivers regulate their emotions in order to protect family members from the emotional impact of a chronic life-limiting illness. There is little material and resources available to caregivers who are overwhelmed by multiple stressors in the context of HIV/AIDS. Demmer (2011: 877) concur with other studies that discovered that the combination of poverty and HIV related stigma compromise the health of the child who is living with HIV/AIDS. Petersen *et al.* (2010: 276) noted in Demmer

(2011: 877) also explains that family caregivers experience both lack of welfare and family emotional support in their care of HIV/AIDS orphans. Meyiwa (2011: 165) in her study acknowledged the self-sacrifice that the caregivers are making; she explains that “caregiving is an intense, emotional and powerful experience that is filled with pride, hope as well as exclusion.”

Well-functioning families play a fundamental role in caring for its members. While care-giving is a normal part of being a parent or primary caregiver of any young child; providing high level of care required by a child with long-term functional limitations and illnesses can become burdensome and can have negative effects on the physical and psychological health of the caregiver” (Riana, O’Donnel, Schwellnus, Rosenbaum, King, Brehaut, Russell, Swinton, King, Wong, Walter and Wood, 2004: 2). Based on the said argument, one can assume that because HIV is a long-term illness this also applies to adolescents who are living with HIV. Leach-Lemens (2012: 1) maintains that “HIV infected adolescents are mostly managed in adults’ programmes, especially in rural settings with no trained personnel to work with adolescents.” It could thus be concluded that these health care workers are not empowered to deal with the emotional and social skills to guide and support the primary caregivers of HIV infected adolescents. Eneh (2010: 1) suggests that meaningful support services improvement for people who are living with HIV must involve caregivers in their design and implementation, as the well-being of sick people depends on the support of the health ones. This assists with the management of health for people who are living with HIV and to alleviate the burden of care for the caregivers.

The majority of young people become infected with HIV during adolescence as a result of their sexual activities (Perrino, Gonzalez-Soldevilla, Pantin, and Szapocznik. 2000: 81). The research findings by Milchielsen, Matthew, Chersich, Luchters, De Koker, Van Rossem and Temmerman (2010: 1193) also support this argument and further suggests that young people in developing countries are particularly vulnerable to HIV infection, other sexually transmitted infections (STI’s) and unwanted pregnancy. They explain that adolescents vulnerability is due to a combination of factors such as their experimental behaviour and poverty. They argue that limited knowledge and socio-cultural factors including, sex inequalities between

men and women and other challenges which could be family relationship related or peer pressure make adolescents more susceptible to HIV infection. This assertion is supported by Makiwane and Mokomani (2010) who maintain "that young people continued susceptibility to HIV infection has been consistently linked to intractable higher risk sexual behaviour. He further explains that factors that are associated with these risk behaviours occur at the individual and community levels which may include issues of race, gender, poverty and susceptibility to peer pressure. Leach-Lemens (2012: 1) and (Petersen *et al.*, 2010: 272-274) conclude that stigma and discrimination, late or non-disclosure home caregivers, adolescents or primary caregiver's denial of HIV, limited access to information are all the problems faced by adolescents with HIV.

Coinciding with the world's greatest HIV/AIDS burden, South Africa is facing another challenge of great quantities of alcohol consumption. Several studies discovered that alcohol is a mostly used psychoactive substance and it is among the most prevalent behavior associated with sexual risk for HIV and other sexually transmitted infections (STI) (Kalichaman, Simbayi, Kaufman, Cain & Jooste (2007: 15) citing Perry *et al.* (2004), Morojeke, Brook & Kochieng'a (2006: 215).

There seems to be a dearth of literature addressing the well-being, experiences and challenges of primary caregivers of HIV infected adolescents. Contrary to that, there is a body of existing South African studies that cover the psycho-social impact and experiences of caregivers of HIV infected people and children. Examples are studied by Majumdar and Mazaleni (2010); Orner (2006: 236); and Hosegood, Preston-Whyte, Busza, Moitse and Timaeus (2007). Therefore, this study will be conducted in a rural-urban community that has high level of unemployment. Similar studies were conducted by different researchers but they all focused on experiences of primary caregivers of HIV infected children with no specific focus to the adolescents. Orner's (2006: 240) study suggests that there is a need to develop the capacity of household caregivers in order to be equipped to deal with day to day challenges they encounter in their role as caregivers. Demmer (2011: 878) views support groups that address economic & psychological needs of caregivers as a useful resource to support caregivers of children with HIV. Hlabyago and Ogunbanjo (2009: 511) recommend that "healthcare workers including social workers and home-based caregivers be

trained for caregiving of HIV/AIDS orphans.”

As a social worker, I observed that adolescents who are on ARV treatment in Makana sub-district are managed in programmes for adults. HIV infected adolescents come to the clinic or hospital after school without their primary caregivers most of the time. They are sometimes referred to a social worker or a psychologist when the nursing professionals identify a clinical problem that may be a result of a social problem. There is no support for adolescents who are infected or affected with HIV/AIDS and their families, except for Hospice support group for their current patients only, their children and their deceased patient's children. Some problems that they are experiencing are emotional and are not easily identifiable without doing a thorough psycho-social assessment by a social worker or a psychologist. Primary caregivers of HIV infected adolescents mostly attend the initial educational session on ARV treatment adherence. The aim of those education sessions is to ensure that the primary caregivers are able to monitor adolescent's treatment adherence at home. They get knowledge for treatment but are faced with the social, personal challenges and the demands of caring for long-term ill adolescents. There are a few organizations that offer support services for their adolescent clients and as well as programmes or services to support the primary caregivers with their emotional problems. It also cannot be assumed that all social workers are equipped to deal with the emotional needs of people who are infected and affected with HIV / AIDS and that those who are attending social work services are taken care of emotionally. In most cases the primary caregivers consult with social workers for administrative issues such as foster care applications and reviews.

Caregivers of orphans and vulnerable children including adolescents are in most cases close members of the family or their parents who often have limited financial means, knowledge and emotional support. The care-giving role under difficult and trying circumstances may have negative effects on caregiver's emotional and psychological well-being, and ultimately on entire family relationships. The burden of care created by HIV/AIDS disease after the person has received medical treatment moves to the families for the long-term management of the person's health. This means that children whose parents have succumbed due to HIV/AIDS related infections have to be cared for by their relatives. Caring for an adolescent with

HIV/AIDS can place physical, emotional, as well as financial demands on primary caregivers, especially those who do not have strong social support.

1.2 Problem Formulation and Motivation of the Study

HIV/AIDS is affecting families in a profound and tragic way. The burden of care created by the disease has moved to the community and the families. Children whose parents have succumbed due to HIV/AIDS related infections have to be cared for by their relatives. Caring for person(s) with HIV/AIDS can place physical, emotional, as well as financial demands on primary caregivers.

The existing research and literature mostly concentrate on adults who are living with HIV and children orphaned due to AIDS. The literature consulted for the purpose of this study indicates that although there is a growing body of literature on family experiences with regard to caregiving in the context of HIV/AIDS; it is very clear that previous studies have not focused on the experiences and challenges involved with the caring of HIV infected adolescents in a family context. What was also confirmed during the preliminary literature review is that, related studies focus on the impact of caring for children who are infected with no specific focus to a complex group of adolescents. This study therefore aims to contribute to the knowledgebase of caregiving within the context of HIV/AIDS by exploring and describing challenges and experiences of caregivers of HIV infected adolescents.

1.3 The Significance of this Study

The South African Nation Strategic Plan for HIV/AIDS and STI 2012 – 2016 first objective is giving a mandate to "address social and structural factors that drive these epidemics, influence the impact and affect the way we care for affected people." Professionals and non-professionals who are working in the context of HIV/AIDS could benefit directly from this study by understanding the psycho-social aspects and dynamics involved in the caring for adolescents with HIV. The study generated knowledge for understanding experiences of caregivers who are involved in caring for HIV infected adolescents. This knowledge could be useful for informing

intervention programmes and policy development and implementation of programmes benefitting for both primary caregivers and HIV infected adolescents.

1.4 Theoretical Framework for this Study

Family Systems Model

The proposed theoretical framework for this study is the Family Systems Model. Bregman and White (2011: 79) explain that Bowen's family system model (1990) is a theory of human behaviour which views family as an emotional unit that uses systems thinking to describe the complex interaction in the unit. This theory is based on the assumption that people do not live in a vacuum but are surrounded by other people, for example, families, colleagues, and friends. Family members profoundly affect each other's thoughts, feelings and actions that often seem as if people are living under the same "emotional skin". Family systems theory explain that connectedness and reactivity make the functioning of family members interdependent. A change in one person's functioning or life is predictably followed by reciprocal changes in the functioning, life or well-being of other family members. In the caregiving context, this is evident when an adolescent is ill and the primary caregiver has to give up his or her other responsibilities e.g. job, social or personal life, although family members differ in the degree of interdependence, but it is always present to some degree. For instance in the case of minor children, they are more dependent on their caregivers. A family member who contributes more in the caregiving role with too much unrealistic expectations from others, literally "absorb" anxiety and the caregiving role affects his or her well-being. A strenuous caregiving role is mostly followed by vulnerability to problems such as depression, alcoholism, physical illness, etc. In this study, the researcher is examining the experiences and challenges of primary caregivers of HIV infected adolescents. This may imply that different family members assist one another because they are sharing the same emotional thoughts and feelings. In the case whereby there is not connectedness among the family members, the one who is the primary caregiver takes a lot of strain. On the same note Shaffer & Kipp (2007: 597) argue that a family is a social system, and functions like the human body. It consists of interrelated parts and each part is affected by every other part as each part contributes to the functioning of the

whole.

This study also adopts certain elements of the strength-based model. Alberta (2010: 2) explains that strength-based practice is a method of working with an individual to resolve his or her problems by identifying the person's resources and strengths that lay the basis to address the challenges resulting from the problems. The family systems, caregiving and strength-based models interlock; the theories acknowledge the fact that the resources that are available to an individual help them to overcome caregiving obstacles. In caregiving model, Carolyn (1995) explains that the family can either be in partnership or teamwork to ease the burden. He further explains that partnership caregiving takes place when two family members contribute relatively equally to the caregiving work, and are in equal authority and responsibility in making & implementing decisions. Both in systems theory and the family caregiving model, family members assist one another and are not prepared to abandon their responsibility although they could anticipate the densification of demand upon them. The strength-based model also focuses on these internal and external resources that caregivers have that assist them to cope with the caregiving demands. As the family systems model explains that families are systems of interconnected and interdependent individuals: it means that individuals cannot be understood in isolation from one another; a person is influenced by his or her background. According to Saleebey's (1992) strength perspective model acknowledges the fact that clients have taken steps, summoned up resources, and coped with their challenges. This suggest that people are not passive individuals who wait for others to solve their problems, they also take measures to deal with their situations. All these theories emphasize the importance of a healthy support system in order to cope with the caregiving challenges and demands.

In choosing family systems model, the researcher acknowledges that families have an emotional bond, what affects one family member affects the other. In raising adolescents, the children who are regarded as being complex due to their developmental stage, the literature emphasizes the importance of caregivers' strong support system. Furthermore, the literature review indicates that caregiving can have negative effects on the primary caregiver's emotional and physical well-being. The caregivers who cope well with their caregiving role are those with a strong support

system Majumdar and Mazaleni (2010); Orner (2006: 236), Hosegood, Preston-Whyte, Busza, Moitse and Timaeus (2007). The family systems model and the above-mentioned interlocking models all emphasize the resources or support that is crucial in a successful caregiving role. Erikson psycho-social developmental stages explains that adolescence is a complex stage whereby one is neither a child or an adult, life is definitely complex as adolescents attempt to find their own identity (Harder, 2002: 1). The family systems theory will best address the goal of the study which is to explore and describe the experiences of the caregivers under the challenging circumstances of caring for HIV infected adolescents.

1.5 Definition of Concepts

1.5.1 Adolescent stage: “Adolescence is a period between puberty and the completion of physical growth, roughly from 11 to 19 years old.” (Dorland’s Medical Dictionary for Health Consumers, 2007)

1.5.2 Primary caregivers: Swanepoel (2003: 3) defines the term “primary caregivers” in her study “as mothers/fathers/grandparents/guardians who serve as parental figures for children and are responsible for the day-to-day care and maintenance of children.”

For the purpose of this study the term “primary caregiver” will be used to refer to mothers/fathers/grandparents/extended family members/guardians of HIV infected children who are responsible for the day-to-day care and maintenance of those adolescents”.

1.5.3 Adherence to treatment: “Is generally defined as the extent to which patients take medication as prescribed by their health care providers.” (Osterberg & Blaschke, 2005: 487)

1.5.4 Stigma and discrimination: The Joint United Nations Programme on HIV/AIDS (UNAIDS) defines HIV-related stigma as: ‘...a “process of devaluation of people either living with, or associated with HIV and AIDS”. Discrimination follows

stigma, and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status' (Churcher, 2013: 12).

1.5.5 Social Support : It is defined as “a measure of how much help you can count or believe you can count on, from your friends and family, especially in crises and hard times” (Casale & Wild, 2012: 260).

1.5.6 Family: “Two or more person related by birth, marriage, adoption or choice, who have emotional ties and responsibilities to each other”. (Shaffer & Kipp (2007: 596).

1.6 Research Question

The research question that guides this study was formulated as follows:

What are primary caregivers' experiences and challenges of being involved in the care of HIV infected adolescents?

1.7 Research Goal and Objectives

Research Goal:

This study sought to enhance the understanding of the experiences and challenges of primary caregivers in caring for HIV infected adolescents by means of an explorative-descriptive and contextual study.

In order to reach this goal, the following objectives were formulated:

Research Objectives

- To describe caregivers' reaction on finding out about the HIV infections of the children and their knowledge and skills to deal with them.
- To explore and describe challenges of primary caregivers in caring for HIV infected. adolescents at household and community level.
- To identify resources and support needed by caregivers of HIV infected

adolescents.

- To explore caregivers' experiences of support and resources for them.
- To provide policy and or programmes recommendations.

1.8 Orientation to the Research Design and Methodology of the study

The research design and methodology will be briefly outlined in this section of the study. The comprehensive discussion for the reflection of the methodology used will be discussed in Chapter Two of this research report.

1.8.1 Research Approach and Research Design

Qualitative Research Approach

The proposed study adopted a qualitative research approach. De Vos, Strydom, Fouche` and Delport (2005: 74) explain that the qualitative research paradigm in its broadest sense refers to research that elicits participant's accounts of meaning, experiences or perceptions. It also produces descriptive data in the participant's own written or spoken words. Bless and Higson-Smith (2004: 37) explain that "a qualitative research can be classified by use of qualifying words or descriptions to record aspects of the world." The researcher chose this approach to be able to explore the participant's experience of caring for HIV infected adolescents. By choosing this approach for the study, the researcher gained a better understanding about the day to day challenges of primary caregivers with their HIV infected adolescents, their plight and the support they need to cope.

Research Design described by De Vos *et al.* (2005: 132) define a research design as a plan or blueprint of how you intend conducting the research.

An exploratory, descriptive and contextual design was employed for this research.

Exploratory studies are used to make preliminary investigations into relatively unknown area of research (Terre Blanche, Durrheim & Painter, 2006: 44). Bless and

Higson-Smith (2004: 41) contended that the purpose of exploratory research is to gain an in-depth understanding of the situation, phenomenon or community or person.

Descriptive Research is described by Terre Blance, Durrheim & Painter (2006: 44) as having the aim to do an intense examination of phenomena, thereby leading to a better understanding and a thicker description of the phenomenon being investigated. The understanding of the phenomenon under the researcher's investigation enabled the research to draw some recommendations for the primary caregivers of HIV infected adolescents and their adolescents to improve their livelihood.

Contextual Research aims at understanding the event against the background of the whole context and how such context confers meaning to the event concerned, that one can truly claim to "understand" the events (Babbie & Mouton, 2001: 272). This study took place in the environment where the participants lived. The study facilitates the understanding of the participants' social dynamics with regard to the caring of HIV infected adolescents.

1.8.2 Research methodology

Research methodology refers to a step-by-step account of all the components, processes and methods used in order to achieve the research goals and related objectives of a given study (Noor, 2008: 1602).

1.8.2.1 Population, sample and recruitment of participants

Bless and Higson-Smith (2004: 84) explains that "a target population is a set of objects or people which is the focus for the research and about which the researcher wants to determine some characteristics". The target population in this study are the primary caregivers (as defined in 5.2) of adolescents who are living with HIV, who are between 11 to 19 years old in Grahamstown, Eastern Cape in South Africa.

This study employed purposive or judgemental sampling whereby "sampling is

based on the judgement of a researcher regarding elements that contain the most characteristic representative or typical attributes of the population” (Strydom in De Vos *et al.*, 2005: 202).

In this study the gatekeepers were operational managers of the selected local clinics on behalf of Department of health Provincial offices. The operational managers were given the researcher’s letter of permission to conduct the study from the Department of Health Provincial office. The operational managers first approached the primary caregivers who met the study criteria and invited them to participate in the study. The operational managers explained the purpose of the study, the duration of the interview session and its ethical considerations. As the researcher then select the sample for the study from the willing participants. A sample of nine caregivers was selected.

1.8.2.2 Method of data collection and process

“In qualitative research, the data is usually collected by means of participant observation and other techniques such as in-depth interviews or analysis of statistical information which may be pre-existing, having been gathered for other purposes or personal documents such as letters or diaries” (Curtis and Curtis, 2011: 40). Data collection was done through semi-structured interviews. De Vos *et al.* (2005: 296) explains that “researchers use semi-structured interviews in order to gain a detailed picture of a participant’s beliefs about, or perceptions or accounts of, a particular topic with the participants.” A pilot study that served as a trial-run for the methodology and research question was done (De Vos *et al.*, 2005: 205). Changes were made according to the outcomes of the pilot study. The researcher used open-ended questions. Curtis and Curtis (2011: 34) explain that “open-ended questions encourage an answer that takes at least a sentence” (see annexure 4 for this study interview schedule).

1.9 Data analysis

Data analysis process for this study was conducted according to Tesch (1990)

eight steps for thematic content analysis. In choosing this method the researcher considered the scale of the study and that because it is a small study, the data analysis method will be done manually to group the themes that are relevant to the research question.

1.10 Data Verification

Data verification was done according to Guba's model of trustworthiness (1985). Krefting (1991: 215) proposed a model for assessing trustworthiness of qualitative data based on four criteria: (1) truth value, (2) applicability, (3) consistency, and (4) neutrality. The use of the criteria will be discussed in detail in Chapter Two of this research report. According to De Vos *et al.* (2005: 331), the term 'trustworthiness' is used to describe the validity and reliability issues in qualitative research.

1.11 Ethical Considerations

Ethical guidelines serve as standard and basis upon which each researcher ought to evaluate own conduct (De Vos *et al.*, 2005: 570). The researcher implemented the principles of social research under the supervision of NMMU. The following ethical considerations were followed:

Privacy and confidentiality: De Vos *et al.* (2005: 61) views confidentiality as a continuation of privacy "which refers to the agreement between persons that limit others' access to private information". The participants were assured in writing that all the information that is obtained during the study will be confidential and it will only be used for the purpose of the research.

Informed consent: According to Terre Blanche & Painter (2006: 294) informed consent is an ethical requirement for all research studies. De Vos *et al.* (2005: 59) suggest that obtaining informed consent implies that all possible or adequate information on the goal of the investigation, the procedure which will be followed during the investigation, the possible advantages, disadvantages and dangers to which respondents may be exposed as well as the credibility of the researcher, be

rendered to potential subjects or their legal representatives. The research participants were given above details about the study before they decided to participate in it and this enabled the research participants to feel free to decide whether to participate or not in the study.

1.12 Chapter Division

The division of chapters in this study is as follows:

Chapter 1: Overview of the Research Study

This chapter gives the introduction and background of the study, the problems formulation and the purpose of the study, the literature on the research topic and theoretical framework, as well as the ethical consideration for the study.

Chapter 2: Research Methodology

This chapter gives detailed description of research designs and data methods that are used in this study.

Chapter 3: Discussion of Findings

This chapter presents the qualitative findings, literature control and the discussion of the study.

Chapter 4: Summary, conclusion, limitations and recommendations

This chapter summarizes the research design, methodology, findings and discusses the limitation of this study. The conclusion for the study will be drawn in this chapter and recommendations will be suggested.

1.13 Chapter summary

This chapter has given the reader an overview of the research presentation. The introduction and background to the study have been presented here, as well as the problem formulation and motivation for the study. Literature on the research topic has been reviewed briefly and the theoretical framework has been explained. The

research design and methodology have been introduced and will be discussed in more details in the following chapter.

CHAPTER 2

APPLICATION OF THE SELECTED RESEARCH METHODOLOGY

2.1 Introduction

In the previous chapter, the introduction and background of the study, the research problem and the purpose of the study were outlined and put into perspective, and the research methodology was explained briefly. This chapter will give detailed description of the application of the selected research designs and methods that were used to enhance the understanding of the experiences and challenges of primary caregivers of HIV infected adolescents. The discussion in this chapter will start by discussing the motivation and application of the qualitative approach chosen for the study, as well as the research design, populations and sample. The chapter will also discuss the procedure that was followed to recruit study participants, the data collection methods and the process employed for the study. The pilot study outcomes, data verification and data analysis process will be discussed and it will be concluded with the ethical considerations for the study.

2.2 Research approach and research design and methods

The following section describes the research approach with the accompanying methodological considerations taken into account during the study.

2.2.1 Qualitative Research Approach

The qualitative research approach was selected as the most appropriate approach to answer the research question of this study, stated as “What are primary caregivers’ experiences and challenges of being involved in the care of HIV infected adolescents?”

Wisker (2001: 138) explains that “qualitative research is used when the researcher wishes to explore and understand meaning and describes experience, ideas, beliefs,

values and thus usually falls into the domain of exploratory and descriptive professional research objectives.” The study aimed to explore the experiences of primary caregivers in caring for adolescents who are infected with HIV in order to get ideas to suggest for the support that is relevant for them.

2.2.2 Research design

De Vos *et. al.* (2005:106) define research design as “a blueprint or detailed plan for how a research study is to be conducted.” The study employed an exploratory, descriptive and contextual design in order to meet its goal and objectives.

2.2.2.1 Exploratory research design

Exploratory studies are used to make preliminary investigations into a relatively unknown area of research (Terre Blanche *et al.*, 2006: 44). Bless and Higson-Smith (2004: 41) maintained that “the purpose of exploratory research is to gain an in-depth understanding of the situation, phenomenon or community or person.” This study employed an exploratory design because other related studies have not explored the caregiver’s experiences of raising HIV infected adolescents. The need for this exploration was further fuelled by the opportunity to make recommendations for the services and programmes that have to be suggested and established to support primary caregivers of HIV infected adolescents and the adolescents who are infected with HIV in Grahamstown. Ruane (2005: 12) also explains that exploratory research often produces qualitative results; therefore their evidence is presented in words, pictures, or some other narrative form that best captures the research subject’s genuine experiences and understanding. The findings for the study will be outlined in order to understand the plight of primary caregivers in caring for HIV infected adolescents, and the recommendations will be suggested based on the findings.

2.2.2.2 Descriptive research design

Terre Blanche *et al.* (2006: 44) explain that “descriptive studies aim to do an intense examination of phenomena thereby leading to a better understanding and a thicker

description of the phenomenon that is being investigated”. This study employed a descriptive design. The use of a descriptive design in this study enhanced the understanding of the caregiver’s day-to-day experiences and the impact of primary caregiving in their lives.

2.2.2.3 Contextual Research

Contextual research allows researchers to understand the particular context in which participants act and the subsequent influence that these actions have on their context. By acknowledging the contextual nature of qualitative studies, researchers are able to understand how events, actions and meanings are shaped by the unique circumstances, in which they occur (Maxwell, 2005: 22). The aim of using this design was to understand the caregiver’s experiences, challenges and reactions against the background within which they took place.

2.2.3 Research methodology

Research methodology refers to a step-by-step account of all the components, processes and methods used in order to achieve the research goals and related objectives of a given study. Noor (2008: 1602) states that the choice of research method is primarily dependent on the nature of the research problem. The following section will provide a detailed account of the research population, sampling and sampling procedures employed as well as data collection and analysis methods selected.

2.2.3.1 Population for the study

Bless and Higson-Smith (2004: 84) explain that “a target population is a set of objects or people which is the focus for the research and about which the researcher wants to determine some characteristic”. The target population for this study is the primary caregivers of adolescents who are living with HIV, who range between 11 to 19 years old in Grahamstown, Eastern Cape in South Africa.

2.2.4. Sampling Strategy and Process

Non-probability sampling was selected for collecting data in this study. In qualitative studies non- probability sampling techniques are utilized as they make it possible for the researcher to seek out individuals who can provide rich information in the context of the phenomenon being investigated, (De Vos *et al.*, 2005: 328).

The study employed purposive sampling. Strydom in De Vos *et al.* (2005: 202) asserts that “purposive sampling is based on the judgment of the researcher regarding elements that contain the most characteristic representative or typical attributes of the population.” Seale (2004: 199) explains “purposive sampling as a situation where participants are selected on the having a significant relation to the research topic.” Purposive sampling thus means selecting participants according to very specific criteria.

The inclusion criteria for recruiting participants for the sample were as follows:

- Participants had to be primary caregivers of adolescents who are infected with HIV,
- The adolescents cared for could be on or off antiretroviral treatment;
- The adolescents in their care had to be between 11 and 19 years and have to be still alive, the primary caregivers and the adolescents had to live in Grahamstown or its surrounding areas.

The recruitment of the sample for this study was based on the researcher’s criteria. The Operational Managers of the clinics of the Department of Health in Grahamstown who acted as gatekeepers on behalf of Department of Health Provincial office selected the study sample based on the criteria that was stipulated by the researcher. The gatekeepers chose deliberately chose the participants to be included in the study on the bases that those selected can provided the necessary information. After interviews with nine primary caregivers the sufficient information was gathered and the recruitment process stopped. The researcher made a follow up with the candidates who agreed to participate in the study and she explained the research goals, process, the duration of the interviews, the research ethics and

made appointments to conduct the interviews.

2.2.5 Entry into the research site

A research proposal was submitted to the Faculty Research Technology and Innovation Committee (FRTI) and the Ethics Committee respectively in order to get approval to conduct the study and to receive ethics clearance for the study. Following the approval of the research by the two NMMU committees, the researcher wrote a request to Department of Health Provincial office to conduct the research study in Grahamstown area. When the permission was granted by Department of Health the researcher gave the copy of the letter to the Department of Health sub-District Manager who gave a verbal go ahead to enter the identified research sites which were the local clinics of Grahamstown. The researcher provided the clinics with the copy of the letter of approval from Department of Health Provincial office to be able to go ahead with the research process.

2.3 Data Collection Method and Process

The researcher employed the use of interviews to gather data for this study. Lune, Pumar & Koppel, (2010: 240-241) defined an interview as a conversation with a purpose. Their further explanation of this definition says interviews tend to be more about discovery than about the recording of facts and that the conversations for the purpose of interviews lead to the answers that even the subject was not aware of initially.

The researcher used a semi-structured interview guide. The interviews were done individually with the participants to allow them to share their personal experiences in a private space. De Vos *et al.* (2005: 296) explain that “researchers use semi-structured interviews to gain a detailed picture of a participant’s beliefs about, or perceptions or accounts of, a particular topic.” They further explain that semi-structured interviews give the researcher and participant much more flexibility in that they have a set of predetermined questions on an interview schedule, but the interview will be guided by the schedule rather than be dictated by it.

This study used open-ended questions. Curtis & Curtis (2011: 34) explain that open-ended questions encourage a detailed answer. With open-ended questions the participants are free to devise their own unique answers to the questions posed (Ruane, 2005: 131). Bless & Higson-Smith (2004: 118) concur with the above that “open-ended questions leave the participants completely free to express their answers as they wish, as detailed and as complex, as long or as short as they feel is appropriate.” For example the following question was asked: “How do you feel about your role as a primary caregiver of an HIV infected adolescent?”

The researcher used a voice recorder while conducting the interviews. All participants had no problems of being audio-recorded – each gave written consent. Lune, Pumar & Koppel (2010: 155) highlighted the importance of obtaining informed consent from the participants prior to the videotaping, filming or recording in any form, unless these activities involve simply naturalistic observations and it’s not anticipated that the recording will be used in a manner that could cause personal identification or harm. De Vos *et al.* (2005: 298) explain that “audio recording allows preservation of a raw data for review at a later stage and therefore allows the researcher to focus on the question/answer and process at hand.” They further suggest that “a recorder should be placed inconspicuously so as not to unnerve the participant or novice the researcher and the researcher applied that.” The researcher took note of that and placed the recorder just next to her while conducting the interviews.

All participants were Xhosa speaking and they used their home language during the interviews. Seale (2004: 182) stated that “one of the reasons qualitative interviewing is a particularly suitable method for accessing complex issues such as values and understanding, is that it is a flexible medium and, to a certain extent, allows interviewees to speak in their own voices in their language.”

2.3.1 Pilot study

The researcher purposefully chose one female primary caregiver of HIV infected adolescent for a pilot study. The pilot study allows the researcher to make adjustments where necessary before embarking on a full-scale research study (De

Vos *et al.*, 2005: 205). Bless & Higson-Smith (2004: 155) provide the most encompassing definition of the pilot study that it is “a small study conducted prior to a larger piece of research to determine whether the methodology, sampling, instruments and analysis are adequate and appropriate.” The researcher conducted a pilot interview to assess the feasibility of the study e.g. whether the time that was estimated for the duration of the interview was realistic or not, and also whether the questions were understandable.

Undertaking the pilot study also helped to improve the success and effectiveness of the interview in the sense that while conducting the pilot study, the researcher made an error of asking some leading questions. The feedback that was received from the research supervisor about some leading questions that were asked by the researcher during the pilot study also benefited the researcher in the sense that necessary changes were made. The researcher also identified that there were some questions that were not easy to understand, for instance “tell me about your personal experiences about being the primary caregiver of the HIV infected adolescent.” The researcher made some changes and rephrased such question and asked “please tell me about your negative and positive experiences of being the primary caregiver of an HIV infected adolescent?” The pilot-study also enabled the researcher to be more familiar with the research questions. The researcher was a bit nervous during the pilot interview; it therefore helped the researcher to gain confidence.

Curtis & Curtis (2011: 37) suggested the following to reduce the nerves of both parties, the researcher to engage in small talks, offering something to drink or eat and attending to one’s body language. The researcher organized the refreshments for the study participants, soft drinks and chocolates. The soft drinks helped in hot weathers. It also helped when the participants were emotional during the interviews to have something to drink although when the researcher initially planned to bring the soft drinks she did not realize they will also serve that purpose.

The audio recorder that was going to be used for the interviews was also used in a pilot study. De Vos *et al.* (2005: 211) who advised that all apparatus that will be used during the study should also be piloted.

2.3.2 The Interviewing techniques and communication skills used

2.3.2.1 The Techniques Used

- **Beginning and during the interview**

According to Terre Blanche *et al.* (2006: 299) “an interview is the process of getting to know one another better.” They explain that at the beginning of the interview, the researcher and the interviewee may not know each other at all and still need to establish or re-establish trust and a working relationship. It is suggested that the researcher need not rush with difficult or sensitive questions right from the beginning of the interview session. The researcher started the interview sessions by introducing herself and allowed the participants to be comfortable and formally introduce themselves. The researcher introduced the purpose of the research. This involves providing clear reiteration for the nature of the research study that will be conducted, explaining ethical considerations for the study and seeking permission to record the interview. The researcher adhered to the above recommendations to start the interview and it helped to create the good atmosphere to conduct the study.

At this stage of beginning an interview, the researcher was aware that the participants were feeling anxious and nervous about the interview. The researcher played the role of the guest while at the same time was confident and relaxed making conversation but avoiding the topic until the interview began (Ritchie & Lewis, 2003: 144). The researcher used her Social Work skills that enabled her to handle the emotions that came up during interviews. The researcher made the participant relaxed and used the tone of voice that kept the participant calm and collected. They were also offered the refreshments. The researcher was friendly but genuine to the participants.

- **During the Interview**

De Vos *et al.* (2005: 288-289) suggests that “if you really need information on what might be regarded by some respondents as sensitive issues, you will need to take extra care in the working and positioning of questions. Some researchers think it is

better to place sensitive questions towards the end.” In this study the researcher asked general questions at the beginning of the interview session. The intention was to build rapport with the participants. The researcher asked question like “how are you?” “How old is the adolescent you are the primary caregiving?”, “What grade is s/he doing now?”

They further suggest that the researcher should “funnel” questions from general to specific, from broad to specific. The interview then followed the general questions with specific questions that could have been a bit sensitive to some participants. The questions were as follow: “What is your experience as the primary caregiver of an HIV infected adolescents?”; “What are your major challenges as the primary caregiver of an HIV infected adolescent?”

As the researcher I had the obligation to interview the participants within the terms of the contract that include the pre-determined length of time, a particular venue, on particular topic and under clear conditions of confidentiality. The researcher adhered to the terms and conditions of the contract that was signed by the participants at the beginning of the interview. Ritchie & Lewis (2003: 145 & 147) suggest that should the contract be changed for any reason, the terms should be negotiated and agreed upon prior the interview and the consent should be received from the participant before proceeding with an interview. During the interview sessions the researcher browsed through the goals and objectives of the contract while she was interviewing the participants so as to make sure that the probes to the participants’ responses were addressing the research aim.

- **Ending the interview**

Curtis & Curtis (2011: 40) state that towards the end of the interviews, the researcher wants to make sure that the participant said everything they consider relevant for the interview and the researcher wants to ensure that s/he has all the information needed before ending the session. On the same note, Ritchie & Lewis (2003: 146) maintain that it is important to check that the participant has not been left with unfinished business such as the feelings that were unexpressed or issues of burning importance left unmentioned. The researcher asked the participants the following

questions: “Is there anything that you wish to say or add before we end our conversation?”

- **After the interview**

The researcher thanked the participant warmly; helped them to move out the interview mode by highlighting how their contribution will help the research. The tape was then switched off after the interview sessions. According to Ritchie & Lewis (2003: 146) what happens after the tape has been switched off is also important. They state that this is also the time to answer any questions raised by the interviewee during the interview, or to give information about the support group or services. In this study, the researcher used her professional capacity to give some participants information about the services that were available for them to help them with some personal problems that were shared during the interviews. For instance, one participant was referred to a local non-governmental organization for a food parcel. Another participant received school uniform and stationary for his child that was available for a donation. Few participants needed clarity about the Foster Care Grant and Care Dependency Grant application procedure and the researcher gave them the information to clarify their concerns. Lastly, the researcher linked the interviewee who was seeking a garden job with someone who needed to employ a gardener.

Curtis & Curtis (2011: 40-41) explain that after the interview, the participants may be debriefed to minimize the risk of any effects. If the researcher knows ahead of time that the interview topic carries a risk of discomfort, s/he may develop a strategy for dealing with their feelings and emotions. The researcher asked the individual participants about their feelings after interviews. For instance, the researcher said to the participants: “I understand that sharing your inner thoughts and feelings might not have been easy and I truly appreciate your openness and willingness to share your experience to this study.” Then the researcher asked the participants “how do you feel now?” There was a plan in place for the participants who needed debriefing. The plan was made to refer the participants who needed debriefing to professional colleagues for counseling. However none of the participants expressed the need to utilize that service. By the time the researcher left the scene or the home

of the participants, the participants who were emotional on certain subjects during the interviews expressed that they were feeling fine.

2.3.2.2 Communication skills used

- **Probing**

The researcher allowed the participants to follow any angle that suited them to respond to the question but she maintained control of the conversation to make sure that the responses given were addressing the research goals and objectives. While some participants responded to certain questions, they also raised points that the researcher noted in order to probe or address at a later stage after the participants exhausted his or her response to the question (Bell, 2005: 144).

Gilbert (2009: 250) explains that probing involves follow-up questions to get a fuller response; it may be verbal or non-verbal.” Ritchie & Lewis (2003: 145 & 147) explained that “the key role of the qualitative researcher is to explore the views and feelings that underlie descriptions of behavior, events and experiences and that help to show the meaning that experiences hold for interviewee”. For example, the researcher asked questions like “how do you feel when your granddaughter is swearing at you?” or “What actions have you taken about her behavior?”

- **Listening and Remembering**

“A fundamental principle of in-depth interviewing is to listen. Listening does not just mean listening to words but trying to hear the meaning of what the participant is saying, understanding where there is a subtext that needs to be explored, and hearing the nuances in the participant’s account.”(Ritchie & Lewis, 2003: 156) The reflection of the researcher’s listening was when she probed and said to the interviewee “you said earlier that ...”

- **Non-verbal communication**

Ritchie and Lewis (2003: 157) suggest that people often convey what they think through their tone of voice and manner of body language. The body language and speech patterns can be important clues that there is more depth to be found. Curtis & Curtis (2011: 38) state that “both the interviewer and the participant will make use of non-verbal cues, consciously or not.” The body language can be extremely useful and sometimes essential sources of information. The researcher in the study took note of the non-verbal gestures that were presented by the participants, for instance the tone of the voice, the different facial expressions of the participant’s when talking about certain issues. The researcher noted the non-verbal gestures and wrote them in italics in the interviews transcripts.

- **Paraphrasing**

This involves “a verbal response in which the researcher will enhance meaning by stating the participant’s words in another form with the same meaning.” (De Vos *et al.*, 2005: 289) More often when the participants were expressing themselves during the interview sessions, the researcher would say what was said by the participants using different words to enhance the meaning of the statement given by the participants.

- **Clarification**

This embraces a technique that will be used to get clarity on unclear statements (De Vos *et al.*, 2005: 289). The researcher said words like, “If I understood you correctly you were saying...” to make sure that she understood what was shared by the participants.

- **Encouragement**

Encourage the participant to pursue a line of thought e.g. “tell me more” (De Vos *et al.*, 2005: 289). The researcher also encouraged the interviewees by paying

attentions to them and also by using body language such as nodding. The researcher nodded, paid attention to the participants when they were sharing their thoughts and feelings and smiled or laughed when there was something funny shared by the participants.

- **Silence**

In in-depth interviews people are asked to think and give view about issues that are not necessarily at the top of their minds. Sometimes the participants require time to think about a particular question to be able to formulate the response (Ritchie & Lewis, 2003: 157). While conducting the interviews, there were some silent moments whereby the researcher acknowledged them as being necessary and crucial moments during the live interviews for the above-mentioned reasons.

2.3.3 Equipment used during the interviews

Seale (2005: 218) recommends that the researcher checks the recorder from time to time if it was still working by a quick glance to avoid disrupting the participant. The voice recorder that was used for the recording of the interviews in this study was not complicated; there was not need to adjust anything other than the ordinary buttons such as on, off, pause and the recording buttons. The researcher randomly checked if the voice-recorder was still recording.

2.4 Data Analysis

Qualitative analysis transforms data into findings. It is a process of bringing order, structure and meaning to the massive raw data collected. The findings are generated and raw data is transformed into new knowledge (Tesch, 1990). The interviews were recorded by the researcher. The recordings were transcribed to convert the raw data into text form. The transcripts provided a clear view of the data collection and gave the researcher an opportunity to become familiar with the content.

In this study, data analysis was done according to Tesch's model which consists of eight steps, focusing the researcher on a logical approach. Based on this model, the data analysis entailed the proposed steps that were followed systematically:

- **Step 1:** The researcher read all the transcripts carefully and ideas were noted to get a sense of what contained in the transcripts.
- **Step 2:** After reading the entire transcript the researcher chose one interview that stood out and read it again tried to understand what it was saying. Notes were made about the messages and ideas that come out of the transcript.
- **Step 3:** After the researcher went through the transcripts thoroughly and making notes of all the messages that came out of the information, the researcher grouped related topics together.
- **Step 4:** Codes were allocated based on similar topics. This exercise was done to all the transcripts.
- **Step 5:** The researcher then grouped the information into themes, sub-themes and categories.
- **Step 6:** The researcher submitted the coding of her topics to the supervisor and the feedback from the independent coder's was given after she the researcher finished her coding.
- **Step 7:** The researcher checked the independent coder's feedback for consensus on the themes, sub-themes and categories.
- **Step 8:** It was not necessary to recode because the consensus was reached, the researcher had to rephrase the wording of some of her codes but the meaning that they carried was exactly the same. The researcher started concentrating on writing up the findings for the study.

2.5 Data Verification

2.5.1 Measures to ensure trustworthiness

According to De Vos *et al.* (2005: 331) "the term trustworthiness is used to describe validity and reliability issues in qualitative research." Morse *et al.* cited in Rolfe (2006: 303) explain that "validity and reliability are achieved when the researcher rigorously follows a number of verification strategies in the course of the research." Verification

strategies incrementally and interactively contribute to building reliability and validity; they encourage rigour. Thus, the rigour of qualitative enquiry should be beyond the question, beyond challenge and provide pragmatic scientific evidence that must be integrated into developing knowledge base.” In this study, the process of data verification was subsequently undertaken according to Guba’s model for trustworthiness (1985). This model focuses on the following four aspects of trustworthiness (1) truth value, (2) applicability, (3) consistency, and (4) neutrality.

Truth-value: According to Lincoln & Guba (1985: 204) truth-value asks whether the researcher has established confidence in the truth of the findings. Krefting (1991: 215) explains that truth value is usually obtained from the discovering of human experiences as they are lived.

An independent coder was appointed to assist with identifying and ensuring trustworthiness of the themes relating to the primary caregivers experiences in raising HIV infected adolescents. The researcher identified the study themes and submitted to the supervisor while the independent coder did the same and submitted to the student’s supervisor. After the feedback from the supervisor, it was confirmed that data saturation was reached. The researcher emerged some of the sub-themes that were going to be discusses together and recommended by the supervisors.

Applicability is concerned with the degree to which the findings of the research study are applicable to other contexts and groups. Applicability can be achieved through the strategy of transferability. Transferability refers to the extent to which we can see similarities in the findings that relate to other settings that have been provided and events taking place (Lincoln & Guba, 1985: 235). Applicability can be enhanced by thick descriptions of the research process. The research process followed by the researcher and the methods used have been described in detail and observation notes were maintained through the research process. The transferability of the research study has been strengthened by the thick descriptions provided in the research report on the motivation and decision making process followed by the researcher in her choice of design, methods, sampling as well as the provision of the interview schedule used during the interviews.

Consistency: Dependability refers to “the stability of data over time and conditions” (Krefting 1991: 216). Polit & Hungler (1999: 430) states that “an audit enquiry allows scrutiny of all data relative.” The researcher’s choice of methodology analysis and theoretical frameworks and involvement of the research supervisors for the study ensured a clear audit trail. The findings were checked for consistency by the researcher and by employing the services of the independent coder who had encoded themes and sub-themes for this study.

Neutrality: This method is achieved through the strategy of conformability. Conformability refers to objectivity or neutrality of data (Pilot & Hungler 1999: 430). According to Lincoln & Guba (1985: 75), conformability is demonstrated when the data is linked to their sources. The conformability of this study involved the transparent description of the research steps from the research proposal until the final step of reporting the study findings. Neutrality was also ensured through the use of the independent coder as stated. Bell (2005: 165) suggests that the audio recorded data be kept until after the research report has been examined and until the researcher is sure that there are no corrections or rewriting are required. The researcher will keep the transcripts of this study until the supervisor indicates that they will not be required anymore for auditing processes and they will be disposed by the researcher.

2.6 Ethical Considerations

Ethical guidelines serve as standard and basis upon which each researcher ought to evaluate own conduct (De Vos *et al.*, 2005: 570). There are four fundamental ethical principles that researchers have to bear in mind in research. These are: (1) autonomy and the respect for the dignity of persons involved in the research; (2) non-maleficence; (3) beneficence; and (4) justice (Wassenaar, 2006: 67-68). These four principles and how they were applied in the current study will be discussed in the following section.

2.6.1 Autonomy and respect for the dignity of persons

In this study, autonomy referred to respecting the rights of participants to participate voluntarily and to provide informed consent. According to Terre Blanche & Painter (2006: 294) informed consent is an ethical requirement for all research studies. De Vos *et al.* (2005: 59) suggest that obtaining informed consent implies that all possible or adequate information on the goal of the investigation, the procedure which will be followed during the investigation, the possible advantages, disadvantages and dangers to which respondents may be exposed, as well as the credibility of the researcher be rendered to potential subjects or their legal representatives. The research participants were given full details about the study before they decided to participate in it and this enabled the research participants to feel free to decide whether to participate or not in the study. The participation in the research was voluntary. All study participants signed a consent form that indicated their voluntary participation in the study and consent for audio recording (see appendix 3 and 4).

2.6.2 Principle of non-maleficence

This principle refers to the avoidance of harm to participants during the research process. The researcher ensured that no participant was subjected to any harm, exploitation or any risks by providing opportunities for debriefing the participants after the interviews. Seale (2004: 120) states that “care regarding data protection needs to be taken at all stages of research although particular sensitivity may be required at different stages.” views confidentiality as “a continuation of privacy which refers to the agreement between persons that limit others’ access to private information” (De Vos *et al.* 2005: 61). The participants were also assured that the researcher will keep the information that they gave her confidential. The researcher explained that their identity was going to be anonymous in the study publication therefore no one was going to be able to relate their identity from the input or statements they made during data collection. It was also explained to the participants that the data that was collected was safely secured in the computer and was going to be destroyed together with the transcripts when the study is completed and the information is no longer needed.

2.6.3 Principle of beneficence

This principle refers to the importance of outweigh the benefits against the harm for participants. Beneficence was achieved by applying the following ways: (i) participants were asked whether they will require feedback after the study had been completed. (ii) The results of the study will be shared with the practitioners who provide services to the caregivers in order to improve the services offered to them. (iii) The researcher provided refreshments to the participants during the interviewing period. (iv) Some of the participants were referred to other resources once a need for additional support was identified.

2.6.4 Principle of justice

In this study, the principle that participants had the right to fair and equitable treatment before, during and after their participation in the study was respected throughout the interviewing process.

2.7 Reflective Discussion on the role of the Social Worker and the Researcher

As a Social Worker of a small community of Grahamstown and also a researcher, it was easy to work with the clients who are or had been on the ARV programme because they were already exposed to being interviewed by either the social worker, the nurses or lay counselors for treatment related issues. The study sample understood that the information they divulged about themselves and their significant others was treated with respect and confidentiality. My role as a researcher and the social worker was to understand better the needs of the recipients of the social support services and to identify the strategies that were appropriate to address their needs. My role as a researcher enabled me to step out of my social work role and understand the day to day struggles of the primary caregivers in a more conducive environment whereby they can ventilate without any fears that the information they divulge might have an impact on some medical decisions about their adolescents' treatment. As the researcher I have discovered that the primary caregivers are

encountering challenges in their role and we as health professionals expect them to do things right with their children's medication without the in-depth understanding of their day to day challenges.

2.8 Chapter summary

This chapter presented an elaborative discussion of the research methodology. The research methodology discussion included the qualitative approach that was chosen for the study, the research population and the method of sampling, entry to the research site, data collection through semi-structured interviews, pilot study, and data analysis through Tesch's model (1990) of content analysis. Trustworthiness was proved through Lincon and Guba's model (1985) and ethical considerations focused on the protection of the participants by informed consent, voluntary participation and lastly privacy and confidentiality.

The next chapter, chapter 3 will discuss qualitative findings.

CHAPTER 3

DISCUSSION OF RESEARCH FINDINGS AND LITERATURE CONTROL

3.1 Introduction

This chapter will present the findings of the semi-structured interviews that were conducted with selected primary caregivers of HIV infected adolescents in Grahamstown. An explorative, descriptive and contextual qualitative study was conducted to enhance the understanding of the experiences and challenges of primary caregivers in caring for HIV infected adolescents. The research participants were asked open-ended questions with the view of answering the research question and meeting the research goals. The participants were asked to share their positive and negative experiences of being primary caregivers of HIV infected adolescents. Probing questions were used to stimulate in-depth responses on particular topics that were of relevance to the study; as well as ensuring that specific areas relating to the research question were asked.

Data analysis, organization and interpretation were done using Tesch's model (1990) that has been discussed in detail in Chapter Two. The discussion of the findings that follows will be structured according to themes and sub-themes that were identified. Relevant quotations from the participants will be inserted to substantiate the findings. Subsequently to this, findings from literature will be compared to the findings of this study.

The following section presents the biographical information of the participants in this study.

3.2 Biographical Information of Participants

Information on the biographical information of the primary carers of adolescents provides the reader with the personal and social context of the participants in the study and enlightens the findings of the study.

Table A: Biographical information of participants

	Age	Gender	Marital Status	Current Occupation	Previous Occupation	Education Level	Age of child	Race	Relationship with Adolescent
1	73	F	Widow	Old Age Pensioner and part-time gardener	Farm worker	Never been to school	12	Black	Paternal Grandmother
2	40	F	Single	Unemployed	Never worked	STD 5	13 & 16	Black	Maternal Aunt
3	59	M	Widower	Disability Grant Pensioner	Labourer (garden part-time jobs)	STD 2	16	Black	Biological Father
4	50	F	Single	Disability Grant pensioner	Never worked	STD 5	16 & 17	Black	Maternal Aunt
5	60	F	Married	Old Age pensioner	General Assistant	STD 6	14	Black	Maternal Grandmother
6	63	F	Widow	Old Age Grant	Housewife	STD 6	16	Black	Maternal Grandmother
7	52	F	Single	Disability Grant Pensioner	Never worked	STD 4	19	Black	Paternal Aunt
8	44	F	Single	Construction Worker	Temporal job	STD 9	13 & 14	Black	Maternal Aunt
9	45	F	Single	Casual worker	Part – time job	STD 7	19	Black	Biological Mother

The biographical profile of participants indicates that their ages varied between 38 and 72 years. Eight participants were female primary caregivers and only one was the male primary caregiver. Five participants were single, one was married and four participants' spouses demised. The study participants are not in the line of professional status, for instance there was a gardener, domestic workers, old age

pensioners, casual workers, and one unemployed. The profile indicates that three candidates receive old age grant, three participants receive disability grant, one participant is unemployed, and two are part-time workers. All study participants had a blood or close family relationship with the adolescents in their care. Five primary caregivers are the grandparents, two are biological parents and three are the aunts of the adolescents.

3.3 Discussion of findings of the Study

Table B: Summary of themes, sub-themes and categories

Table B, below presents a summary of the main themes and categories that emerged from the research findings. The discussion that follows will be structured accordingly. The verbatim responses by the participants will be added to reflect on significant non-verbal communication of the participants where relevant as explained in Chapter Two, paragraph 2.6.4.3.

Themes	Sub-themes	Categories
<p>3.3.1. Challenges experienced by primary caregivers of HIV infected adolescents.</p>	<p>3.3.1.1. Challenges related to the negative behaviour of HIV+ adolescent</p> <p>3.3.1.2 Challenges related to financial stressors and poverty</p> <p>3.3.1.3 Challenge related to poor social support</p> <p>3.3.1.4 Challenges related to HIV stigma and discrimination,</p>	<ul style="list-style-type: none"> • Sexual activity, multiple partners and early pregnancy of HIV infected adolescent. • Alcohol use and abuse of adolescents. • Adolescents not taking responsibility for own treatment and health. <p style="text-align: center;">+</p> <ul style="list-style-type: none"> • Adolescents poor school attendance and abscondment <p style="text-align: center;">.</p>

	<p>3.3.1.5 Challenges that are related to disclosure of HIV status</p> <p>3.3.1.6 Challenges related to finding out about HIV infection and lack of skill to deal with adolescents' emotional needs</p> <p>3.3.1.7 Primary caregivers struggles with own poor health</p>	
<p>3.3.2 Helpful assistance that made caring easier</p>	<p>3.3.2.1 Training and support enabled caregiver to understand more about HIV infection, health requirements, the treatment and to cope better.</p> <p>3.3.2.2 Adolescents taking responsibility of taking his/her own medication</p> <p>3.3.2.3 Available community resources help carer to cope.</p> <p>3.3.2.4 Good and supportive relationship between the primary caregiver and the adolescent provides a structure that benefits the HIV + adolescent</p> <p>3.3.2.5 Family Support and prayer enabled acceptance of the situation</p>	
<p>3.3.3. Suggestions by primary caregivers to assist them.</p>	<p>3.3.3.1 Emotional care of caregivers</p> <p>3.3.3.2 Material needs of primary caregivers</p> <p>3.3.3.3 Children to be re-educated by people outside the family about importance</p>	

	of treatment 3.3.3.4 Support groups for both caregivers & children	
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In the section that follows, the research findings will be discussed in terms of the identified themes and their supporting sub-themes and categories. This will be supported by verbatim extracts from the collected data, followed by the theoretical interpretations and integrated discussions of the findings, as guided by the literature control. The findings are divided into three themes: challenges experienced by primary caregivers of HIV infected adolescents; helpful assistance that made caring easier; and suggestions by primary caregivers about the service that they felt are crucial to support and assist primary caregivers of HIV infected adolescents. Each of these themes with their related sub-themes and categories will be discussed below.

3.3.1 Theme 1: Challenges experienced by primary caregivers of HIV infected adolescents.

This theme emanated when the participants were asked to share their personal experiences and challenges in raising HIV infected adolescents; and how they felt about their role. Some of the behaviour related challenges raised by the participants were the general challenge of primary caregiver of adolescents regardless of the adolescents’ HIV status and others were related to their HIV status. The general challenges shared by the participants about adolescents’ negative behavior were the following: their sexual relationships, abscondment from school and alcohol use. The participants also shared adolescents’ behavioural challenge which is as a result of their HIV infections: the adolescent’s failure or refusal of taking the responsibility of their own health and their emotional problems which the primary caregivers feel are a challenge as they are not equipped to deal with them. The participants further shared their personal challenges which were as a result of caring for an HIV infected child such as: financial stressors and poverty, challenges relating to poor social support, HIV stigma and discrimination, challenges relating to poor understanding of HIV infection and lack of skills to deal with adolescents emotional needs, and their primary caregiving role that affected their health. The participants’ main concern with

their childrens' behaviour was exacerbated by the fact that their adolescents were infected with HIV and that could have negative impact in their lives.

Erikson's theory of psychosocial developmental (1963) as cited by Shaffer & Kipp, (2007: 51, 332) explains that children are active, curious explorers who seek to adapt to their environment, rather than passive slaves to biological urges who are molded by their parents. He describes adolescence as a crossroad between childhood and maturity. Adolescents grapple with the question of identity On the same note, Santamaira, Doleza, Mellins, Marhefka, Hoffman, Ahmed & Elkington (2011: 257) highlighted that adolescence is a very challenging period for young people; it is often characterized by experimentation with sexual and drug risk behavior, and other health risk behaviors such as non-adherence to medication in the context of increasing autonomy for medical treatment and care.

The following seven sub-themes emerged from their responses:

3.3.1.1 Sub-theme 1: Challenges related to the negative behaviour of HIV+ adolescent

This sub-theme emerged when the participants were asked to share their experiences with caring for HIV infected adolescents. The participants shared their experiences about the negative behaviours of their adolescents that they felt posed a threat in their health and lives. The challenges raised by the participants were adolescents' sexual activity and early pregnancy; alcohol use; failure to take responsibility to their treatment. The participants also shared the general challenges they experience with their HIV infected adolescents that were not health related which included poor school attendance and abscondment from school. These will be discussed below:

- **Sexual activity, multiple partners and early pregnancy of HIV infected adolescents**

This theme emerged from the above-mentioned challenges raised by the participants. It was evident that their adolescents' sexual behaviour was a matter of

concern. The participants shared that their HIV infected adolescents were engaging in sexual activities at a young age, having multiple partners and fall pregnant at a young age. Five participants in the study reported that their adolescents were sexually active. Out of that five two participants reported that their adolescents were involved in multiple relationships (they had more than one sexual partner). From the five adolescents that are sexually active, two adolescents had two children before the age of 18 years. The primary caregivers who expressed the problem of a risky sexual behavior but their adolescents feel that their efforts to stop and reprimand them were in vein as there was no positive change.

The following are some of the verbatim responses from the participants:

Uqale ukungamameli ngo 2011, wathi chatha ngo 2012...Ndizamile ukuthetha naye ndimthibaza kodwa naleyo khange incede...Ndihleli nje ndihamba ndimkhangela kulamadoda akhe ndiqonde andikhathalele noba ndihlatyiwe, kuthiwe ebelapha, ebelapha, ndimfumane nakulama 'kwere-kwere' etown, ukhe ahlale nawo...Hayi maan bekhe ndathi kutishara wakhe lomntwana akayifumenanga le ntsholongwane kwi Rape njengamntu owayekhe wadlwengulwa kokukuhamba kwakhe ngobusuku, uyifumene ekutshintsha-tshintsheni amadoda ngoba kudala ndisiva ngendlela aziphethe ngayo(kutsho umakazi oneminyaka eyi 40).

(She started mis-behaving in 2011 and he got worse in 2012. I tried to talk to her but that did not help...I always look for her when she is missing. I would follow the clues of her whereabouts and I do not care even if I get stabbed. I sometimes find her from the foreigner guys in town because she sometimes stays with them. You know what, I recently told her teachers that it is possible that her HIV infection is not as a result of the rape she experienced but might be as a result of her bad behavior because I have been hearing about it, said the 40 year old aunt).

Ukhe angagoduki iintsuku, uyakwazi ukuza ebusuku xa silele nenkwenkwe yakhe kulendlu yethu inamagumbi amathathu alale nayo kwigumbi lokuhlala elingaphambili, akho mntu unokuthetha ngoba siva ngaye apha endlini (kusitsho umakazi oneminyaka eyi-50).

(She does not come home for days, she brings her boyfriend over to our small house, spends the night with him in our three roomed house and sleeps in our dining room with him, and no

one can say anything because she has a final word, said the 50 years old aunt).

Intombi yam yayineminyaka eyi 13 ukukhulelwa kwayo. Umntwana wokuqala wayengenantsholongwane...akukhonto ndandinokuyenza njengoba wayesele ekhulelwe kodwa ndamxelela ukuba kufuneka afunde kwiimpazamo zakhe...Ufunyaniswe ukuba uchaphazelekile phambi kokuba akhulelwe umntwana wesibini eneminyaka eyi 16 (kusitsho umama oneminyaka eyi 45)

(My daughter fell pregnant at the age of 13 years. She had no HIV at the time, there was nothing I could do because she was already pregnant but I told her she must learn from her mistakes. She was diagnosed with HIV when she was pregnant with her second child at the age of 16 years, said the 45 years old mother).

One of the major hurdles that adolescents face is figuring out how to manage and express their sexual feelings on issues that are heavily influenced by the social and cultural contexts in which they live (Shaffer & Kipp, 2007: 223). Amatoeng & Sabiti (2013: 151) discovered that some of the challenges of the South African youth include their sexual behavior such having multiple sexual partners, unprotected sex, unplanned pregnancies and the risk of sexual transmitted infections such as HIV and AIDS, especially among the country's African population. Mashala, Esterhuisen & Basson (2012: 50) cited Mkhize (1995) who conducted a study on experiences and challenges of adolescents during pregnancy and noted that parents of pregnant adolescents become angry and blame their daughters for being irresponsible. They also noted that parents also expressed concern about another mouth to feed. They cited Macleod (1999) who reported that in South Africa; very few families neglect their pregnant daughters.

Another challenge that was shared by some primary caregivers is the adolescent's alcohol and drug use.

- **Alcohol/drug use of adolescents**

Alcohol and drug use among adolescents emerged as one of the challenges that were mentioned by the participants when they were asked about their experiences of

caring for HIV infected adolescents. Two participants reported that their children are using substance/alcohol. One of the primary caregivers reported that her daughter was in a relationship with someone who was using drugs although they did not know if she was also using them or not; but the primary caregiver complained of her aggressive behaviour.

The following are the responses from the primary caregivers:

...ngamanye amaxesha ubuya endlini esele utywala nangona engaseli rhoqo. Andimazi usela kangakanani ngoba ubuya ebusuku kakhulu.

(Sometimes she comes back home drunk although she is not a regular drinker. I do not know how much she drinks because when she is here she comes back late at night).

Umfo wakhe usebenzisa iziyobisi...yena ufuna imali yokutshaya ngenkani apha kuthi; ubanomshindo ukuba asinayo. Siye siboleke emntwini xa eyifuna ngenkani kuba sifuna ukuthomalalisa loo msindo (kusitsho umama oneminyaka eyi 45).

(Her boyfriend is using drugs...she demands money from us to buy him cigarettes; she gets very upset if we don't have it. We loan money from someone when she demands it to calm her down, said the 45 years old mother).

...ngenye imini ndabona ngaye sele ebuya elila esithi udlwengulwe. Uthi wayese Tavern wathengelwa i 5litre yotywala ngomnye umfana, wahamba lomfana yena wayisela netshomi yakhe. Xa egoduka eyokulala kulo tshomi udibana nalo mfana uyabuza buphi utywala bakhe, athi yena hayi kaloku khange ufike thina sibugqibile. Uthi ke wamtsala wamdlwengulela ngakwamanye amatyotyombe (kusitsho umakazi oneminyaka eyi 40).

(...The other day I saw her coming back home crying and telling me that she had been raped. She says she was at the tavern and one guy bought her five litres of alcohol and he left her drinking it with her friends. On her way from the tavern, she met this guy who bought him alcohol; he asked her where his alcohol was. She says she responded by saying she drank it all with friends because he did not come back. She says he dragged her to the shacks that are in that area and he raped her, said the 40 years old maternal aunt).

Morojelo, Brooke & Kachieng'a (2006: 1 & 218) in their study found that drug use and HIV/AIDS are major problems among adolescents in South Africa. In their study adolescents commentaries suggest that drug use enhances effects of underlying risk factors for sexual risk behavior. For example, boys were believed to be motivated by drug use to have multiple partners. In addition to that, Morojelo, Brooke, Kochieng's, Makoko, Noko, Parry, Nkowane, Mosha and Saxina (2006: 218) viewed alcohol consumption to be making people become flirtatious, sexually provocative and courageous and less inhibited about revealing their sexual desire to others. They cited Fitz *et al.* (2002) who further argued that the use of alcohol is increasingly being recognized as a key determinant of sexual behavior and consequently an indirect contributor to HIV transmission in sub-Saharan countries. Page and Hall (2009: 369) report that high risk sexual behaviour is associated with both psychological distress and alcohol use. Different studies acknowledge that parental practices are beneficial in reducing adolescents' alcohol use. Watkins, Howard-Barr, Moore and Werch (2006: 448) note that parental monitoring, communication and emotional support have positive effects on adolescents' alcohol problems. Nash, McQueen and Bray (2005: 19) are of the same view as they argue that family interactions, processes and parenting are recognized as a significant influence on adolescents' development, behavior and substance abuse. They mention that greater parental disapproval is associated with less involvement with friends, less peer influence to use alcohol and lowers subsequent alcohol use and related problems.

Another major concern and challenge for primary caregivers is the adolescents' non-compliance to treatment.

- **Adolescents refuse to or do not take responsibility of treatment for his/her own health**

The participants were asked to share their experiences with their adolescents in taking treatment. Three participants reported that the children complained of the treatment side effects and say they encouraged them to continue and explained the benefits of treatment on their health. Two participants reported that their children refused to go to the clinic all together. Four participants reported that their

adolescents were not adhering to treatment: they took the treatment as they pleased without considering the guidance they are given at the clinic or hospital.

The following are the quotes of the primary caregivers who are also experiencing challenges with their adolescents with taking the treatment:

Lo mntwana akabambeki ngoba kudala kufuneka eqale I ARV'S. I ARV's azimfuni umntu ongabambekiyo. Wakhe waqaliswa kwi bico nezinye iipilisi, zange azitye. Uzishiye endlini wahamba khange aziqalise ukuzitya (kusitsho dabawo oneminyaka eyi 52).

(This child is not easy to be found because she was supposed to start ARV long time ago. ARV's do not want someone like that. She was once given bico and other tablets but she never used them. She left home without her medication; she never used them, said the 52 years old paternal aunt).

Wakhe neepilisi akazitya kakuhle, wathethiswa ngugqirhakazi, wamxelela ukuba uxakekile makazitye naxesha liphina (kusitsho utata oneminyaka eyi 59).

(He once stopped his medication and the doctor told him that if he is too busy he can take the medication anytime, said the 59 years old father).

Bekufanele ukuba ukuzo kodwa wala kwaphela ngoba wathi yena soze atye ipilisi ubomi bakhe bonke. Ngoku zikhona ipilisi azityayo ezokuba enentsholongwane ekhulelwe (kusitsho umakazi oneminyaka eyi 50).

(She is supposed to be on treatment but she completely refused taking them and said she will never take tablets for the rest of her life. She is now on another medication for being HIV positive and pregnant, said the 50 years old aunt).

Kukho le treatment ayityayo ndifumanisa ukuba uyamtyhafisa. Xa bendengekho ndize ndithi xa ndibuya ndimbuze ba uzityile na ipilisi, athi hayi makhulu mna ndidiniwe zezi pilisi (kusitsho umakhulu oneminyaka eyi 60).

(There is a tablet from the tablets she is taking that I notice is making her tired. When I am not at home and when I come back I ask her if she took the treatment, she says no grandmother I am sick and tired of these tablets, said the 60 years old grandmother).

“Uyazithatha ipilisi kodwa ehleli nje unezikhalazo ngazo.Uthi zimenza umqala wakhe ubebuhlungu.Ukuba uyityile kusasa akazokuyitya ngokuhlwa ngoba uthi xa eyityile ayimlalisi kakuhle.Ipilisi zakhe uzohlula phakathi, ezinye zihlala kuthi endlini, ezinye azigcine kule ndoda yakhe”, kusithso uamama uneminyaka eyi 45.

(She takes her medication but she is full of complaints about it. She says it makes her throat sore. If she takes them in the morning, she does not take them at night because she says if she takes the evening doze she does not sleep well. She divided her medication in half; she keeps one half in our house and keeps the other half at her boyfriend’s place, said the 45 years old mother).

According to Department of Health (2013: 4) in the Antiretroviral Treatment (ART) Guidelines “the goals of antiretroviral treatment is to save and improve the quality of life of people living with HIV, and to mitigate the impact of HIV and AIDS”. Yeap, Hamilton, Charalambous, Dwadwa, Churchyard, Geissler and Grant (2010: 1101) explain that good adherence to antiretroviral treatment from an early age has been identified as a major challenge in the administration of ART to HIV infected children. He maintains that excellent adherence to treatment is one of the most important factors in determining treatment success and preventing viral resistance. Davies, Boulle, Faker, Nuttal and Elley (2008: 2) contended that “research from rich countries suggests that compliance to treatment may be more complex in children compared to adults due to many factors including reliance on caregivers who may be ill themselves; or may not be the child’s parent; or complex dosing treatment regimens, etc.” Emotional and behavioural problems including depression, conduct problems and alcohol use some adolescents present are also associated with non-adherence to treatment in older adolescents (Malee, Williams, Mantepiediam, McCabe, Nichols, Sirois, Storm, Farley, Kammerer and PACTG 219c Team: 2011: 192). Leach-Lemens (2012: 1) maintains that “HIV infected adolescents are mostly managed in adults’ programmes, especially in rural settings with no trained personnel to work with adolescents yet evidence from a number of treatment programmes shows that adolescents have specific challenges in relation to antiretroviral treatment and living with HIV.” It could thus be concluded that these health care workers are not empowered to deal with the emotional and social skills to guide and support the primary caregivers of HIV infected adolescents. He further

argues that experiences that have been learnt from developed countries suggest that HIV/AIDS has affected all spheres of life and therefore to address the challenges that are facing adolescents requires not only addressing biomedical issues but also adolescents' psycho-social needs.

Two participant shared that their adolescents do not go to the clinic beyond the efforts that the health care workers are making to accommodate them. The following are the participant's response:

Mna ndixelelwa ngumntwana womnye umnakwethu ophangela ekliniki ukuba intombi le yam iyafunwa ekliniki ngoba kufuneka yena nomntwana batye ipilisi (kusitsho umakazi oneminyaka eyi 52).

(I was told by my cousin's child that the clinic is looking for her because she and her child are supposed to start treatment, said the 52 years old paternal aunt).

Ndingathi njengokuba efunda nje kwathiwa ekliniki mandimthathela iipilisi, aze xa ekwi khofu eziyele ngokwakhe ukuze aqhele ukuzithathela ipilisi zakhe. Kweli khofu lika December ndithe ndimkhumbuza ukuba ayokuthatha ipilisi zakhe ekliniki wathi andincingi ndiyokuzithatha. Wathi andiyi Gogo, andiyi! Ndathi kaloku uyayazi kufuneka kujongwe impilo yakhe kodwa wala kwade kwaphela. Kwathiwa endlini inoba ikhona into ebangela lonto qha mna andizokuyazi mandiyi ndiyokumthathela...Akakhuphi nto, akathethi nto uvele athi akasoze aye ekliniki (kusitsho umakhulu oneminyaka eyi 63).

(I can say because he is a learner, I was told at the clinic that I should collect his medication for him and when it is school vacation he must go himself so that he gets used to taking his treatment himself. Last December holiday, I reminded him to go fetch his treatment from the clinic and he said he will never do that. He said I am not going grandma, I am not going. I told him he is supposed to do medical check up and he refused, said a 63 years old grandmother).

Naswa & Marfatia, (2010: 10) indicated that many young people do not access needed healthcare services for fear of disclosing their HIV status to their parents or guardian." Mutwa, Nuil, Asimwe-Kateera, Vyankondorera, Pool, Rihirimbua, Konakuze, Reiss, Geelen, van de Wilgert & Boer (2013: 25) added that adolescents avoid going to the clinic to obtain their drugs as they are concerned that the

community members will know about their health status. Nyblade, Stangl, Weiss and Ashburn (2009: 1758) added that “health related stigma and discrimination are the key barriers to delivering of quality services by health providers and for their utilization by community members and health providers.”

- **Adolescents’ poor school attendance and abscondment**

While the participants were sharing the problem behaviour of the adolescents in their care, poor attendance and dropping out of school was one of the challenges and concerns that were raised. Three participants reported that their adolescents dropped out of school; and two reported that the school reported that their adolescents had poor attendance at school.

The following are the responses of primary caregivers:

Ewe usafunda kodwa usihamba kakubi isikolo, uyanyamalala endlini. Ndiyacenga, ndimfownele ndithetha kamnandi naye, ndimcenge ukuba makagoduke, athembise. Akagqibeki naxa esendlini soze uyazi ukuba ufikelwe yintoni engqondweni yakhe avele aphinde ahambe (kusitsho umakazi oneminyaka eyi 40).

(Yes she is still at school but her school attendance is bad, she disappears from home. I beg her, phone her and speak so nicely with her that she must come back home. She is unpredictable, even when she is at home you will never know what comes to her mind, she just vanishes, said the 40 years old aunt).

Bekhe ndabizwa esikolweni, ndaxelelwa ukuba uyazimela akazingeni ikhosi; naxa egqib’ okutya akahlambi sitya sakhe usuka asilahle phezu kwenzinye...Badixelele ukuba akaqhubi kakuhle nasezifundweni (kusitsho utata oneminyaka eyi 59).

(I was recently called at his school and they reported that he abscond classes; also when he finished eating he just throws his dishes and not wash them...they informed me that his school performance is not good, said the 59 years old father).

Sakhe saya naye koonontlalo-ntle kuba engafuni ukuhamba isikolo, wathi kubo ukuba ndifuna aye eskolweni ndingathatha impahla yakhe

yesikolo ndiyinxibe ngokwam ndiye eskolweni (kusitsho umakazi oneminyaka eyi 50).

(We have been to Social Workers because she did not want to go to school, she told them that if I want her to go to school I can take her school uniform and wear it and go to school, said the 50 years old maternal aunt).

Wasiyeka isikolo xa eneminyaka eyi 13 iminyaka. Safumana ingxelo evela eskolweni ethi akasayi eskolweni, ndiyothuke lonto ngoba uphuma apha engathi uya khona...Uyeke eHigher Primary kwaye ebengumntwana okrele-krele qha ingxaki izokuba xa eqalisa ukutshintsha isimilo; wavuma inkwenkwe (kusitsho umakazi oneminyaka eyi 52).

(She dropped out of school at the age of 13 years. We received a report from school that she was no longer attending school and I was shocked because she left the house as if she was going to school... She dropped out at Higher Primary and she was very bright but the problem started when she had a boyfriend, said the 52 years old paternal aunt).

Akasafundi nokufunda wayeka esese Primary (kusitsho umama oneminyaka eyi 45).

(She stopped school at Primary, said the 45 years old mother).

Li, Jaspán, Brien, Rabie, Cotton and Natras (2010: 753) argue that HIV affected social interactions and even separating adolescents from their peers. On the same note, Petersen *et al.* (2010: 973) argued that, it is difficult for adolescents upon finding out about their HIV status to come to terms with their identity. He further mentioned that 36% of adolescents in his study reported that they withdrew from their friends and social activities on finding their HIV status as they were feeling “different” from their peers. Shaffer and Kipp (2007: 228) cited Coley & Chase-Lansdale, 1998; Fergusson & Woodward, (2000) who discovered that, “for adolescents who give birth, the consequences are likely to have an interrupted education, loss of contact with her social networks and she is one of the 50 percent who drops out of school, a future of low paying (or no) jobs that perpetuate her economic disadvantage”. In countries hard hit by the HIV epidemic in Southern Africa, AIDS is best thought of as a family disease. Families carry the heaviest load in treating, caring for and protecting children and other members directly affected by

the epidemic. Well-functioning families play a fundamental role, which is not fully recognised in the fight against HIV and AIDS (Richter, Sherr, Adato, Belsey, Upjeet, Desmond, Drimie, Haour-Knipe, Hosegoed, Kimour, Madhavan, Mathambo and Wakhweya *et al.*, 2009: 4)

Other challenges that were raised by primary caregivers are the financial problems and poverty.

3.3.1.2 Sub-theme 2: Challenges related to financial stressors and poverty

This sub-theme also emerged when the participants were sharing their challenges with HIV raising HIV infected adolescents. The financial problems that the participants are experiencing in caring for the HIV infected cannot be separated from poverty that the participants experienced as it resulted in insufficient food security at home and lack of financial means to pay for the needs of a sick child. All the participants in the study expressed that they encountered financial hardship in their caregiving role. Table A presents the biographic information of the participants and indicates that six participants depend on Government Social Grants; one participant was unemployed and two participants had part-time casual jobs. Three participants who reported that they have social grants now reported that there was a time when the children were very ill and they had no income at all. Two participants who have casual employment report that there are times when the jobs are not available and they do not have the income to sustain the needs of the family. During those difficult times, participants rely on other family member to assist with the financial needs of the adolescent or the whole family. All primary caregivers that were interviewed in this study reported encountering additional financial problems at different stages of their primary caregiving role since children who are HIV positive require special care, healthy nutrition, urgent medical care and regular clinic or hospital visits and access to support services.

In relations to the experiences of poverty and financial problems, the participants expressed the following:

Bukhona ubunzima ngokwasezimalini ngoba akukho mnandi ukuhlala nomntu otya ipilisi kuze endlini kungabikho nto ityiwayo...Ndiqale ukufumane I disability grant yam ukuqala kwalonyaka upheleleyo kodwa nayo ayaneli ukuba isombulele ingxaki zethu, ngoba kufuneka ndiyisebenzisele iingxaki zekhaya nokujonga iimfuno zalonyana wam uchaphazelekileyo yintsholongwane, yilento ndingenakuze ndiyiyeke eminye imisebenzi yam yegadi (kusitsho utata oneminyaka eyi 59).

(I am struggling financially because it is not nice to live with the child who takes tablets when there is not food at home... As from last year, I started receiving disability grant but it is not enough for the family needs and those of my child who is infected with HIV hence I cannot stop doing my part-time jobs, said the 59 years old father).

Ndifumana Care Dependency grant yomntwana kadade wethu. Udade wethu uyazazi ukuba unomntwana xa iyindodla, ayifunele kuye nangona engamkhathalelanga nje. Nowam umntwana uyayifumana indodla yokugula kodwa eyakhe yile kufuneka ndithenge ngayo ukutya kosapho lonke kwaye sibhatala nomasingcwabane wekhaya kwakuyo ngoba akuphangelwa apha kweli khaya. Khange afumane nempahla ze Christmas kulo nyaka upheleleyo ngoba ndiyisenbenzise indodla yakhe ukwenza izinto zekhaya (kusithso umakazi oneminyaka eyi 50).

(The two children get Care Dependency grant but my sister knows that she has a child when she gets the grant and wants it for herself although she is not involved with caring for her daughter. I use my daughter's Care Dependency Grant to buy grocery for the family; we pay family funeral policy from it because no one is working in our household. Last year, she did not even get Christmas clothes last year because I used her Care Dependency grant money to run the household, said the 50 years old aunt).

Ndiyaya kumaziko okunceda uluntu kodwa bathi kuba ke mna ndisaphila akhonto ndikwaziyo ukuyifumana ngaphandle ba ibingunkosikazi ebesele nabantwana. Ngeloxesha ndandisokola kakhulu ngaba bantwana. Ngoku ndifumana ichild support grand kunye nendodla yam yokugula endiqale ukuyifumana kulonyaka upheleleyo kuba ndikhathazwa sisifuba. Ndandikhe ndayifumana ifood parcel eyayimane isiwa kum qho ngenyanga kodwa ke yaphela nayo lonto. Lonto ke nandingekabinazo nezizingxungxo ngoko (kusitsho utata oneminyaka eyi 59).

(I do go to institutions for help but I was told that because the wife is the one who passed away and as the father I am still alive there is nothing they can do unless it was the wife who

was left with children. At that time I was struggling with my two children. I am now getting his Child Support Grant and my disability grant which I started receiving last year for Asthma. I used to get the food parcel that was delivered to me every month but that also stopped and at that time I did not even have the odd jobs I am doing now, said the 59 years old father).

Demmer (2011: 877) in his study of experiences of families caring for an HIV-infected children discovered that primary caregivers felt that their future was quite bleak. They focused their energies on living day to day. Finding money to buy food, let alone nutritious food, was a constant preoccupation and source of stress. Bejane, Havenga and Van Aswegen (2013: 76) in their study of primary caregivers' challenges related to caring for children with HIV discovered that primary caregivers had challenges of meeting the basic needs of the whole family and the children living with HIV. For primary caregivers, this problem was compounded by the fact that the children living with HIV had special needs in order to acquire and maintain the health status. The special needs of children who are living with HIV included adequate nutrition, taking meals before administering medication and attending healthcare facilities.

Another concern that was raised by some primary caregivers is that they do not get support from their families.

3.3.1.3 Sub-theme 3: Challenges related to poor social support

This sub-theme emerged as one of the challenges that were shared by the participants when they were asked to share their experiences with caring for an HIV infected adolescent. Social support refers to “a measure of how much help you can count or believe you can count on from your friends and family, especially in crises and hard times” (Lara, Leader, Klein and Kendler, 1998: 6) cited by (Casale & Wild, 2012: 260). Five participants reported family relations problems with some members of the family and had no strong support system other than the people that they lived with. One participant reported that she had the support of the family members that she did not stay with; and that she had never disclosed her grandchild's HIV status

to any family member because she cannot rely on them. They never supported her when her son died. Two participants reported that poor relationship with their families resulted to emotional abuse. Two participants expressed that the caregiving role was overwhelming at times and they did it because they felt desponded as they had no other choice but to carry on because there was no one else in their families who was keen to take over or share the responsibility with them.

The following quotes express how the participants experienced lack of family support and how the negative family relations affected them:

Andifumani ncedo efemeleni yam. Akukho mntu ndiya kuye ndihlala endlini yam. Ngubani umntu onokundinceda bezakusuka bahlekise nje. Ukuba uya e next door okanye kusapho lwakho bazakuse bahlekise ngengxaki yakho. Ukhona udade wethu endimolekelayo, andichubi nakuye ingxaki zam... Hayi ndenziwa kukuba kubhubhe utata walomntwana zange kubekho mntu ondincedayo. Ndinayo ifemeli yomzi wam ehlala eBhayi, hayi yona indithe khu, indigcinile (kusitsho umakhulu oneminyaka eyi 73).

(There is no help from my family. I do not go to anyone. No one will help me, instead they will make fun of me. If you go to your next door neighbour or to your family they will make fun of you. I have a younger sister who lives closeby; I do not even share my problems with her. It is because I lost my son, the father of this child and no one helped me with anything. I have my in-laws who live in Port Elizabeth, they are very supportive, said the 73 years old grandmother).

Yonke into ixhomeke kum. Umama wam wasweleka sisebancini washiya mna, nodade wam kunye nomnakwethu ongasekhoyo kwakunye notate wethu naye ongasekhoyo. Sikhule kabuhlungu kakhulu thina aphaya endlini. Besifunda singatyi apha esiswini ndaza ndayeka isikolo ngenxa yentsokolo... Yena umnakwethu wancedwa kuba ethandwa yenye itishara yamthatha wahlala kuyo zangcono izinto kuye. Mna ke ndavuma inkwenkwe endisenayo nangoku eyayimane indithengela ukutya. Iphi ifemeli ngeloxesha eyayithembisa sigqibo kungcwaba umama ukuba iyakusijonga kodwa sikhule silamba! Akho mntu ukhathalayo noba uchaza imeko yakho... Ndizinceda ngokwam, kodwa ukhona omnye umama phaya ekuhlaleni omane ethetha, andomeleze. Athi kum inokuba ndiyakungcwatywa ngaba bantwana. Athi kum ngabona bantwana bazakujonga aba (kutsho umgcini mntwana oneminyaka eyi 40).

(I am the only person who is responsible for everything. My mother passed away when we were still young. She left me behind with my brother and father who also passed away. We grew up under difficult circumstances. We were going to school without having anything to eat and I ended up dropping out of school as a result of those difficult circumstances... My brother was so fortunate to be liked by one of his teachers and he ended up staying with him and he had a better life. I dated a boyfriend who helped; he used to buy me food and I am still dating him. Where was the family at that time which told people at my mother's funeral that they will take care of us but we grew up starving? No one cares, even if you are telling them about your situation. I help myself but I have a neighbour who gives me moral support. She says to me maybe you will be buried by these children one day, said the 40 years aunt and mother).

Ndiyakhubeka kwaye ngamanye amaxesha ndiziva ngathi andinayo enye indlela kufuneka ndiqhubekile (kusitsho umakazi nokwangumama oneminyaka eyi 50).

(I get discouraged at times and feel like I do not have the choice, I have to carry on).

...mna ndikhalela kum, ndizithuzele kwangokwam, ayikho enye indlela ndizakude ndithini (kusitsho umakazi oneminyaka eyi 40).

(...I cry to myself, who else can comfort me; there is no other way, what else can I do, said the 40 years old maternal aunt).

The above statements by the participants confirm the theoretical framework that is adopted for this study which is Bowen's family systems model (1978) cited in (Shaffer and Kipp, 2007: 599). Shaffer and Kipp (2007: 599) maintain that the implication of viewing the family as a system is that interaction between any two family members are likely to be influenced by the attitudes and behavior of a third family member. A family does not only influence the behavior of every other, but the kind of relationship that two family members have can affect interaction and relationships of the rest of the family. When we consider that family members develop relationship change and that all family dynamics are influenced by the broader social context in which families are embodied, it then becomes quite clear that socialization with the family is best described not as a two way street between

parents and children, but as the busy intersection of other many avenues of influence. Demmer (2011: 873) notes that most caregivers rely on one or two family members for material and emotional support. He discovered that it is far from adequate as a person needs a strong support system to cope with the caregiving.

Stigma and discrimination was also raised as one of the challenges that were experienced by some primary caregivers in this study.

3.3.1.4 Sub-theme 4: Challenges related to HIV stigma and discrimination

When the participants were asked about their experiences and challenges, they raised stigma and discrimination of their adolescents as one of the challenges that they experienced. HIV stigma and discrimination refers to the unjust and unfair treatment that is directed to people who are infected with HIV; and the process of devaluing people who are living with HIV (Churcher, 2013: 12). Three primary caregivers who were interviewed in this study shared their family's negative reaction toward the children when they learnt about the child's HIV infection. They also shared how they protected their children from stigma and discrimination.

The participants shared their experiences:

Umntakwethu uthetha izinto zokuba akho nento anokuyenza kulendlu ngoba siyafa sonke. Athi landlu izele abantu abane HIV kunye ne TB. Iyandihlupha kakhulu lonto! Mva nje naxa efownile, unento entsha yokufownela ummelwane abuze zinjani eza zigulane, nathi sifumane lo miyalezo ukhubekisayo kubammelwane.

(My brother says there is nothing he can do in our home because we are all dying. He says our house is full of people who have HIV and TB. That worries me a lot! Lately when he phones, he has a habit of phoning the neighbours and asks how those sick people are; we get those messages that are unpleasant).

Uyabona babengamfuni lo mntwana apha emzini wam (elila kakhulu). Babengamthandi kub wayefike egula kakhulu kodwa ke utatazala wam wayeseceleni kwam. Babesithi uzakosulela abantwana babo ngesifo. Ndandimthumela ekhaya emini ukuze angabi kunye nabo ixesha elide (kutsho umakhulu oneminyaka eyi 63).

(You see my in-laws did not want this child, they did not like him because he was very ill when he arrived. My late father-in-law was very supportive. My in-laws said that my grandson is going to infect their children with HIV **(crying)**. I used to send my grandson home during the day so that he does not spend too much time with them, said the 63 years old grandmother).

Wathi unkosikazi wam akusweleka ngo 2006, ndaya kwa SASSA ndiyokwenza indodla yabantwana. Kwakufumaniseka ukuba umntwana wam ebefumana indodla yokugula (Care Dependency Grant). Umsebenzi wakwa SASSA wandibuza ukuba unyana wam ugula yintoni ndamxelela ukuba andiyazi ndifuna uncedo kuba ndiswelekelwe ngu nkosikazi umntu ebekade ebandodlela. Wandixelela lo msebenzi ngendlela ephoxisayo ukuba indodla yomntwana imile ngoba uphilile. Ndathi kuye ndiyavuya ukuyazi ukuba akukho nto iwrongo nomntwana wam. Ndandimbona ukuba uyahlekisa ngam ngokuba ndingayazi ukuba ithini imeko yakhe yokugula abe ebekade efumana indodla. Qha ndazixelela ukuba andizokuzihlupha ngaye. Wandithumela kugqirha ukuba ndenze isicelo esitsha esathi asamkeleka.

(When my wife died in 2006, I went to SASSA to apply for child support grant. I then found out my son was receiving care dependency grant (for sickness). SASSA officials asked me what my son's sickness was and I told them I do not know. The grant was taken away after my wife passed away. The officials told me in a sarcastic way that the grant has been stopped because my son is well. I told them that I am glad that there is nothing wrong with my son. I could see they were making fun of me by not knowing my child's health conditions and yet he was receiving the grant for being sick. I told myself that I will not allow that to get to me. They referred me to the doctor for re-application and it was turned down).

HIV is one of the most highly stigmatized medical conditions worldwide and HIV-related stigma is particularly severe in sub-Saharan African countries (Singh, Chaudoir, Escobar and Kalichman, 2011: 840) citing Dlamini *et al.*, 2007; Kipp, Tindyebwa, Rubaale, Karamagi, & Bajenja 2007). Although caregivers may not be HIV infected themselves, they may incur the negative effects of "associative stigma". Kipp *et al.* (2007) also cited Bogart *et al.* (2008); Holzemer *et al.*, (2007); Mwinituo and Mill (2006); Pirraglia *et al.* (2005); Wight, LeBlanc, and Aneshensel (1998) who argued that caregivers often experience negative consequences of HIV stigma, feel highly burdened, and experience mental and physical health problems because of

the demands of their role. Heeren, Jemmott III, Sidloyi, Ngwane & Tyler (2012: 52) citing Bikaako-Kajura *et al.* (2006); Blasini (2004); Santamaria *et al.* (2011) and argue that “for caregivers stigma leads to considerable concern that the informed child might want to disclose inappropriately to others and the gossipers would spread the information through the community with consequences so adverse that caregivers avoid informing the children and even change clinics when health-care providers press too much for disclosure.”

Closely linked to the issue of stigma are the challenges related to the disclosure of HIV status which will be discussed in the next section.

3.3.1.5 Sub-theme: 5 Challenges related to disclosure of HIV status

The term disclosure in this context will be used to refer to “a child gaining knowledge of his/her HIV status” (Vreeman, Gramelspacher, Giscre, Scanlon and Nyandiko, 2013: 1). The discussion of disclosure emanated when the participants were sharing their challenges in caring for HIV infected adolescents. Three participants in the study expressed that apart from dealing with HIV that challenged them; they were also confronted by the challenge of disclosing to the children that they had HIV. Participants reported that after getting advice from the clinic, they had to tell the children they are HIV status themselves. Therefore, the participants had to disclose to the children as it was required by the clinic to do so, to re-inforce adherence to treatment. The participants reported that they were concerned that the children were going to be emotionally hurt after the disclosure and they had no capacity to handle their reaction. Six participants expressed that they kept the child’s HIV diagnosis within the family and to very close significant others. Some participants mentioned that they discouraged their children from telling their peers with the fear that other children will treat them differently.

The following are some of the verbatim responses from the participants:

Unesi wathi mandimxelele kuqala ngokwam ukuba ugula yintoni ngoba ukuba uthe weva komnye umntu uyakundizonda. Kwanzima kum ngoba ndandingayazi ukuba ndizakuthini na! Ndathenga izinto ezimnandi, ndalinda kwangokuhlwa. Yangathi uyabethelwa.

Akangomntu ofane abuze ikhadi lakhe le kliniki, wabuza kum zithini iziphumo zakhe, ndathi akhonto ziyithethayo. Ndathi suka! Sapha elokhadi! Kungoba ngelaxesha kwakukhona nenye intwazana kadade wethu eyayizokudlala kuye ndaqonda mandizulise. Sathi xa sisobababini ngokuhlwa, ndathi hayi ke ungeza nalo ikhadi ke ngoku. Kuqala esemncinci sasimxelele ukuba unesifo seswekile. Ndathi kuye ntombazana ndini, kufuneka siye e kliniki sobabaini. Uzakunikwa kengoku ezinye ipilisi, ziyatshintshwa ezi ubuzitya. Ndambuza, uyayazi umama wakho wabulawa yintoni? Wathi hayi andiyazi. Ndabuza uyayazi utata wakho yena wabulawa yintoni wathi hayi andiyazi. Ndamxelela ukuba babenalentsholongwane kagawulayo. Ndathi ke umama wakho wakuncancisa, kwakufunekanga engazange akuncancise, wasuleleka kengoku njalo. Ngoku ke uzakutya ezi pilisi ubomi bakho bonke. Zange abonakale akhathazekile nokukhathazeka oku, ndandicinga ukuba uyakuba rongo. Aa akabina niks. Emva koko saya ekliniki. Kwabuzwa kuye ekliniki umakhulu ukuxelele ntoni, wachaza (kusitsho umakhulu oneminyaka eyi 73).

(I was told at the clinic I should disclose to her myself because if she hears her HIV status from someone else, she will never trust me again and it will break our relationship. It was difficult for me. I bought eats and waited until the evening. She was suspicious, she asked me where her clinic card was and she had never asked me before. She asked me what are her clinic results and I said there is nothing that they show. I said give me back that clinic card. At that time her cousin was at home with us visiting and when we were alone in the evening, I told her she can bring the clinic card. When she was younger we told her she was suffering from diabetes. I said to her we must go to the clinic together because she will be started on another treatment. I asked her if she knew what killed her parents and she said no. I told her that her mother breastfed her and that is how you got infected with HIV. I told her she will have to take tablets for the rest of her life. She did not look worried at all, although I thought she will be devastated. She never did! After that we went to the clinic and the nurses asked her what did I tell her, and she told them, said the 73 years old grandmother).

Consistent to the findings, the majority of caregivers rely on clinical support for disclosing the HIV diagnosis to the child. Clinic personnel assess the child's readiness for disclosure and determine the appropriate time for telling the child. (Merzel, van Devanter & Irvin, 2008: 4). Santamaira *et al.* (2011: 258) recommended that adolescents who are living with HIV must be informed of their diagnosis so that they get empowered to tackle issues of their illness, consider consequences of their sexual behavior and participate in their own medical treatment.

One participant shared how difficult it was for her to disclose to the child that she was infected with HIV because she was concerned about how it will affect her emotionally:

Ndisandula ukumxelela kakuhle-kakuhle kulonyaka uphelileyo kuba ebuza uzityela ntoni ezi pilisi. Bekade ndimoyikisela ngoba apha ekudlaleni nabanye abantwana, ebekhe andixelele ngabantwana abathuka abanye abantwana abachaphazekileyo; ndiqonde kengoku ndiyamonqena, ndiyamoyikisela andifuni ave kabuhlungu.

(I just disclosed her diagnosis to her fully last year because she was asking me what she is taking medication for. I have been over protecting her because she once shared with me that when they play with other kids, others insult those who are infected with HIV; I then thought I should protect her because I do not want her to get hurt).

Edward, Reis and Webber (2013: 1) indicate that parents fear the unknown situations or topics that arise if they talk about HIV. Parents find it difficult to talk about topics about safe sex and HIV as their parents never talked to them about those. Demmer (2011: 877) in his study argues that, caregivers' concern is their lack of skills to communicate effectively about HIV with their children. He further states that in his study primary caregivers are concerned about the reaction of children and entrenched stigma as a result of that they choose not to disclose to the children. In this study one participant expressed that she preferred to keep the HIV status of her two adolescents within the family and discouraged them from telling their peers due to the fear that they might be stigmatized.

Sibaxelele ukuba lo ngumcimbi wethu apha endlini qha kwaye nabo bonwabile ngoba ke iitshomi zabo akukho nto ziyaziyo, nabo abohlukanga kwabanye abantwana (kutsho umakazi oneminyaka eyi-47).

(We told them that their sickness is a family matter; they are happy because their friends do not know anything and they are also not different from other children, said the 47 years old aunt).

Li *et al.* (2010: 753) assert that adolescents keep their HIV status a secret to their friends; their secrecy is motivated by the fear of stigma. HIV disclosure to potential

partners is recommended for sexually involved individuals to be able to take precautionary measures in order to decrease the risk of HIV transmission including transmission of ART resistance to partners (Santamaira *et al.* 2001: 258).

Primary caregivers raised poor understanding of HIV and lack of knowledge to deal with the adolescents emotional problems as one of the challenges that they face.

3.3.1.6 Sub-theme 6: Challenges related to finding out about HIV infection and lack of skill to deal with adolescents' emotional needs

This sub-theme emerged when the participants were asked what they understood about HIV and antiretroviral treatment. The participants shared their first encounter with HIV; their reactions when they heard that the children had HIV; and how they dealt with the situation. Based on what was shared by the participants, the children in this study contracted HIV in different ways. Some were infected perinatally, through their sexual encounters and others through rape or child sexual assault. Participants also shared that the adolescents had some emotional problems that they felt they were not equipped to deal with.

Two participants shared their initial encounter with having a child who has HIV infection in the family that their challenge was to look after a child who had HIV without any knowledge about the disease. The participants also expressed that they were shocked because all they knew at the time their children were diagnosed with HIV, was that a person who has HIV does not live for long. None of the participants indicated receiving on-going or long-term emotional support or counselling other than the support from the professionals such as Social Workers for Social Grants, and one case that was referred to the Psychologists for the child who was raped at a young age. The support they had was clinical which they got from the nurses and doctors that mostly focused on health related issues or clinical management of HIV related diseases.

The following are the participants' comments:

Kuqala ndaziva kabuhlungu kwaye ndothukile kakhulu ndakuva ukuba umntwana wam nomzukulwana wam bachaphazelekile yi HIV ngoba ngelaxesha sasisazi ukuba umntu onentshoolongwane akaphili xesha lide.

(At first I was shocked and hurt to when I heard my granddaughter and daughter were HIV positive because at that time all we knew was that a person who is infected with HIV does not survive for long).

Ndandikhathazekile...into eyayingumceli-ngeni kum yilento yokugulelwa ndingayazi ne HIV, ndiqala ukusibona esi sifo, abe engumntwana omncinci egulayo...Ndandisoyika ndingayazi ukuba mandithini ndingenalwazi.

(I was so worried...What was most challenging for me was to have a sick family member who had HIV, and yet I had no knowledge of the disease, my grandson was still very young and sick...I was scared and I did not know what to do as I had no knowledge).

Different research studies highlighted that caregivers have not been the focus in the fight against HIV/AIDS, as well as the intervention strategies for children who are infected and affected with HIV/AIDS. Richter, Sherr, Adato, Beslay, Upject, Desmond, Drimie, Haour-Knipe, Hosegoed, Kimour, Madhavan, Mathambo and Wakhweya (2009) cited Desmond (2008) and Wakheyva, Dirks & Yeboah (2008) who argue that families provide care for children in a natural and sustainable way. Thabethe (2011: 790) is also of the same opinion that the needs of the caregivers are often ignored, while too much focus is on people who are living with HIV. He further argues that, the burden of care for people who are living with HIV cannot be shifted entirely to the community with the false assumption that caregivers are able to cope. In his study, he suggests the necessity for a model of care geared towards addressing the plight of caregivers.

All nine primary caregivers that were interviewed in the study reported behavioural, psychological and/or emotional problems with the adolescents that they cared for. Their problems varied in their negative impact to the caregivers, as some were

temporal challenges and others were on-going and more serious as they posed danger in the adolescents' lives. Primary caregivers were struggling to help the adolescents to cope with their emotional and psychological pain.

The following are some of the verbatim responses from the participants:

Lo mntwana ungumntwana ovayo kakhulu, kodwa isimilo sakhe siye saguquka kakhulu kunyaka ophelileyo akube exelelwe isigulo sakhe. Ubuya ebusuku endlini, ubuya naxesha liphina. Xa ndithetha naye ufuna ukundiphendula nanjanina, akasandihloniphi. Athi tata kaloku nawe bendikuthembile ithe kanti akundithandi. Kanti ubundifihlela into enkulu kangaka...Ndaxakwa ke nam, ndiyazama ukumbonisa qha andiyazi noba unalento yokuba unentsholongwana, akazokuphila ixesha elide.

(He used to be a good boy; his behaviour changed last year after he was told his HIV status. He comes home late. When I talk to him about that, he does not show any respect, he just talks anyhow... I am also confused; I do not know what to do. I try to show him the way but I do not know whether it is knowing his health HIV status and that he will not live for long that is affecting him).

Uqale ukungamameli ngo 2011, wathi chatha ngo 2012. Kuqala ndacinga uzakuba right ndiqonda kungokuba nje esaqala ukufikisa. Uhlala ezitshomini, sihamba simfuna nomnakwabo, sishiye nemiyalezo nasezitshomini zakhe ukuba bamxelele agoduke xa bembonile. Ndizamile ukuthetha naye ndimthibaza kodwa naleyo khangence.

(She started misbehaving in 2011 and she got worse in 2012. At first I thought she is entering adolescence and she will be fine. She left us at home. Myself and his younger brother went looking for her, leaving messages with her friends that when they see her she must come back home. I always tried to talk to her, trying to show her the way but that did not help).

Kudala engumntwana onomsindo none stress oko emva kokuba wadlwengulwa kula mjikelo wokuqala. Wadlwengulwa kabini; okokuqala wayesese Lower Primary kwaye wayesemncinci kakhulu ngelo xesha. Waphindwa kwakhona eseHigher Primary epha kwiminyaka eyi-13 kodwa wayengekabina mntwana ngoko...Ungumntu one stress umjongile nje (kutsho umama wentombi eneminyaka eyi-45).

(It has been a while since she has been stressed ever since she was raped the first time. She was raped twice; the first incident occurred when she was in Lower Primary and she was still very young. She was raped again when she was in Higher Primary when she was 13 years old and that was before she had a child... Even when you look at her you will see she is stressed, said the 45 years old mother).

Ubanomsindo xa ndimnqanda kwezi zinto zigwenxa azenzayo kangangokuba ngoku ndimncamile (kusitsho umakazi oneminyaka eyi 50).

(When I reprimand her when she is misbehaving, she gets very angry, said the 50 years old aunt).

Adolescents with HIV do not only face the problem of accepting their HIV status, they also have to cope or deal with the challenges of taking the life-long treatment. The challenges that are presented by adolescents with taking treatment have been discussed in Paragraph 3.4.1.4.

The 75 years old grandmother of a 12 years old child whose parents died a year apart shares how much she sees her grandchild suffer emotionally at times as a result of losing both her parents at a young age.

The participant commented as follows:

Sihlelisene kakuhle, qha nto kunayo ikhe ifike lanto yabazali bakhe. Umbone ukuba u 'wringo', qha ke ndandisele ndixelelwa ukuba kuzakukhe kubekhona elaxesha loba kukho umnyuphu. Uyibone ukuba inomnyuphuse lento. Qha ke mna ndihle, ndingamhoyi xa ndiyibona ba isafikile lento ithe nyuphu (kutsho umakhulu oneminyaka eyi 73).

(We live in peace; it is such that sometimes I can see the loss of her parents affects her emotionally. I would see that she is not well but I was warned that she will have those moments whereby she is moody and sad. I calm down and ignore her when I see she is in a bad mood, said the 73 years old grandmother).

Adolescents are an emotionally vulnerable group and the way in which they will respond to their disease status can never be predicted (Santamaira *et al.* 2001: 258). In the study that was conducted by Li *et al.* (2010: 753) adolescents describe HIV as a physically and emotionally painful experience and that they felt angry and fearful about the virus. The life-long nature of the illness is distressful. The challenge for family members who have to take over the care of a child who is infected with HIV after the parent(s) die is to help the child to cope without feeling rejected (Demmer, 2011: 877). Adolescents also have sad memories of their lost parents and big questions for the future regarding their health, education, carrier and marriage (Naswa & Marfatia, 2010: 2).

Another challenge that was raised by primary caregivers is the fact that the caregiving role was affecting their health.

3.3.1.7 Sub-theme 7: Challenges related to primary-caregivers' struggles with own poor health while they have to care for adolescents infected with HIV

All the participants reported health problems which they related to the stress of primary caregiving. The participants suffered from different health problems. The following are some responses that were shared by the participants:

Yhuuuu, wethu nangoku nditya ipilisi ze high-blood pressure. Bekhe ndalaliswa iintsuku ezintathu esibhedlele, benexhala abantwana nangoku ndiphaya bamane bendifownela bendibuza ndinjani, ndiqonde ndizakubothusa ndithi kubo ningaphindi nindifownele ngoba nifuna ndife, andindikhathalelanga.Xa ndicinga ngalo uyintombi andiziva mnandi.Abantu bathi mandingazikhathazi ngaye, mandingacingi kakhulu ngemeko yalo mntwana.

(I take high-blood pressure treatment. I was recently admitted for three days at the hospital and the children were so worried. While I was there, they kept on phoning me asking how do I feel, and I would just scare them and say stop calling me because you want me to die; you do not care about me... When I think hard about her situation, I do not feel well. People plea me not to worry much about her and ask me not to think too deep about her situation).

Impilo yam ayikho ntle, ndingumntu okhuthelayo umthetho lo wam kwaye yonke into yalapha endlini imelwe ndim. Ndikhathazwa ngumqolo oqaqambayo kwaye andisazi isizathu. Amajoni am omzimba aphezulu kakhulu kodwa ndsezintlungwini”, kusitsho umama oneminyaka eyi 45 (enobuso obunxungupheleyo).

(My health is not good at all. I am normally a hands on person... I am suffering from a terrible headache because everything depends on me. My CD4 count is very high and I do not know why I am always in pain, said the 45 years old mother said **(with a sad face)**).

Yhuu ndandi wrongo (ekhathazekile), ndandikhathazekile, sasingayazi thina I HIV ngoko. Andifuni kuxoka ndandicinga ndim oyakubhubha kuqala. Iswekile yam ndayifumana ngeloxesha.

(Yhuu I was not feeling good about their sickness **(looking worried)**, we did not know HIV then. I do not want to lie; I thought I was going to die first. I started suffering from diabetes at that time).

Caregiving responsibility takes an overwhelming toll on the physical and psycho-social well-being of caregivers. The caregiving role has psycho-social and economic effects on an individual (Jankey & Modie-Moroka, 2011: 219). The argument by Toseland (2004: 1) and Evans and Thomas (2009: 111) in the literature review in Chapter One is also of the same view that caregivers' strain can have negative effects on primary caregiver's health. As the family caregiving model suggests, Meyiwa (2011: 166) citing (Macklin 1987) who adopted its principles for his study with it; he argued that it is not only the life of an individual that is challenged, but an entire circle of people who are also profoundly affected. They are like the main victims also; they need care and support. The above argument by Macklin (1987) is and suggests that what happens or affects one family member can affect the rest of the family. President Barack Obama made a press statement that acknowledged caregivers' "labour of love". He stated that the research discovered that caregiving can result in caregivers' physical, psychological and financial hardships. He commended the caregivers for putting their own health and well being at risk while assisting their loved ones. He further recommended a family caregivers support programme whereby the caregivers will be provided with information, assistance, counselling, training, support groups and respite care (Obama, 2010: no page number).

In spite of all the challenges experienced, caregivers do find ways of coping that will be highlighted in the discussion of the second theme that emerged.

3.3.2. Theme 2: Helpful assistance that made primary caregiving easier

More insight was gained into the participant's coping mechanisms when they were asked "what is helping you to cope with your role as the primary caregivers of an HIV infected adolescent?" The probing question was asked in order to find out more about the resources that helped the primary caregivers. The participants were asked: "what community resources are available to assist you in your primary-caregiving role of an HIV infected adolescent?" Five sub-themes emerged in the responses to these questions. The following are the sub-themes that were stated by the participants: training and support of primary caregivers to understand more about HIV infection, a healthy lifestyle and treatment requirements; taking responsibility of taking his/her own medication; available community resources helped primary caregivers to cope; good and supportive relationship between the primary caregivers and the adolescents enabled the primary caregivers to provide the structure that benefits the HIV infected adolescent; and social support and prayer enabled acceptance of the situation.

3.3.2.1 Sub-theme 1: Training and support enabled caregivers to understand more about HIV infection health requirements, the treatment and to cope better

This sub-theme emerged when the primary caregivers were asked "what helped you as the primary caregiver to cope or overcome the challenges, the frustrations and the fear of caring for an HIV infected child?" All participants expressed that the education they are getting at the clinics, awareness talks that were organized by the employer and television programs gave them the skills, knowledge and confidence they now have.

The following are some of the participants' responses:

Ndixelelwe naye uxelelwe ukuba kufuneka ayitye I treatment ubomi obu bakhe kungenjalo uzakugula afe (kusitsho umakhulu oneminyaka eyi 73).

(I was told and she was also told that she must take her treatment for the rest of her life or she will get sick and die, said the 73 years old grandmother).

Ndafundiswa ekliniki ukuba kufuneka engumntwana oziphetha kakuhle, atye ukutya okuya egazini kwaye alandele ezi zingcebiso azifumana kumaziko empilo. Nam ke ndiyayibona lonto apha kuye ukuba ziyamnceda kakhulu ezi pilisi. Ndiyambona ukhula kakuhle, unxibelana nam ngempahla (kusitsho utata oneminyaka eyi 59).

(I was taught at the clinic that he must behave, that he must eat healthy food and follow health instructions. I can also see that in him because the treatment is helping him a lot. I can see he is growing up well and he is wearing the same clothing size as mine, said the 59 years old father).

The findings are consistent with those of Santiesteban, Castro, Colvo (2012: 1) who suggested a need for communication skills training, that primary caregivers need in their efforts to discuss HIV related information with adolescents. The participants in their study noted that through the education they received from health care facilities when they were confronted with the life threatening disease, they gained some insight about HIV/AIDS. Prat (2000: 6) highlighted that knowledge is empowering – it gives people confidence, control and choices in life, and it has lasting value. Thus training (including regular refresher courses) plays a central role in the management of stress and burnout among carers. Casale, Wild and Kuo (2013: 1204-1205) in their study of HIV positive caregivers perspective on the role of social support for health, found instrumental support (material items or other forms of practical assistance), information support (e.g. advice), appraisal (constructive feedback) and emotional support (e.g. love care and comfort) to be crucial in helping primary caregivers of HIV infected people.

3.3.2.2 Sub-theme 2: Adolescents taking responsibility of takings his/her own medication

This sub-theme emerged when the participants were asked to share their current experiences with their adolescents in taking treatment. Three participants reported that it became easier when the children became more responsible and were able to

take their own medication as it relieved some of the burden and their role was to monitor that. The other nine participants indicated that their adolescents' had challenges with taking their treatment (as indicated in 1.1.3). The participants commented as follows:

Naxa ndingekhoyo akanangxaki, uyakwazi ukuzityela ipilisi zakhe ngoba wafundiswa ngo nesi nam ndiyamjonga.Lonto yenza izinto zibelula. Siqhubana kakuhle...

(When I am not at home she has no problem of taking her medication of her own, she was taught at the clinic. It makes thing easier. We are doing very well...)

Uyazithathela ipilisi...akananiki ngxaki (kusitsho umakhulu).

(He takes them on his own...he does not give me problem, said the grandmother).

Sabafundisa ukuthatha ipilisi inguye nomntwakwabo ngoba ke bakhulu ngoku, kwaye bayakwazi ukufunda. Noko ngoku ipilisi abayityayo inye umntu uyithatha kanye qha kwaye yenza izinto zibe lula.

(We are teaching them to take their treatment now that they are older and they are able to read. At least now they take the treatment only once a day which makes things much easier).

The findings of this study are consistent to those of Merzel *et al.* (2008: 985) who studied adherence to antiretroviral therapy among older children and adolescents. The findings from his study are that “adherence to antiretroviral regimens among older children and adolescents are shaped by the interplay of factors which fluctuate across situations, and as a child matures.” Patients need to be involved with their treatment decision-making. They have to be free to discuss their treatment decisions with their provider as those decisions have both personal and health related consequences that should be communicated by the patients (i.e. medication side effects and lifestyle inconveniences). If these issues are not communicated they may act as barriers to antiretroviral treatment medications (Marelich, Roberst, Murphy & Callari, 2002: 17-18).

Another help that was mentioned by primary caregivers that helped them in their role is the community resources.

3.3.2.3 Sub-theme 3: Available community resources helped primary caregivers to cope

This sub-theme emerged when the participants were asked a probing question that asked them to identify the resources in their community that helped them to cope. The participants expressed that they benefited from the community resources although some of those community resources are no longer offering those services. The participants mentioned that they feel happy too when their children are happy. Some primary caregivers were not familiar with the local resources to assist them in their caregiving role. They found personal strength and spiritual fulfillment to cope with their problems. The participants in the study were exposed to the clinical care and management of HIV. They were also familiar with the financial aid of government social grants especially the Care Dependency Grant which was known by all of them although very few were receiving it.

The following resources were accessed by five participants for their children which they found to be useful as they helped them in the time of need: Raphael Centre (lifeskills education, support group and food parcels), Health Development Forum (food parcels), SASSA (social grants), Department of Social Development (for foster care), Hospice support visits and support groups, Department of Health (clinical care and awareness education about HIV and Child Welfare (foster care).

The following are comments made by the participants:

Pha eRaphael Centre ngelaxesha bendihamba kuyo bebebathatha abamtwama bethu babafundise ngamanqaku obomi. Kanti mva nje bekukhona abafundi base Rhodes ebesenza iproject bazokubaboleka bahamba nabo babafundisa malunga ne HIV...Ngoku awasekho loomancedo, kusitsho umakazi okwanguye nomama wabantwana abafikisayo ababini abaphila nentsholongwana kagawulayo.

(At Raphael Centre when I went there they used to take our children and teach them lifeskills. Even after that, there were students from Rhodes University who were doing their project who came and asked for our children to take them and teach

them about HIV... They no longer offer those services, said the 50 years old aunt who is also a mother of HIV infected adolescents).

The same participant commented as follows:

Besifundiswa umsebenzi wezandla kwakunye namanqaku ababesifundisa wona malunga nokumelana nengxaki zobomi. Ezo zinto bezizigcina ingqondo zethu zixakekile kwaye izinto ababesifundisa zona bezisanceda sikwazi ukuziphilela umzekelo ndafundiswa khona ukwenza imiqamelo. Babebathatha abantwana bethu bayokubonwabisa, xa bebuyayo babuye bonwabile bebalisa izinto ezimnandi kubemnandi nakuthi. Ndiyowaba xa ndisazi umntwana wam wonwabile. Yehlisa nelaxhala nentlungu endicinga unayo yokuzazi ukuba uphila nentsholongwane yeHIV.

(We were taught hand work and other lifeskills. Those things used to keep our minds occupied and the skills they gave us helped us to be able to earn a living, for instance we were taught to make pillows. They used to take our children and entertained them and they came back with great excitement telling us what they did. I become happy when I know that my child is happy. It relieves the pain of knowing that your child is living with HIV).

Bakhona no Nontlalontle abamane besiza apha endlini owase Child Welfare nase Hospice. Uyeza owase Hospice kuba bekhe ndagula banexhala ukuba lomntwana akazokuba namntu wokumjonga.

(There are social workers from Child Welfare and Hospice who come to our house. The one from Hospice visited because I was sick and they were concerned as to who was going to look after my grandchild).

...ndingalo ulwazi emva koba onesi bandifundisile e kliniki(kusitsho umakazi oneminyaka eyi 40).

(...I have some knowledge because nurses taught me at the clinic, said the 40 years old aunt).

Lukhona ngoku ulwazi endinalo ngoba siyafundiswa ekliniki(kusitsho umakhulu oneminyaka eyi 60).

(I do have some knowledge now because they teach us at the clinic, said the 40 years old grandmother).

Koen, van Eeden & Rothmann (2013: 155) maintained that, there are currently no conceptual frameworks or models available regarding the psychosocial well-being of families in a South African context. They recommended that the model that was formulated in their study of a model for psychosocial well-being of families in a South African context be further operationalized, evaluated and validated through research. Bejane, Havenga, and Van Aswegen (2013: 78) in their study of primary caregivers' challenges related to caring for children with HIV in a semi-rural rural area in South Africa, recommended holistic health services that should include services addressing the health of primary caregivers, a 24-hour government sponsored telephonic support line where primary caregivers can access information (for example on dealing with diarrhea or the side effects of ART) to support primary caregivers who are caring for HIV infected children. They also suggested that the process of accessing grants should be improved. In addition, the structures and processes to enforce financial responsibility by parents (specifically fathers) should be a government priority. Eneh (2010: 16) in his study that assessed the support service needs of primary caregivers of HIV and AIDS infected children, identified emotional and psychological services such as training on strategies for breaking bad news to friends and family members, and grief counselling support. Although the study was conducted in United States of America, when taking into consideration the literature review that was conducted for this study, the needs of their primary caregivers of HIV infected children are also relevant in the South African context. He also suggested social support services such as basic support of emergency food supply, housing or home repairs, assistance with household items such as furniture, stoves, refrigerators and beds, clothing, transportation to and from medical appointments, auto insurance, car repairs and maintenance, parental education on HIV, parenting coaching and mentorship, planning for the future, home health care techniques, resource on patient-parent network and support groups, legal protection and child health advocacy, child care assistance such as help with household tasks.

In spite of the challenges that are presented by the adolescents, good and supportive role between them and their primary caregivers are a good foundation for the fruitful relationship.

3.3.2.4 Sub-theme 4: Good and supportive relationship between the primary caregiver and the adolescent enables primary caregivers to provides a structure that benefits the HIV + adolescent

The participants were asked how their relationship was with the adolescent(s) they were caring for. Some participants had a very good relationship with the children they were caring for, apart from the general challenges they experienced as adults who had the parenting responsibilities to those children, e.g. financial problems and the fear of the child being stigmatized by others should they know that they are infected with HIV. Two participants who had a good relationship with their adolescents highlighted that positive and honest conversation between the adolescents and the primary caregivers is a strong foundation for a good, healthy and solid relationship.

The following are some of the comments from the primary caregivers:

Sihleli kakuhle. Ngabantwana abamamelayo, xa umntwana ephazamile uyakwazi ukuthi hayi kuye, acele uxolo kwaye angayiphindi nyani lonto. Bangabantwana ababamelelayo (wayiphinda ukuyithetha); phakathi evekini baya eLibrary kude kubethe u 6 ngokuhlwa, ngolwesiHlanu bayaphumla nangoku bakhaphe omnye umntwana.NgemiGqibelo siya enkonzweni (kusitsho umakazi oneminyaka eyi 44).

(We live very well. They behave well and when they realize they have done something wrong they apologize and not repeat it again. They behave well! During the week they go to the Library until 6pm, on Friday they rest, even now they have they just left the house, they are accompanying another child. On Saturdays we go to church, said the 44 years old maternal aunt).

Uyabona apha phakathi evekini andinayo ingxaki konke konke ngoba uvuka kwangethuba silungiselela kuba ezakuya nasesikolweni.Xa iyimpela-veki kufuneka nditshintshe amaxesha akhe okuthathatha i treatment ngoba akakuthandi ukuvuka.Naxa ndingekhoyo akanangxaki, uyakwazi ukuzityela ipilisi zakhe ngoba wafundiswa ngo nesi nam ndiyamjonga. Siqhubana kakuhle.Uyatya ndimthengele nokutya okusempilweni.

(You see during the week we have no problem at all because she wakes up very early in the morning to get ready for school. During the weekends, I change her medication time because

she does not enjoy waking up to early. When I am away she has no problem of taking treatment on her own because the nurses taught her and I monitor her. We are fine. She has a good appetite and I buy her healthy food).

Parents' efforts to monitor, control, and supervise their adolescents' school performance and future aspirations contribute to influence their adolescent's behavior in a positive way. There are also positive benefits for adolescents who are involved in the community, religious functions and peer interaction (Amatoeng & Sabiti, 2013: 135). Healthy families influence the emotional, physical and social well-being of its family members in a positive way. Healthy functioning families are also better equipped to cope with stressful experiences and deal with unexpected challenges that they are confronted (Koen, van Eeden & Rothmann 2013: 155). Families are the most profound and fundamental social system in influencing child development. Families provide many of the factors that protect adolescents from engaging in sexual risk behaviour. Among these are positive family relations, effective communication about sexuality and safer sexual behaviour, enhancing and support of academic functions and monitoring of peers activities (Perrino, Gonzalez Soldevilla, Pantin & Szapocznic, 2000: 81).

In addition to the positive relationship between the child and the adolescent, social support and prayer also enabled the primary caregivers to cope.

3.3.2.5 Sub-theme 5: Family (social) support and prayer enabled acceptance of the situation

Five participants expressed that their religious beliefs are their source of strength when they are feeling overwhelmed with their role, confronted with fears, challenges and when they did not know what to do or where to go for help. The participants reported that they found comfort in prayer.

The following are the participants' responses:

Into endincedayo ukuba ndimelane neengxaki zam ngumthandazo, ayikho enye into. Ukuba uyaguqa ngedolo ayikho enye into, uThixo uyakupha.

(What is helping me to cope is prayer, there is nothing else. If you go down on your knees, God will give you what you ask for, said the 73 years old grandmother).

...UThixo uneendlela zakhe akamyekeli umntu Wakhe. Imingangaliso isenzeka nizibone nityile noxa ke singakwazi ukutya okutya okusegazini njngokuba sifundiswa.

(...God has his ways and does not leave His people. Miracles still do exist. We manage to have something to eat even if it is not the healthy food that we are supposed to eat, as we were taught).

Ngumthandazo ondincedayo. Ndihamba icawa ndiphoswe yonke imithwalo yam kuThixo, kwaye nditya neepilisi zam...Niyathandaza ndizive ngcono emva koko.

(Prayer keeps me going. I go to church and I give all my burdens to God and I also take my treatment regularly...I just pray to God and I feel better afterwards).

Ndandicinga uzakusweleka, ndamcela uThixo amgcine, nasecaweni babendincedisa bendomeleza...Wandipha uThixo ngoba ke nanku ekhulile ngoku (kusitsho umakhululu oneminyaka eyi 63).

(I never thought he would make it, I prayed to God too keep him alive, my church members and my Priest supported me a lot. God helped me because here he is now, he has grown and has good health, said the 63 years old grandmother).

Lo mntwana wakhe ukhula ngo Nkosi sikelela...NguThixo owenza izinto zenzeke ngoba ndisuke ndimbone sezibuyela lomntwana kwezohambo zakhe.

(Her child grew up with God's mercy... It is God who make things possible because sometimes I see my niece coming back home from her ways).

The findings of this study concur with those of other studies that revealed that religious beliefs and spirituality has strengthened the caregivers when they are confronted with challenges of looking after family members who have HIV/AIDS related sickness (Demmer, 2011: 877). Kimani-Murage, Manderson, Norris and Khan (2010: 25) concurs with that counseling from health providers and personal spirituality helped caregivers accept the child's status and to cope with health implications. Richards, Wrubel, Grant and Folksman (2003: 2) explain in their study that "prayer is the central activity of religious and spiritual practice and is a vehicle for personal connection to the sacred." "Spiritual care which conserves the dignity of each client and their families can help those who would normally have suffered through stigmatization and guilt imposed by themselves for family and community members, to acquire hope in an otherwise seemingly hopeless situation" (Van Wyngaard, 226).

The participants who were interviewed in the study who had a strong family (social) support coped better with challenges they encountered with primary caregiving for HIV infected adolescents. Social support refers to "a measure of how much help you can count or believe you can count on, from your friends and family, especially in crises and hard times." (Casale, Wild & Kuo, 2012: 260)

The following are participants their views:

Inkxaso ndiyifumana kusapho lwam endihlala nalo apha endlini qha...Sihlala sonke apha endlini silusapho, nomama wakhe ukwahlala apha ndikwajonge ne treatment yomntwana phofu ndincedisana nomama wakhe (kusitsho umakhulu oneminyaka eyi 58).

(I get support from my family that lives with us... We all live together as a family and the mother lives with us and we are both involved with the child's treatment, said a 58 years old grandmother).

Utata wakhe ungumntu okhathalayo, ngumntu ofownayo abuze impilo.Omnye umntu omane emkhangela ngudade wabo, amtsalele umnxeba qha ke akabina namba enye uyazitshintsha-tshintsha.

(Her father is a very caring person, he phones and asks about her health. Another person who cares about her is her sister. She phones but sometimes she does not have her number because she keeps on changing cellphone numbers).

Merzel *et al.* (2008: 982) highlighted that social support can be an important source for primary caregivers in dealing with multiple challenges in caring for a child with HIV. On the same note, Casale *et al.* (2013:1 205) found that social support is associated with better outcomes among caregivers of HIV infected children that it may be an important component of intervention aimed at safeguarding the wellbeing of caregivers. According to Hayer *et al.* (2010: 234) “psycho-social support can help a person to adjust to an illness and improve psycho-social well-being, the quality of life and the general health.” A wealth of global literature suggests that social support can play an important protective role for the well-being of caregivers of children and the children in their care. “In South Africa, where the caregiving burden is intensifying and the prevalence of HIV and other physical and mental health disorders is elevated, strengthening social support services may be the key to more effective carers and child health.” (Casale & Wild, 2012: 260-261)

One participant who has no family support and was completely alone in the primary caregiving role and shared that what motivated her was her neighbour’s moral support.

Nabamelwane bangabantu abamamelayo, nabancomayo ukuba siyakwazi ukunyamezela (kutsho umama). Sizibona nathi sinyamezele kulento singabantu abakhonzayo abathembe uThixo! (kutsho umakhulu womntwana)

(Our neighbours are people who listen and they praise us for being able to hang in there. We just hang in there and endure the pain. (Both grandmother and mother of 19 years old girl said that with very sad faces). We are church people, we trust God (grandmother was very tearful at this stage). We trust God, it is not easy! It is not easy!)

The findings concurred with those of Prat (2000: 6) that recommend that for the sake of carers’ morale and self-confidence, they at every level need to know that their work is recognized and valued.

The participants were asked to share a positive thing or experience about being the primary caregivers of HIV infected adolescents. The participants who reported earlier that they had no good relationship with their adolescents also had some positive things that they recalled or shared about their primary caregiving role. They reported that they are proud of caring for HIV + adolescents and able to enrich each other's lives.

Three participants shared their positive experience about the caregiving role. The following are the participants' responses:

Yena ndimenza umntwana wam (encumile). Akho nento andihlupha ngayo. Uyandincedisa nalapha endlini. Naxa kubhe bhee endlini bendishiyile, ndishiyeka naye lo uneminyaka eyi 13 anancedise ngento yonke (kusitsho umakazi oneminyaka eyi 38).

(I think of him as my baby **(smiling)**. He does not bother me about anything. He helps me a lot with cleaning the house. When they all leave the house on weekends, he remains with me, said the 38 years old paternal aunt).

Sihlelisene kakuhle kakhulu, singathi singabahlobo ungumntwana omnandi (kusitsho umakhulu oneminyaka eyi 58).

(Our relationship is good, we are like friends. She is a sweet child, said the 58 years old grandmother).

Unelizwi elimnanci, uyacula, soze ulilibale ilizwe lakhe ukuba mnandi kwalo. Nasesikolweni babemsebenzisa kakhulu emculweni ngenxa yelizwi lakhe elimnandi. Unengqondo kakhulu, beqhuba kakuhle nasesikolweni... Ndibaneentloni ngangendlela andithuka kakubi ngayo (kusitsho umakhulu oneminyaka eyi 73).

(She has a very beautiful voice that you will never forget when you hear it. Even at school she was involved in music because of her beautiful voice. At school she is very brilliant... I get so embarrassed about the way she swears at me, said a 73 years old grandmother).

Kumnandi ngoku xa sele bekhona ngoba benza nezinto ezimnandi. Yaphela nalanto sasinayo kuqala yokoyika ngoba ke yayasoyikeka le ngculaza kodwa ngoku zizinto ezingenamsebenzi. Ngangendlela endivuya ngayo, ndivuyiswa kukuba ngobukho babo ndifunde ukuba umntu onengculaza uphathwa njani. Ndikhe ndibawele nomnye

umntwana onengculaza akhe azokuhlala kum, afumane lento ifunyanwa ngaba bam abantwana...Kumnandi ukuhlala naba bantu (ehleka kakhulu) (kusitsho umakazi).

(We enjoy having them because they bring joy in our lives and do beautiful things. We used to be scared of HIV because it was a major threat but now it is no longer our problem. We no longer fear, instead the experience taught us a lot. We now know how to take care of people who are living with it. I am proud to be part of their lives. The experience taught me to know how to handle the situation. When I see other children who are not cared for, I wish they could get the kind of treatment I gave my children. It feels good to live with them **(laughing out loud)** said the maternal aunt).

The study of Jankey and Modie-Moroka (2011: 223) report that the caregiving role provided the primary caregivers of HIV infected adolescents with education, and knowledge they were able to translate into benefits in their everyday lives. He further asserted that, caregiving is regarded as a rewarding experience, especially if rendered to the neediest members of the community.

Through the experience that the primary caregivers acquired in caring for HIV infected adolescents, they were in the better position to suggest the essential services and resources that are necessary to assist primary caregivers of HIV infected adolescents.

3.3.3 Theme 3: Suggestions to assist primary caregivers of HIV infected adolescents

This theme emerged when the researcher asked the participants to identify the services that they thought could be of assistance to primary caregivers. The exercise enabled the primary-caregivers to evaluate their situation as primary caregivers and identify the services that are necessary for primary caregivers who are in positions similar to theirs. Four sub-themes which are to provide care for the carers (emotional care for caregivers); material needs of primary caregivers; children to be re-educated by people outside the family about the importance of treatment; and support groups for both caregivers and adolescents emerged in response to this question.

The following are the sub-themes that were identified:

3.3.3.1 Sub-theme 1: Emotional care of primary caregivers

This sub-theme emerged from the suggestions that were raised by the primary caregivers of HIV infected adolescents about the services that are crucial to assist the primary caregivers who are caring for HIV infected adolescents. Most participants in the study mentioned their need for emotional care and the fact that there is nowhere they go to when they are experiencing challenges in their primary caregiving role. The common kind of support they get is the different social grants that they receive from government. The study reflected without a doubt that so much focus was on the clinical management of adolescents who are living with HIV but the emotional needs of the primary caregivers have not been prioritized. Four participants reflected that the adolescents occasionally receive some emotional stimulation from the local organizations such as Raphael Centre, Rhodes University and other places. None of the primary caregivers who were interviewed in this study ever received individual counselling or in a support group from any of the professionals e.g. Social Workers or Psychologists. When primary caregivers consult with Social Workers, it had been about the welfare of the children in their care.

One participant shared his unpleasant experience with going out for help:

Ndiyaya kwiindawo ezinceda abanye abantu kodwa ndixelelwa ukuba njengokuba mna ndingu Tata ndisaphila akukhonto ndinokukwazi ukuyifumana, banceda abantu abangoo mama abaswelekelwe ngabayeni (kusitsho utata oneminyaka eyi 59).

(I do go to places that help other people but I was told that when as the father I am still alive there is nothing they can do, they help woman when their husbands die, said the 59 years old father).

There is no other disease that evokes such a devastating social impact or threatens the family unit as HIV/AIDS does. Caregivers are characterized as AIDS “unseen victims” or “hidden patients” of the epidemic (Anderson, Ryna, Taylor-Brown, White-Gray, 1999; Schuster, Kanouse, Morton, Bozzette, Miu, Scott and Shapiro. 2000). A

suggestion from an American study on assessment of services for primary caregivers of children highlighted that a comprehensive HIV care response must offer all caregivers unlimited and on-going access to support services information, an assurance of food and nutrition security of full or partial financial compensation, respite care and capacity building opportunities, periodic recognition for their work, respect and supervisory support (Eneh, 2010).

The participants identified material needs of the primary caregivers of HIV infected adolescents as one of the crucial resources that will assist them.

3.3.3.2 Sub-theme 2: Material need of Primary Caregivers

The following are the material needs that were suggested by the primary caregivers of HIV infected adolescents who participated in this study: food parcels with special nutritional products, financial assistance is needed for child's tertiary education after age 18 when grants stop; support groups for both caregivers & children. One participant reported that she had no support from her family, and the family member who lived out of town discriminated against them for having many people in their home who were living with HIV. This participant had a unique need from the rest of the participants as she needed her own place to stay because they lived as a big family in a very small house and that resulted to conflictual relationship. The problems that lead to material needs in the care of a sick child were discussed in Paragraph 3.1.1.2. Orner (2006: 239) in his study of psycho-social impact of caregivers of people living with AIDS mentioned that the respondents wanted to be assisted with "what will make a difference"; the participants mentioned supply of an adequate amount of food, counseling for all members of the household to help them accept the situation, and the training to enable optimal caring work. They also wanted to be acknowledged by the health authorities and other stakeholders for the role they are playing. They felt that their acknowledgment together with other support would have a positive impact on their mental health.

The primary caregivers identified re-education of HIV infected adolescents about treatment and HIV infection as important to emphasize what they teaching them at home.

3.3.3.3 Sub-theme 3: Children to be re-educated by people outside the family about the importance of treatment

One participant raised a need for on-going education for the children. She suggested the importance of treatment education that has to be re-enforced by people outside the family about importance of treatment. Two participants also identified the importance of the information that their children get when they attend the support groups as being crucial to revise their knowledge.

The participant commented as follows:

U right qha ingxaki yam mna naye kukuba xa engekho phambi kwam ekwesinye isikolo uzakuzitya na ezi pilisi ngoba ngoku ufunda u Grade 12 kwaye ukrele-krele ufuna ukuqhubeka afunde. Ndiyafuna ukuba akhe acaciselwe kwakhona ngezi pilisi ukulungiselela xa engasahlali kunye nam.

(He is fine but my concern is when he is not with me as he is now doing Grade 12; he is intelligent and he wants to go further with his studies. I want him to be re- education about treatment adherence, for it to be explained again to prepare him for when he is no longer staying with me).

The findings were consistent with those of Merzel *et al.*, (2008: 984) who maintain that that “adherence support mechanisms need to go beyond reminder systems and devote specific attention to fitting the medication into daily schedules that can include changes in routines, going away from home and being in a variety of social situations.” He further argues that as children are getting older and are able to go out on their own, providers and caregivers need to help them develop solutions to dealing with potential barriers to adherence. The extent to which medication regimens can accommodate rather than interfere with social activities may be an important means of re-enforcing and improving adherence, particularly among adolescents.

Primary caregivers suggested support groups as a resource that benefits them and their children.

3.3.3.4 Sub-theme 4: Support groups for both caregivers and adolescents

The sub-theme also emerged from the suggestions of primary caregivers. Four participants mentioned the support group as the resource that is necessary for the well-being of primary caregivers and adolescents with HIV. Some primary caregivers mentioned that their children attended support groups but there was no support group for them.

The following are the participants' responses:

Ndandihamba i support group, ndikwalilo nelungu lase Raphael Centre...lona olwase Raphael Centre ne TAC alusekho oloncedo (kusitsho umakazi okwanguye nomama wabantwana abachaphazelekileyo oneminyaka eyi 50).

(I used to attend the support group and I was also a member at Raphael centre...the services at Raphael Centre and TAC are no longer available, said the aunt who is also a mother of infected children who is 50 years old).

Xa aba bantwana bekwezi centres, nathi bazali sibalapho, siziva kamnandi xa sidibana nabazali abakwezi meko zethu. I support group yinto apha enokusinceda thina nabantwana bethu (kusitsho umakazi wabantwana ababini abachaphazelekileyo oneminyak eyi 44).

(When our children are at these Centres, us as their parents we feel good when we meet other parents who are in the similar situation. The support is something that can help us and our children, said the 50 years old aunt who is looking after two infected children).

Sikhe sabasa eRaphael Centre kabini badibana nabanye abantwana. Yhuu babuya beyithandile gqith lonto ngoba phaya kuthethwa yonke into kwaye imeko yabantwana iyafana. Babone abantwana ababaziyo, nabafunda nabo abachaphazelekileyo kwaye bonke batya ezi pilisi zinye (kusitsho umakazi oneminyaka eyi 40).

(We have been to Raphael Centre two times and the children met others. They really loved that because there they discuss everything and the children's situation is the same. They saw other children who are in their school that are also HIV positive and they are also on treatment, said the 40 years old aunt).

Hayer, Mabuza, Couper and Ogunbanjo (2010: 234) recommend that individuals can benefit in support groups emotionally through forming new friendships through companionship, through isolation being reduced and through increased self-confidence. They can also benefit through receiving information such as up-to-date information about treatment for HIV/AIDS, coping skills, daily living, and legal aspects. Support groups furthermore provide instrumental benefits through teaching skills and through supporting behavioral change. In the light of the said arguments, the needs of the primary caregivers are in line with what the studies recommend in order for them provide the necessary care for the adolescents that they are responsible for.

3.4 Chapter Summary

This chapter was devoted to presenting the perspectives of research participants as emerged from the data process of data analysis. The participants perspectives were presented by three themes, sub-themes and categories that emerged from the interviews conducted with the primary caregivers of HIV infected adolescents.

The following chapter will focus on the summary of findings, limitations of the study and the conclusions drawn by the researcher and recommendations.

CHAPTER FOUR

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

4.1 Introduction

This chapter constitutes the final phase of this research study. In the introductory chapter, an overview of the research study was presented and the problem statement was described. Chapter Two incorporated the research design and methodology. In Chapter Three, the data that was gathered during the semi-structured interviews with the primary caregivers of HIV infected adolescents, data analysis was done; and themes, sub-themes and categories that reflected their experiences were identified. This final chapter provides the summary of the research methodology and main findings. This chapter also points out limitation of the study, draws a conclusion and makes recommendations based on the finding of the investigation.

The goal of the research was to enhance the understanding of the experiences and challenges of primary caregivers in caring for HIV infected adolescents by means of an explorative-descriptive and contextual study.

Four objectives were formulated in an attempt to reach this goal:

- To describe primary caregivers reaction on finding out about HIV infection of the children in their care and their knowledge and skills to deal with them.
- To explore and describe challenges of primary caregivers of HIV infected adolescents at household and community level.
- To identify resources and support needed by primary caregivers of HIV infected adolescents.
- To provide policy and programme recommendation.

To attain this goal, the study employed a qualitative, explorative, descriptive and contextual design as discussed in Chapter Two of this study. The core findings will be presented in the following section.

4.2 Summary of Research findings

Three themes and the main findings are presented below:

4.2.1 Theme 1: Challenges experienced by Primary Caregivers in caring for HIV infected adolescents

The findings indicate that primary caregivers who are caring for HIV infected adolescents experience a number of challenges such as the negative behaviour of adolescents; financial stressors and poverty; poor social support, HIV stigma and discrimination; disclosure of HIV status; finding out about the infection of the child and lack of skills to deal with the adolescents emotional needs, and primary caregivers struggles with their own poor health.

4.2.1.1 Sub-theme 1: Challenges related to the negative behaviour of HIV infected adolescent

The negative behaviour of adolescents is not a unique challenge but for HIV infected adolescents it poses a threat in their lives. The negative behaviours that the primary caregivers experience with their HIV infected adolescents include the following general adolescents' behavioural problems: adolescents' risky sexual behaviour, having multiple partners, falling pregnant at a young age; alcohol use and abuse; poor school attendance and abscondment. The primary caregivers in this study also experience challenges of adolescents not taking responsibility for their own health.

- **Sexual activity, multiple partners and early pregnancy of HIV infected adolescents**

The behaviour of the adolescents is one of the major challenges that are facing primary caregivers. Adolescents who are infected with HIV engage in sexual

relationships, they have multiple partners and fall pregnant at a young age. Some adolescents in this study have two children before the age of eighteen. The concerns of the primary caregivers about the adolescents' high risk sexual behaviour in this study is exacerbated by the fact that their adolescents are living with HIV, therefore their sexual activities pose a threat in their lives and the lives of their sexual partners. In addition, when they fall pregnant and have babies, the primary caregivers will have an extra burden as they will have to take responsibility of the children.

The literature confirms that the primary caregivers of HIV infected adolescents become frustrated about their adolescents' negative behaviour, and their efforts to discipline them fail (Petersen *et al.* 2010; Leach-Lemens 2012; Perrino *et al.* 2000, Amoeteng & Sabiti 2013; Mashala *et al.* 2012).

- **Alcohol/drug use of adolescents**

Participants in this study reported alcohol/drug use of HIV infected adolescents as one of the negative behaviours they present, which also have negative effects on their lives. Studies reflect that adolescents who are under the influence of alcohol are vulnerable to sexual abuse or may willingly consent to sex. In South Africa, alcohol use and HIV /AIDS are a major problem among adolescents and the use of drugs or alcohol is recognized as a contributing factor in risky sexual behaviour among adolescents (Morjelo, Brooke & Kachieng'a 2006; Morjelo, Brooke, Kochieng's, Makoko, Noko, Parry, Nkowane, Mosha & Saxina 2006 & Fitz *et al.* 2002).

- **Adolescents refuse or do not take responsibility of treatment for his/her own health**

The findings of this study indicate that primary caregivers struggle to keep their adolescents' adherent on antiretroviral treatment and other medication they get from health facilities. Primary caregivers report that their adolescents complain of antiretroviral treatment side effects; they are reluctant to go to the clinic for the reasons that are not communicated clearly to the primary caregivers; they take their treatment as they please without following the instructions given to them; and

adolescents are unstable as they live in different places and others completely refuse to go to the clinic. The primary caregivers reported that they are concerned about the medical consequences as they will become resistant to treatment and eventually get very ill.

Studies reflect that children who are infected with HIV face more treatment compliance challenges than adults who are also infected with HIV due to a number of problems such as emotional, social and medical problems that HIV infected adolescents encounter (Davies, Boule, Faker, Nuttal and Elley 2008; Yeap *et al.*, 2010; Malee, Williams, Mantepiedia, McCabe, Nichols, Sirois, Storm, Farley, Kammerer & PACTG 219c Team 2011).

- **Adolescents Poor School Attendance and Abscondment**

For an adolescent to find out about their HIV infection is a very emotional experience. In general, they view HIV infection negatively and find it difficult to come to terms with living with HIV. HIV infection affects the social interaction of adolescents; it also separates them from their peers as it makes them to feel different from them. They end up dropping out from school as the result of the negative feelings that they experience. Primary caregivers have a responsibility of supporting the adolescent in their care, in good and bad times, like any loving parent would do. When the adolescents who drop out of school grow up, the little education gives them a minimal chance of acquiring good jobs and they even struggle to get employed at all. The primary caregivers are concerned that without proper education they do not have a bright future although the antiretroviral treatment promises better and prolonged lives (Li *et al.* 2010; Petersen *et al.* 2010; Shaffer & Kipp 2007; Richter *et al.* 2009).

4.2.1.2 Sub-theme 2: Challenges related to financial stressors and poverty

Lack of financial support and poverty are one of the major obstacles reported by primary caregivers in this study. Primary caregivers had a challenge of meeting the basic needs of their families and those of the sick children in their care. Caring for a sick individual, especially a child who is living with HIV requires good nutrition and

financial means to access health and welfare facilities on a regular basis. Primary caregivers often have to carry their role without any form of support from Government or non- governmental organizations to provide those essential needs. Most primary caregivers as indicated in **TABLE A** in this report, rely on social grants as a source of income. Some use their income to provide for the needs of the sick children in their care. Different studies concur with the findings that suggest that primary caregiving places financial strain and poverty on primary caregivers (Demmer 2011; Bejane, Havenga, Aswegen 2013; Meyiwa 2011; Makiwane and Mokomani 2010; Petersen *et al*, 2010; Orner 2006).

4.2.1.3 Sub-theme 3: Challenges related to Poor Social Support

The findings of this study indicate that primary caregivers of adolescents who are infected with HIV have a huge responsibility, and they have poor support from their family members or significant others. Caring for an adolescent who presents behavioural problems is alone very demanding, in addition caring for adolescents who are infected with HIV also has its challenges which require primary caregivers attention. Some primary caregivers felt despondent as they had no one to carry on with the caregiving role or who will assist them. The family plays a very crucial role in giving material and emotional support to its members, and without that support the system collapses. The Family Systems Model indicates the interaction between any two family members are likely to be influenced by the attitudes and behaviour of a third family member. The family plays a very important role and different studies reflect that primary caregivers of HIV infected adolescents need strong family support to cope with the caregiving demands (Demmer 2011; Shaffer & Kipp 2007: 599; Orner 2006).

4.2.1.4 Sub-theme 4: Challenges Related HIV Stigma and Discrimination

The findings of this study indicate that beyond the efforts that South Africa has made to conscientise people about HIV and AIDS, the stigma that is attached to the disease still exists. The study revealed that primary caregivers become greatly affected when their children are stigmatized for being infected with HIV. Primary caregivers play a pro-active role to protect the children in their care from being

stigmatized or discriminated against. The primary caregivers of children who are living with HIV become defensive or overprotective to protect the children from any kind of existing, potential harm or ill-treatment. They encourage the children to keep their HIV status within the family as they fear that they will disclose inappropriately to other children who might stigmatize them. The primary caregivers reported that their children have been stigmatized and discriminated by their family members, community members and some government officials. HIV stigma also prevents people from accessing health care services.

Literature confirms that HIV/AIDS is still a highly stigmatized medical condition. The fear of stigma and discrimination attached to HIV/AIDS limits HIV disclosure and hinders accessing support from family, friends, health and welfare services (Singh, *et al.* 2011; Prat 2006; UNESCO 2001; Petersen *et al.* 2010 & Demmer 2011).

4.2.1.5 Sub-theme 5: Challenges Related to Disclosure of HIV status

The participants in this study indicate that HIV disclosure is a very challenging task that they have to go through with their HIV infected children. Children who are living with HIV have to be informed about their HIV infection in order for them to gain the insight about the importance of their medical care, and other important reasons such as living a healthy lifestyle. Primary caregivers reported that they find it challenging to tell children about their HIV status because of their fear of how they will react and that they will be hurt on finding out about their HIV status.

The literature indicates that primary caregivers of HIV infected adolescents find HIV disclosure very challenging as they find it difficult to talk about HIV and sex even if the topic rises (Merzel, van Devanter & Irvin 2008; Santamaira, Doleza, Mellins, Marhefka, Hoffman, Ahmed & Elkington 2001; Edward 2013; Demmer 2011).

4.2.1.6 Sub-theme 6: Challenges related to finding out about HIV infection and lack of skills to deal with adolescents emotional needs

Initially, the primary caregivers were not aware of their children's HIV status and later they found out that they contracted HIV in different ways. Some contracted HIV

through sexual abuse; others were born with HIV through mother to child transmission, and other children got infected through their sexual activities at the adolescence stage. The primary caregivers were shocked and traumatized when they initially found out about the HIV infection of their children. Their understanding of HIV infection was that someone who is infected with HIV gets very ill and eventually dies. The primary caregivers were in a dilemma that they had to take care of children who had the disease they mostly feared and that they thought were going to die. The findings also revealed that the primary caregivers also felt despondent because the children were their flesh and blood. It was also reported that the primary caregivers of HIV infected adolescents do not only have to deal with health of their HIV infected adolescents but also have to deal with their emotional problems because children who are infected with HIV face several challenges such as living with a highly stigmatized disease, taking treatment for the rest of their lives and having lost one or both parents. They are not empowered with skills and knowledge to deal with the emotional needs of adolescents who are infected with HIV.

Different studies indicate that there has been so much focus on children who are infected and affected with HIV and AIDS but their caregivers have not been a focus. The responsibility of care and support for children who are infected with HIV rests on the families although they are not being prioritized when developing the strategies to mitigate HIV/AIDS (Richter, Sherr, Adato, Beslay, Upject, Desmond, Drimie, Haour-Knipe, Hosegood, Kimour, Madhavan, Mathambo & Wakhweya 2009; Thabethe 2011; Majumdar and Mazaleni 2010; Orner 2006; Hosegood, Preston-Whyte, Busza, Moitse and Timaeus 2007).

4.2.1.7 Sub-theme 7: Primary Caregivers Struggle with Own Poor Health

Caregivers of HIV infected adolescents play a crucial role in providing them the care in the most natural way and ensuring that they get the medical treatment they need. The participants in this study indicated that the caregiving role places a considerable demand and strain on them. Participants associated their physical illnesses with the stress they experience. The findings of this study indicate that primary caregiving responsibilities have negative effects on the physical, financial and psycho-social well-being of primary caregivers.

A number of studies confirm the basic assumption of a family systems model that indicated that, in the family context it is not the lives of the individuals who are living with HIV that are challenged by the disease but an entire circle of people who are in the life of the sick family member (Jankey & Modie-Moroka 2011; Toseland 2004; Meyiwe 2011; Obama 2010; Evans and Thomas 2009; Orner 2006).

4.2.2 Theme 2: Helpful Assistance that made Caring Easier

The findings indicate that beyond the challenges that primary caregivers reported about their role, some helpful assistance made the caring role for primary caregivers of HIV infected adolescents easier. Some participants reported that with the help that they received from others and certain organizations, it alleviated their stress and challenges. The participants reported that the following assistance enabled them to cope better: training and support about HIV infection, healthy lifestyle and treatment requirements of the child who is infected with HIV; adolescents taking responsibility of their own medication; available community resources; and a good and supportive relationship between the primary caregivers and the adolescents in their care.

4.2.2.1 Sub-theme 1: Training and support enabled primary caregivers to understand more about HIV infections, health requirements, and treatment in order to cope better

Basic training and support of the primary caregivers of HIV infected children, adolescents and adults who are living with HIV is necessary to give them the skills and the knowledge about HIV, treatment and other health issues that will enable to perform their role effectively and efficiently. The participants in this study report that they felt overwhelmed when they were confronted with having a sick child that they had to be responsible for. They did not have much information about HIV and the treatment. The participants' understanding of HIV was that children who were infected with HIV will die as a result of the infection. The training or information and support they received at the clinic and the health awareness talk, one participant received at work, gave them the insight about how to care for children and people who are living with HIV. Gaining the insight about HIV also helped to ease the fear the primary caregivers had, that their children will get very ill and eventually die and

as a result they now report that they live normal lives with the children in their care. The training and support also gave the participants confidence to be better carers.

The literature reviewed confirmed that there is a need to train and support primary caregivers of HIV infected children to be equipped to deal with day to day challenges they encounter in their primary caregiving role (Santiesteban, Casto, Colvo 2012; UNAIDS 2000; Casale, Wild & Kuo 2013; Orner, 2006).

4.2.2.2 Sub-theme 2: Adolescents taking responsibility of his or her own treatment

The participants in this study indicated that caring for an HIV infected adolescent is easier when the adolescent takes some responsibility of their health, and when they take their treatment responsibly then their role becomes that of monitoring them.

The literature confirms that the factor that contributes to good adherence to treatment is the adolescents' maturity and being involved in decision making for their own treatment (Marelich, Roberst, Murphy & Callari 2002; Merzel et al. 2008).

4.2.2.3 Sub-theme 3: Available community resources help primary caregivers to cope

The participants reported that they accessed the following local services when available: Raphael Centre for life skills education, support group and food parcels; Health Development Forum for food parcels; SASSA for social grants; Department of Social Development for foster care services; Hospice for support visits and support groups; Department of Health for clinical care and awareness education. They also reported that some of the helpful Grahamstown resources that assisted them such as the food parcels from Health Development Forum and the support groups, provision of food parcels by Raphael Centre were discontinued. The available community resources that the primary caregivers mentioned are for the children who are living with HIV and were not targeting them as their carers. It should be noted that the primary caregivers who accessed those services through the children in their care, only about half of the participants of this study received them.

The participants who did not access Grahamstown resources that were offered by different organizations indicated that they did not know where to go for help when they were in times of need. In Grahamstown, there are no known public services or resources that are targeting the primary caregivers of HIV infected children or adolescents.

Different studies highlight the need to provide the primary caregivers of children with the emotional and material resources that will assist them with the caring of the children and adolescents who are infected with HIV/AIDS (Eneh 2010; Bejane, Havenga, Aswegen 2013; Koen, van Eeden & Rothmann 2013).

4.2.2.4 Sub-theme 4: Good and supportive relationship between the primary caregivers and the adolescent provides a structure that benefits adolescent

The behaviour of adolescents as it has been indicated in the previous section of this study is a major challenge for primary caregivers. The primary caregivers who reported having a good and supportive relationship with their adolescents highlighted honest and open conversation with the adolescent as the foundation for their healthy relationship. The healthy relationship between the adolescent and the primary caregivers enabled the primary caregivers to influence adolescents' emotional, physical and social well-being in positive way (Koen, van Eeden & Rothmann 2013; Perrino, Gonzole-Soldevilla, Pantin & Szapocznic 2000; Amoeteng & Sabit 2013).

4.2.2.5 Sub-theme 5: Family support and prayer enabled acceptance of the situation

The process of giving care to adolescent who are affected by HIV causes lot of strain to the primary caregivers and they are often confronted with no resources or support to assist them. The participants in this study reported that caring for an HIV child has its own challenges that are as a result of many factors such as financial problems and poverty, poor support from family, stigma and discrimination and seeing the children very ill and not being able to do much about. During those trying times, prayer kept the participants going and growing from strength to strength.

A number of studies indicate that prayer and strong religious beliefs are a source of strength for carers of people who are living with HIV. (Richards, Wrubel, Grant & Folksman 2003; Kimani-Murage 2010; Demmer 2011).

The primary caregivers who deal with multiple challenges in caring for adolescents who are living with HIV disease also indicated that good support from their families enabled them to cope better with the challenges they encountered. The support they get from their families help with their emotional well-being, to come to terms with the illness of the children and to be more effective carers (Merzel et al. 2008; Casale et al. 2013; Hayer et al. 2010; Casale & Wild 2012).

4.2.3 Theme 3: Suggestions to assist primary caregivers of HIV infected adolescents

The participants in this study suggested some interventions to assist and support primary caregivers of HIV infected adolescent. The participants suggested the following interventions for primary caregivers of HIV infected adolescents: emotional care; provision of material needs; children to be re-educated about HIV and, treatment and counselled for their emotional challenges.

4.2.3.1 Sub-theme 1: Emotional Support of Primary Caregivers

The process of taking care of an HIV adolescent as expressed by their primary caregivers has so many challenges and causes emotional strain. The primary caregivers not only have to look after a child that is not physically well but also have to take care of their emotional well-being. The primary caregivers indicated the need for emotional help to debrief them with the challenges they go through. The primary caregivers of HIV infected adolescents also need on-going professional help from Psychologists or Social Workers for emotional support to be able to cope better with the challenges that overwhelm them.

A number of studies indicated the need to assist primary caregivers of HIV infected adolescents with emotional support (Schuster *et al.* 2000; Eneh, 2010; Casale, Wild & Kuo 2013; Obama 2010).

4.2.3.2 Sub-theme 2: Material Needs of Primary Caregivers

The participants in this study suggested material resources to alleviate the poverty and other practical challenges of primary caregivers of adolescents who are living with HIV. The participants suggested the provision of food parcels to sustain the nutritional requirements of HIV infected children, financial assistance to be able to pay for the adolescents needs such as transport, clothing, school uniform, etc. The financial aid for children who are going to tertiary since their grants stops at the age of 18 was also suggested. Another participant also indicated the need for the house to live in a stress free environment with the HIV infected adolescents in her care. The primary caregivers who were stricken by poverty also indicated the desire to get the jobs which they believe would ease their burden.

The need to provide primary caregivers of adolescents and children who are infected with HIV is suggested in different studies (Schuster *et al.* 2000; Eneh 2010; Orner 2006; Bejane, Havenga, Aswegen 2013; Casale, Wild & Kuo 2013).

4.2.3.3 Sub-theme 3: Adolescents to be re-educated about HIV and treatment and counselling

The participants indicated the need to have people who are not the family members to re-educate children about HIV and treatment, especially the adolescents who are at the age of leaving their primary caregivers to study in tertiary institutions. Marzel *et al.* (2008) findings confirm that as children who are on antiretroviral treatment are getting older, they have to be educated and taught the strategies to overcome the barriers of treatment.

4.2.3.4 Sub-theme 4: Support Groups for both caregivers and adolescents

The participants who had the experience of support groups through their children who attended them indicated that the support groups provide great benefits for its members. They indicated that there is a need for adolescents who are infected with HIV and their primary caregivers to have access to support groups. Support groups

provide a platform for people who have a common problem or interest to interact and learn from each other's experiences.

Different studies recognized the need of having the support groups to support the caregivers who are burdened by the challenges of taking care of children and adolescents who are infected with HIV (Demmer 2001; Hayer *et al.* 2010; Eneh 2010; Obama. 2010).

The researcher draws core conclusion based on these findings and presents recommendations that specifically relate to the conclusions in the following section.

4.3 Conclusion & Recommendations

4.3.1 Conclusions related to the findings of the study

Based on the findings of this study, the researcher concluded that the primary caregivers of adolescents who are infected with HIV in Grahamstown have ongoing challenges with caring for those adolescents. There are no support programmes or interventions for them although previous research studies have long identified HIV infected adolescent as the most challenging group in the management of HIV disease. Adolescents who are infected with HIV also present the behavioural problems that most of their peers who are not infected with HIV present. The participants indicated that the adolescents' negative behaviour is frustrating them because their adolescents HIV infections could be worsened by alcohol abuse and a risky sexual behaviour. The stress that confronts the primary caregivers who are caring for adolescents who are infected with HIV affect their physical and emotional well-being. Although the participants in this study indicated that their role as primary caregivers has so many challenges and is affecting them in a negative way, they are determined in caring for adolescents who are infected with HIV. Through their personal experiences, they are able to suggest interventions that will enable primary caregivers of HIV infected adolescents to be effective carers.

The findings of this study are clearly supported by Bowen's Family Systems Model (1990) which is based on the assumption that people do not exist in a vacuum; they

are surrounded by other people. The findings of this study clearly indicate that primary caregivers need the support of their family members and the enabling community resources to cope better with the demands of caring for an HIV infected adolescent. The family systems model best addresses this research study goal as it helps to describe the family relationship, acknowledging the families bond and how the complexity of the relationship between two or more family members may affect other family members if not the entire family.

4.3.2 Conclusions related to the research process

- The goal and objectives of this study guided and directed the research process. The choice of a qualitative research approach supported by an explorative, descriptive and contextual design was best suited for this study, for the following reasons:
- Qualitative research aims to discover meaning that people attach to their own experiences. The study focused on the experiences of the primary caregivers who are in care for HIV infected adolescents.
- Qualitative research methods and processes have greater flexibility. This was important for the study as decisions about methods had to be reviewed and adjusted throughout the study. The pilot study enabled the researcher to amend the interviewing techniques as well as some of the research questions. The choice of semi-structured interviews enabled the researcher to meet the goal and objectives of the study.

4.3.3 Recommendations

4.3.3.1 Recommendations for Practice

The Social Workers and Psychologists of Department of Health need to play a more proactive role in developing psycho-social interventions and the programmes to assist primary caregivers with their ongoing challenges of caring for HIV infected adolescents. And more specific to;

- Social Workers, Psychologists and other Health Professionals who are equipped with counselling skills need to train or guide the primary caregivers of HIV infected children and adolescents before they embark on the disclosure journey with the children to avoid inappropriate disclosure that could result to emotional and psychological harm to a child.
- Primary caregivers need to be provided with necessary knowledge and skills by Nursing Professionals or relevant staff on how to look after the children who are infected with HIV as soon as they are confronted with the problem, and the primary caregivers need to be referred to professional counsellors for support and guidance.
- There is an urgent need to prioritize the implementation of adolescent friendly clinics in Grahamstown so to address the discomfort adolescents experience when attending the primary health care clinics that they have to access on regular basis for their treatment and health monitoring.
- Department of Health and Non-Governmental Organisations need to prioritize the care and support programmes for primary caregivers of HIV infected adolescents to address their challenges and their suggestions as identified in this study and other related studies. In this regard, a one-stop centre to address the diverse challenges of primary caregivers is a priority.

4.3.3.2 Recommendations for Policy

The Department of Health needs to engage its Social Work Professionals with the current research findings from national and internal studies in order for them to implement the services and programmes based on the findings and recommendations in order to address what is found to be relevant.

There is a need to have clear policy frameworks and models that address the plight of primary caregivers of children and adolescents who are infected with HIV.

4.3.3.3 Recommendations for future studies

In order to build on the findings of this study, it is recommended that future research investigates the following:

There is a need to evaluate the effectiveness of the current HIV/AIDS care and support programmes in Grahamstown in order to determine whether the programmes that are targeting people who are infected and affected with HIV/AIDS are addressing their needs. The proposed research study will also suggest if those services or programmes could be used as a model for the implementation of care and support programmes for primary caregivers of HIV infected adolescents.

4.4 Limitations

This study is qualitative in nature and as such only explored and described the experiences of a selected group of participants. It is not supposed to be generalised to other settings although literature as indicated in the study supports the experiences, challenges and needs of carers.

The researcher is working for Department of Health although the participants were mostly not the people she worked with. The researcher is well known in the small community of Grahamstown and that could have limited the participants' responses by trying to say what they think the researcher who is known as a Social Worker wanted to hear. I addressed the participant's tensions by ensuring them referring to my social work professional and research ethics that I have the obligations to keep their information confidential and their identity anonymous. I also used the communication skills as explained in Chapter Two, section 2.3.2.2.

Most of the literature of this study came from the literature that is addressing the psycho-social aspects of children who are living with HIV, and there was not much literature that was addressing the primary caregivers of adolescents who are living with HIV psycho-social aspects. The dearth of the literature on the subject could

have impacted on the basic assumptions as well as the findings that could have been backed up with more literature.

4.5 Conclusion

This chapter summarises the conclusions researched by the researcher concerning the study. The researcher also discussed the conclusions and recommendations. The study objectives as discussed in Chapter One of this study were attained. The limitations of the study were highlighted. The study provided evidence that primary caregivers of adolescents encounter many challenges that may affect their social, emotional and physical well-being. The study also found that there is not adequate support to assist primary caregivers of HIV infected adolescents with their challenges.

LIST OF REFERENCES

Alberta, C. 2010. Principles of Strength Based Practice. *Resiliency Initiative*. [online]. Available: <http://www.resiliencyinitiative.ca>. Accessed on 5 May 2013.

Allen, J. Cornelius, E. & Lopez, C. 2011. Family Systems Theory. *Frank Porter Graham Child Development Institute*. [online]. Available: http://dss.mo.gov/cd/info/cwmanual/section7/ch1_33/sec7ch1.htm. Accessed 5 May 2013.

Amatoeng, A.Y. & Sabiti, I.K. 2013. Social Structures & Sexual Behaviour of Black African Adolescents in the North West Province, South Africa. *South African Review of Sociology*, 44(1), 131-157.

Anderson. G., Ryna, C., Taylor-Brown, S., & White-Gray, M. 1999. *Children with HIV/AIDS*. United States of America: Children Welfare League of America, Inc.

Avert. 2013. HIV and AIDS Stigma and Discrimination. *Averting HIV and AIDS*. [online]. Available: <http://www.avert.org/hiv-aids-stigma.htm>. Accessed 2 September 2013.

Babbie E. R. & Mouton, J. 2001. *The Practice of Social Research*. Cape Town: Oxford University Press.

Bejane, S.M., Havenga, Y., van Aswegen, E. 2013. Primary Caregivers' Challenges related to caring for Children living with HIV in a semi-rural area in South Africa. *Journal of Nursing and Midwifery*, 15(1) pp. 68–80.

Bell, J. 2005. *Doing your research project: A guide for first-time researchers in education, health and social sciences*. 4th edition. England: Open University Press.

Bless, C. & Higson-Smith, C. 2000. *Fundamentals of Social Research Methods: An African Perspective*. 3rd Edition. Cape Town, South Africa: Juta Education (Pty) Ltd.

Bregman, O.A. & White, C.M. 2011. *Bringing Systems Thinking to Life: Expanding the Horizons for Bowen Family Systems Theory*. New York: Taylor & Francis Group.

Carolyn, K. 1995. Family Caregiving Systems: Models, Resources, and Values. *Journal of Marriage & Family*, 57(1),179-189.

Casale, M., & Wild, L. 2012. The Relationship between Social Support and the Health of HIV Positive Caregivers of Children: A Review of Empirical Literature. *Vulnerable Children & Youth Studies*, 7(3), 260-282.

Casale. M., Wild, L. & Kuo, C. 2013. "They give us hope": HIV Positive Caregivers' Perspective on the Role of Social Support for Health. *Aids Care*, 25(10), 1203-1209.

Churcher, S. 2013. Stigma related to HIV and AIDS as a barrier to accessing health care in Thailand: a review of recent literature. *WHO South-East Asia Journal of Public Health*, 2(1). [online]. Available: <http://www.searo.who.int/publications/journals/seajph>. Accessed 27 October 2014.

Curtis, B., & Curtis, C. 2011. *Social Research: A practical introduction*. Los Angeles: Sage Publishers.

Davies, M., Boulle, A., Fakir, T., Nuttal, J. & Elley, B. 2008. Adherence to antiretroviral therapy in young children in Cape Town, South Africa, measured by medication return & caregiver self-report: prospective cohort study. *BMC Pediatrics*. [Online]. Available: <http://www.biomedcentral.com/1471-2431/8/34>. Accessed 3 February 2013.

Demmer, C. 2011. Experiences of families caring for an HIV-infected child in KwaZulu – Natal, South Africa: an explanatory study. *AIDS Care*, 23(7), 873-879.

Department of Health. 2013. South African Antiretroviral Treatment Guidelines. Department of Health, Republic of South Africa. [Online]. Available: www.auruminstitute.org/phocadownload/guidelines-short.pdf. Accessed 15 August 2014

De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L. 2005. *Research at grass roots: for the social sciences and human service professions*. (3rd Ed). Pretoria: Van Schaik.

Dorland's Medical Dictionary for Health Consumers. 2007. [online]. Available: <http://www.dorlands.com/wserch.com>. Accessed 1 June 2013.

Edward, L.L., Reis, J.S & Webber, K.M. 2013. Facilitators & Barriers to Discussing HIV Prevention with Adolescents: Perspectives of HIV – Infected Parents. *American Journal of Public Health*, 103(8), 1468-1475.

Eneh, B.C. 2010. Assessment of Support Services Needs of Primary Caregivers of HIV & AIDS Infected Children: A review of Literature and Suggestions for Practices. Wright State University Masters of Public Health Program.

Evans, K., & Thomas, F. 2009. Emotional Interactions and an ethics of care: caring relations in families affected by HIV/AIDS. *Emotion, Space & Society*. [Online]. Available: <http://www.elsevier.com/locate/emospa>. Accessed 24 March 2013.

Harder, A.F. 2002. *Erikson Theory Stages of Psycho-social Development*. California: Child and Family Study Centre.

Hayer, A.S., Mabuza, L.H., Couper I.D., & Ogunbanjo, G.A. 2010. Understanding participation in a hospital-based HIV support group in Limpopo Province, South Africa. *South African Family Practice*, 52(3), 234-239.

Heeren, G.A., Jemmott III, J.B., Sidloyi, L., Ngwane, Z. & Tyler, J.C. 2012. Disclosure of HIV Diagnosis to HIV Infected Children in South Africa: Focus Group for Intervention Development. *Vulnerable Children & Youth Studies*, 7(1), 47-54.

Hosegood, V., Preston-Whyte, E., Busza, J., Moitse, S. & Timaeus, I.M. 2007. Revealing the full extent of household's experiences of HIV & AIDS in rural South Africa. *Social Science & Medicine*. [Online]. Available: <http://www.elsevier.com/locate/socscimed>. Accessed 3 February 2013.

Jankey, O. & Modie-Moroka, T. 2011. The Daily Grind of the Forgotten Heroines: Experiences of HIV/AIDS Informal Caregivers in Botswana. *Ethics & Social Welfare*, 5 (2), 217-224.

Kalichman, S.C., Simbayi, L.C., Kaufman, M., Cain, D. & Jooste, S. 2007. Alcohol Use and Sexual Risk for HIV/AIDS in sub-Saharan Africa: Systematic Review of Empirical Findings. *Prev. Sci*, 8(2),141-151.

Kimani-Murage, E.W., Manderson, L., Norris, S.A. & Khan, K. 2010. You opened your eyes: care-giving after learning a child's positive HIV status in rural South Africa. *Health & social care in the Community*,18(3), 264-271.

Kipp, W., Tindyebwa, D., Rubaale, T., Karamagi, E., and E. Bajenja. 2007. Family caregivers in rural Uganda: the hidden reality. *Health Care Women Int*, 28(10), 856-871.

Koen, V., van Eeden C., & Rothmann, S. 2013. A Model for Psychosocial Well-Being of Families in a South African Context. *Journal of Psychology in Africa*, 23(1), 155–164.

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy*, 45 (3), 214-222.

Leach-Lemens, C. 2012. Needs of Adolescents with HIV need greater attention, AIDS 2012 hears. *UNICEF*. [online]. Available: <http://www.aidmap.com/Needs-of-adolescents-with-HIV-need-greater-attention-2012-hears/page/2461884/>. Accessed 3 February 2013.

Li, R.J., Jaspán, H.B., Brien, V. O., Rabie, J., Cotton, M.F. & Nattras, N. 2010. Positive futures: a qualitative study on the needs of adolescents on antiretroviral therapy in South Africa. *AidsCare*, 22(6),751-758.

Lincoln, J.S & Guba, E.G. 1985. *Naturalistic Inquiry*. Newbury Park: SAGE Publications Inc.

Lune, H., Pumar, E.S., & Koppel, R. 2010. *Perspectives in Social Research Methods & Analysis: A reader for Sociology*. Sage Publications, Inc. United Kingdom.

Makiwane, M. & Mokomane, Z. 2010. South African youths' higher-risk sexual behaviour: An eco-developmental Analysis. *African Journal of Aids Research*, 9(1), 7-24.

Majumdar, B., and N. Mazaleni. 2010. The experiences of people living with HIV/AIDS of their direct informal caregivers in a resource-poor setting. *Journal of Interational AIDS Society*, 13(20), doi: 10.1186/1758-2652-13-20

Malee,K., Williams, P., Mantepiediam, G., McCabe, M., Nichols, S., Sirois, P.A., Storm, D., Farley J., Kammerer,B. & PACTG 219c Team. 2011. Medication Adherence in Chidlren & Adolescents with HIV Infection: Associations with Behaviour Imparment. *Aids Potential Care & STD's*, 25(3), 191-200.

Marelich, W.D., Roberst,K.J., Murphy, D.A.& Callari, T. 2002. HIV/AIDS Patient-involvement in Antiretroviral treatment decisions. *Aids Care: Psychology & Social Medical Aspects of HIV/AIDS*, 14(1), 17-26.

Mashala, P., Esterhuizen, K., Bosson, W. & Nel, K. 2012. Qualitative Exploration of the Experiences & Challenges of Adolescents during pregnancy. *Journal of Psychology in Africa*, 22(1), 49-55.

Maxwell, J. A. 2005. *Qualitative research design: An interactive approach*. (2nd ed.) Thousand Oaks, CA: Sage.

Mclnerney, P. & Brysiewicz, P. 2009. A systematic review of the experiences of caregivers in providing home-based care to persons with HIV/AIDS in Africa. *JBI Library of Systematic Reviews*,7(4), 130-153.

Merzel, C., Van Devanter, N. & Irvin, M. 2008. Adherence to Antiretroviral Therapy among Older Children and Adolescents with HIV: A qualitative Study of Psychosocial Context. *Aids Patient Care and STD's*, 22(12), 977-987.

Meyiwa, T. 2011. Constructing an alternative family unit: families living with HIV/AIDS redefine African traditional parenting patterns. *Social Dynamics*, 37(1), 65–177.

Michielsen, K., Matthew, F., Chersich, M. F., Luchters, S., De Koker, P., Van Rossem, R. & Temmerman, M. 2010. Effectiveness of HIV prevention for youth in sub-Saharan Africa: systematic review and meta-analysis of randomized and non-randomized trials. *Aids Care*, 24(8), 1193-1202.

Morojelo, N.K., Brooke, J.S. & Kochieng'a, M.A. 2006. Perception of Sexual Risk Behaviour and Substance Abuse among Adolescents in South Africa: A qualitative Investigation. *Aids Care*, 18(3), 215-219.

Morojelo, N.K., Kachieng'a, M.A., Mokoko, E., Noko, M.A., Parry, D.H., Nkowane, A.M., Moshia, K.M., & Saxina, S. 2006. Alcohol use and Sexual Behaviour among Risky Drinkers and Bars and Shebeen Patrons in Gauteng Province, South Africa. *Social Science & Medicine*, 62 (1), 217-227.

Mutwa, P.R., Van Nuil, J.I., Asiimwe-Kateera, B., Kestelyn, E., Vyankondondera, J., Pool, R., Rihirimba, J., Konakuze, C., Reiss, P., Geelen, S., van de Wilgert & Boer, K.R. 2013. Living situation affects adherence to combination antiretroviral therapy in HIV-infected adolescents in Rwanda: a qualitative study. *PLoS One*, 8(4):e60073.

Nash, S.G., McQueen, A. & Bray, J.H. 2005. Pathways to adolescent alcohol use: Family environment, peer influence and parental expectations. *Journal of Adolescent Health*, 37(1) 19-28.

Naswa, S. & Marfatia, Y.S. 2010. Adolescents HIV/AIDS: Issues and Challenges. *Indian Journal of Sexual Transmission Diseases*, 31(1), 1-10.

Noor, K.B.M. 2008. *Case study: A strategic research methodology*. *Applied Science*, 5:1602-1604

Nyblade, L., Stangl, A., Weiss, E., & Ashburn, K. 2009. Combating HiV Stigma in Health Care Setting: What Works? *Journal of International Aids Society*, 12(15), no

pages numbers.

Nyirenda, M., McGrath, N., & Newell, M. 2010. Gender differential in the impact of parental death: Adolescents sexual behaviour & risk of HIV infection in rural South Africa. *Vulnerable children & youth studies*, 5(3), 284-296.

Obama, B. 2010. President Proclamation- National Family Caregivers Month. *The White House*. [online]. Available: <http://whitehouse.gov/the-press/2010/10/29/presidentialproclamation-national-family-caregivers-month>.

Accessed 14 August 2014

Orner, P. 2006. Psycho-social impact on caregivers of people living with AIDS. *Aids Care*, 18(3), 236-240.

Osterberg, L. & Blaschke, T. 2005. Drug Therapy Adherence to Medication. *New England Journal of Medicine*, 353(5), 486-497.

Page, R.M. & Hall, C.D. 2009. Psycho-social Distress and Alcohol Use as Factors in Adolescents Sexual Behaviour among sub-Saharan African Adolescents. *Journal of Health*, 79(8), 369-379.

Petersen, I., Bhana, A., Myeza, N., Alicea, S., John, S., Holst, H., McKay, M & C. Mellinse. 2010. Psychosocial challenges and protective influences for socio-emotional coping of HIV adolescents in South Africa: a qualitative investigation. *AIDS Care*, 22(8), 970 -978.

Perrino, T., Gonzalez-Soldevilla, A., Pantin, H., and J. Szapocznik. 2000. The Role of Families in Adolescent HIV Prevention: A Review. *Clinical Child and Family Psychology Review*, 3(2), 81-96.

Polit, D.F. & Hungler, B.P. 1999. *Nursing research: principles and methods*. 6th ed. Philadelphia: Lippincott.

Prat, P. 2006. How to Reduce Stigma & AIDS Keynote Address Symposium at the

XV1 International AIDS Conference, Toronto. *UNAIDS* [online]. Available: <http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/speechexd/2006/200608012>. Accessed 1 June 2013.

Riana, P. ,O'Donnel, M., Schwellnus, H., Rosenubaum,P. ,King,G.,Brehaut,J. , Russell, D., Swinton, M., King, S., Wong, M., Walter, S.D., and E. Wood. 2004. Caregiving process & caregiver burden: Conceptual Models to guide research. *BMC Pediatrics*. [Online]. Available: <http://www.biomedcentral.com/1471-2431/4/1>. Assessed 3 June 2013.

Richards, T.A., Wrubel, J. & Grant, J. & Folksman, S. 2003. Subjective Experiences of Prayer among Women who care for Children with HIV. *Journal of Religion & Health*, 42(3), 201-219.

Richter, L.M., Sherr, L., Adato, M. Belsey, M., Upjeet, C. Desmond, C., Drimie, S., Haour-Knipe, M. Hosegoed, V., Kimour, J. Madhavan, S., Mathambo,V. & Wakhweya. 2009. Strengthening Families to Support Children Affected by HIV/AIDS. *AIDS Care*, 21(51), 3-12.

Ritchie, J. & Lewis, J. 2003. *Qualitative Research Practice: A guide for Social Science Students & Researchers*. London: Sage Publications Ltd.

Rolfe, G. 2006. Methodological Issues in Nursing Issues.Validity, Trustworthiness & Rigour: Quality & Idea of Qualitative research. *Journal of Advanced Nursing*, 53(3), 304-310.

Ruane, J.M. 2005. *Essentials of Research Methods: A guide for Social Science Research*. Blackwell Publications co: United Kingdom.

Saleebey, D. 1992. *The strengths perspective in social work practice*. New York: Longman.

Santamaira, E. K., Doleza, C., Mellins, C.A., Marhefka, S.L., Hoffman, S., Ahmed, S., and K. Elkington. 2011. Psychosocial implications of serostatus disclosure to youth with perinatally acquired HIV. *AIDS Patient Care and STDs*, 25(4), 257-264.

Santiesteban. Y., Castro, M. & Colvo, M. 2012. Mental Health of Pirmary Caregivers for Children and Adolescents with HIV/AIDS in Cuba. *Medic Review*, 14(2), 30-34.

Schuster, M.A., Kanouse, D.E., Morton, S.C., Bozzette, S.A. Miu A., Scott, G.B. & Shapiro. 2000. HIV-Infected parents and their children in the Unites States. *American Journal of Public Health*, 90(7), 1074-1081.

Seale, C. 2004. *Research Society and Culture*. 2nd Edition. London: SAGE.

Shaffer, D.R. & Kipp, K. 2007. *Developmental Psychology Childhood and Adolescents*. 7th ed. Wadsworth Language Learning: United States.

Singh, D., Chaudoir, S.R., Escobar, M.C & Kalichman, S. 2011. Stigma, burden, social support and willingness to care among caregivers of PLWHA inhome-based care in South Africa. *Aids Care*, 23(7), 839-845.

South African National Aids Council. 2013. South African National Strategic Plan for HIV/AIDS & STI 2012 – 2016. *South African National Aids Council*. [Online]. Available: www.sanac.org.za/nsp/the-national-strategic-plan. Accessed 14 May 2013.

Strydom, H. 2005. Sampling and sampling methods. In, *Research at Grassroots: For the social sciences and human service professions*, edited by De Vos, A. S., Strydom, H., Fouche, C. B., and Delpport, C.S.L. 3rd Edition. Pretoria: Van Schaik Publishers.

Swanepoel, Y. 2003. Primary caregivers' experiences of raising children with autism: a phemenomological perspective. MA Thesis published at Rhodes University. Available: www.contentpro.seals.ac.za/iii/cpro/app?id...itemId=1002576...def. Accessed 3 September 2013

Terre Blanche, M., Durrheim, K., & Painter, D. 2006. *Research in Practice*. Cape Town, South Africa: UCT Press.

Thabethe, N. 2011. Community home-based care - a cost-effective model of care: who benefits. *AIDS Care*, 23(7), 787-791.

Tesch, R. 1990. *Qualitative research: analysis types and software tools*. Bristol: Falmer.

Toseland, R.W. 2004. Caregiver, education & support programmes: Best practices models. *Family Giver Alliance*. Institute of Gerontology, School of Social Welfare State University of New York.

Udjo, O.E. 2011. Magnitudes of trends in orphanhood among younger persons in the era of HIV/AIDS in South Africa, 2001-2015. *African Population Studies*, 25(2), 267-285.

UNESCO. 2001. Human Rights People in Action. UNESCO. [online]. Available: www.undep.org/global-youth-network.html. Accessed 12 September 2014.

Van Wyngaard, A. 2013. Addressing the Spiritual Need of People Infected and Affected by HIV/AIDS in Swaziland. *Journal of Social Work End of Life and Palliative Care*, 9, 226-240.

Vreeman, R.C., Gramelspacher, A.M., Giscre, P.O., Scanlon, M.L. & Nyandiko, W.M. 2013. Disclosure of HIV Status Children in Resource-Limited Settings: A systematic Review. *J Int Aids Soc*.16 (1), doi: 10.7448/IAS.16.1.18466

Wassenaar, D. 2006. Ethical issues in social science research. In M. Terre Blanche, K. Durrheim & D. Painter. (Eds). *Research in practice: Applied methods for the social sciences* (2nd Ed). 60-77. Cape Town.

Watkins, J.A., Howard-Barr, E.M., Moore, M.J., & Werch, C.C. 2006. The mediating role of adolescent self-efficacy in the relationship between parental practices and

adolescent alcohol use. *Journal of Adolescent Health*, 38(4), 448-450.

Wisker, G. 2001. *The Postgraduate Research Handbook: Succeed with your MA, MPhil, EdD and PhD*. Basingstoke: Palgrave.

Yeap, A.D., Hamilton, R., Charalambous, S., Dwadwa, T., Churchyard, G. J., Geissler, P. W. and A.D. Grant. 2010. Factors influencing uptake of HIV care and treatment among children in South Africa - A qualitative study of caregivers and clinic staff. *AIDS Care*, 22(9), 1101-1107.

APPENDIX 1: INTERVIEW SCHEDULE

•PO Box 77000 • Nelson Mandela
Metropolitan University

•Port Elizabeth • 6031 • South Africa •

www.nmmu.ac.za

Tel no: 046 602 5158 or Cell: 083 335 8326



**Nelson Mandela
Metropolitan
University**

for tomorrow

SEMI-STRUCTURED INTERVIEW SCHEDULE FOR PRIMARY CAREGIVERS EXPERIENCES OF CARING FOR HIV INFECTED ADOLESCENTS STUDY

Introduction

- The researcher will establish the rapport by shaking hands, introducing herself and the purpose of the study.
- The researcher will then ask the participant the permission to use the audio-recorder.
- If the participant is giving the comfortable with audio recording, the consent form will be signed.
- If the participant is not comfortable with the audio-recorder, it will not be used.
- The researcher will allow the participant to introduce his/herself.
- The researcher will explain the process to the research participant.
- The researcher will explain that the interview will take 30-45 minutes.
- The researcher will obtain the written consent for participation in the study.
- The consent will be explained verbally from the participant.
- The participant will be asked to sign the consent form after the verbal agreement.

Transition (the researcher will then say, let us now focus on your personal experience as the caregiver of the HIV infected adolescent)

- What are your experiences as the caregiver of an HIV infected adolescent (negative and positive experiences)?
- How is the relationship between you and the adolescent you are caring for?
- What do you understand about living with HIV?
- How did your adolescent contract HIV infections?

- What do you understand about taking the antiretroviral treatment?
- Is the adolescent you are looking after on anti-retroviral treatment?
 - If yes what are your experiences with her or him of taking the antiretroviral treatment?
 - If no, has your child ever been on antiretroviral treatment and if the child was taking treatment but is no longer taking treatment: could you please explain why the adolescent is no longer on treatment.
- What kind of support do you get from your family?
- What kind of support do you get from your friends?
- What kind of support services are available for you as the primary caregiver of an HIV infected adolescent?
- What services do you think should be provided for primary caregivers of HIV infected children.
- What have been your major challenges as the care-giver?
- How have you coped with those challenges?

Concluding words:

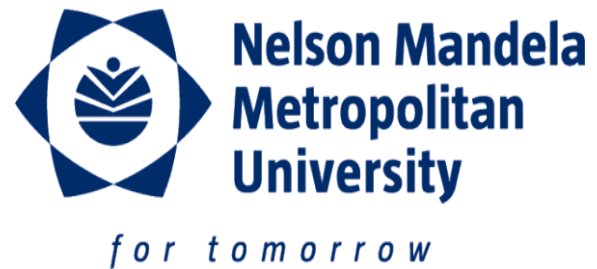
- The researcher will thank the participant for taking part in the study.
- The researcher will make the participant aware that if there are follow up questions after this interview she will make contact again.
- The researcher will also make the participant aware that the copy of the research will be available if the participant needs it.
- The researcher will provide refreshments or the incentive for the participant as a token of appreciation for his or her participation in the study

The audio-recorder will then be switched off.

Researcher: Dineo Matebese
Supervisor: Dr. Z. Soji
Co-supervisor: Professor S.S. Terblanche

APPENDIX 2: INFORMED CONSENT

• PO Box 77000 • Nelson Mandela Metropolitan University •
Port Elizabeth • 6031 • South Africa • www.nmmu.ac.za
Email: dineomatebese@yahoo.com
Tel no: 046 602 5158 or Cell: 083 335 8326



113 b Vellem Street
Joza Location
GRAHAMSTOWN
6139

Dear Sir/Madam

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

I wish to conduct a research study entitled, "Primary caregivers experiences of caring for HIV infected adolescents". The goal of this study is to enhance understanding of the experiences of primary caregivers who are raising HIV infected adolescents to make recommendations for programme and policy development based on the findings.

You are kindly requested to participate in this research study. You will be supplied with the information that will assist you to understand the study. You are free to ask for an explanation.

The following has been explained to me:

- Goal of the study
- Procedure of the study
- Confidentiality and Anonymity
- Voluntary participation
- Possible benefits
- Access to findings
- Use of audio recorder

You will be asked to give your written informed consent to participate by signing at the bottom of this page.

Ms Dineo Matebese
Masters Degree Student – NMMU

CONSENT AGREEMENT

I _____(name of the participant) hereby give consent to be

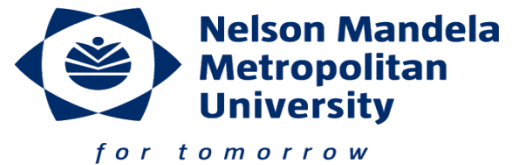
interviewed for the purpose of this study.

Signed on this ____ day of _____ 2014 at _____

Signed _____

Appendix 3: Written information to the participant prior the study

• PO Box 77000 • Nelson Mandela Metropolitan
University
• Port Elizabeth • 6031 • South Africa •
www.nmmu.ac.za
Email: dineomatebese@yahoo.com
Tel no: 046 602 5158 or Cell: 083 335 8326



Dear _____

You are being asked to participate in a research study. We will provide you with the necessary information to assist you to understand the study and explain what would be expected of you as a participant. The interview session take 45 minutes to an hour. Please feel free to ask the researcher to clarify anything that is not clear to you. Participation in research is completely voluntary. If you choose not to participate in psycho-social related research, your present and/or future social and medical care will not be affected in any way and you will incur no penalty and/or loss of benefits to which you may otherwise be entitled.

The researcher will use the audio recorder but if the participant is not comfortable with that it will not be used. To participate, it will be required of you to provide a written consent that will include your signature, date and initials to verify that you understand and agree to the conditions.

Furthermore, it is important that you are aware of the fact that the ethical integrity of the study has been approved by the Research Ethics Committee (Human) of the university. The REC-H consists of a group of independent experts that has the responsibility to ensure that the rights and welfare of participants are protected and that studies are conducted in an ethical manner. Queries with regard to your rights as a research subject can be directed to the Research Ethics Committee (Human), Department of Research Capacity Development, PO Box 77000, Nelson Mandela Metropolitan University, Port Elizabeth, 6031. If no one could assist you, you may write to: The Chairperson of the Research, Technology and Innovation Committee, PO Box 77000, Nelson Mandela Metropolitan University, Port Elizabeth, 6031.

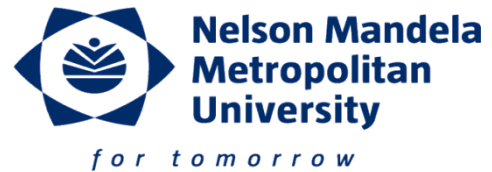
Although your identity will at all times remain confidential, the results of the research study may be presented at scientific conferences or in specialist publications.

Yours sincerely

Dineo Matebese (Ms)
RESEARCHER

APPENDIX 4: LETTER TO GATEKEEPERS

• PO Box 77000 • Nelson Mandela Metropolitan University
• Port Elizabeth • 6031 • South Africa • www.nmmu.ac.za
Email: dineomatebese@yahoo.com
Tel no: 046 602 5158 or Cell: 083 335 8326



05 September 2013

For attention: Mr. Z. Merile

Department of Health

BISHO

Cc Mrs. Mtoba (Local Service Area Manager)

Cc Mrs Moyake (Settlers Hospital Manager)

REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY AT DEPARTMENT OF HEALTH – MAKANA SUB- DISTRICT (GRAHAMSTOWN)

Dear Sir

My name is Dineo Matebese, and I am a Social Work Masters student at the Nelson Mandela Metropolitan University in Port Elizabeth. I am working as a Social Worker for Department of Health at Settlers Hospital. I wish to conduct a research study for a **Treatise which is a partial fulfilment of the requirement for the Masters degree in Social Work. The aim of the study is to explore and describe primary caregivers experiences of caring for HIV infected adolescents.** This study will be conducted under the supervision of Ms Zoleka Soji and Prof. Terblanche(NMMU, South Africa).

I am hereby seeking your consent to approach the primary caregivers of HIV infected adolescents who are accessing Department of Health Services in Makana Sub – district. The areas for the study will include: Settlers Hospital and Primary Health Care clinics in Grahamstown.

I have provided you with a copy of my treatise proposal which includes copies of the forms to be used in this study, as well as a copy of the approval letter from the NMMU Research Committee.

Upon completion of the study, I undertake to provide the Department of Health with a copy of the full research report. If you require any further information, please do not hesitate to contact me.

Thank you for your time and consideration in this matter.

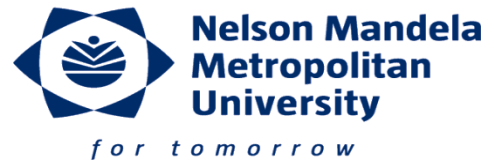
Yours sincerely

[Dineo Matebese](#)

Nelson Mandela Metropolitan University

APPENDIX 5: PERMISSION AND RELEASE FORM – RECORDINGS AND TRANSCRIPTIONS

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 • Port Elizabeth • 6031 • South Africa • www.nmmu.ac.za
 Email: dineomatebese@yahoo.com
 Tel no: 046 602 5158 or Cell: 083 335 8326



USE OF AUDIO RECORDINGS AND WRITTEN MATERIAL FOR RESEARCH PURPOSES – PERMISSION AND RELEASED FROM

Participant Name: _____

Participant's Address: _____

Telephone no: _____

Name of the researcher: Miss Dineo Matebese

Level of research: Masters in Social Work (Social Development and Planning)

Brief title of the research: Primary caregivers' experiences of caring for HIV infected adolescents

Supervisor: Dr. Z. Soji

Co-supervisor: Mrs. S. Terblanche

Declaration

(please sign in the block next to the statement that apply)

1. The nature of the research and the nature of my participation have been explained to me verbally and in writing.	Signature:
2. I agree to participate in the interview and to allow audio-recording for these to be made.	Signature:
3. The audio recordings will only be transcribed only by the researcher	Signature:
4. Once the data has been transcribed the recordings will	Signature:

be destroyed	
Date:	
Witnessed by the researcher:	