

**EXPERIENCES OF PRIMARY CAREGIVERS CARING FOR CHILDREN
LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS ATTENDING THE
WELLNESS CLINIC AT JUBILEE HOSPITAL HAMMANSKRAAL**

by

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DECLARATION

I Stella Mmatsatsi Bejane declare that the dissertation EXPERIENCES OF PRIMARY CAREGIVERS CARING FOR CHILDREN LIVING WITH THE HUMAN IMMUNODEFICIENCY VIRUS ATTENDING THE WELLNESS CLINIC IN JUBILEE HOSPITAL HAMMANSKRAAL is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references. Neither the whole work nor any part of it has been, is being or shall be submitted for another degree at this or any other university, institution of higher learning or examining body.

Date: 2012 / 01 / 13

Place: University of Limpopo (Medunsa Campus)

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DEDICATION

This dissertation is dedicated to:

The memories of my late parents, Petrus Rasekgapa and Rahab Rangoato Bejane; as well as my late brother Simon Chuene Bejane. I thank God for the love and sweet memories we shared and for the values you taught me, and in encouraging me to pursue the path of professional development in order to be a success in life.

All primary caregivers of children living with HIV who are committed and dedicated to caring for these children with love despite the daily challenges they face.

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ABSTRACT

Background and problem statement

The increase in AIDS related deaths of parents leave many children orphaned and some of these children live with HIV. These children are cared for by primary caregivers who are mostly elderly women. The primary caregivers experiences challenges when caring for the children living with HIV. These challenges may be physical, spiritual, psychological and social. The researcher conducted a study in order to explore the experiences of primary caregivers caring for children living with HIV.

Aim and objectives

The aim of the study was to promote the mental health of primary caregivers who provide care for children living with HIV attending the Wellness Clinic at the Jubilee Hospital in Hammanskraal.

The objectives of this study were to: i) describe the biographical data of primary caregivers who provide care for children living with HIV; ii) explore and describe the experiences of primary caregivers who provide care for children living with HIV; and iii) make recommendations which are based on the findings of this study in order to assist the nursing personnel at the Wellness Clinic in the promotion of the mental health of primary caregivers based on the findings of this study.

Research Design and method

A qualitative, exploratory, descriptive and contextual design was utilised to enable the primary caregivers to share with the researchers their experiences of caring for children living with HIV. The setting was the Wellness Clinic at the Jubilee hospital, Hammanskraal. Ethical principles were adhered to in order to protect the rights of the primary caregivers. Throughout the process, the methods to ensure trustworthiness of the study were followed. A purposive sample of eight primary caregivers was chosen for the unstructured interviews. Data were analysed by the researcher and an independent coder using the Tesch method.

Research Findings

Consensus was reached after consultation with an independent coder, about the following categories i) primary caregivers' experiences in caring for a child living with HIV related to the self of the caregiver; ii) primary caregivers' experiences related to the decision to disclose the child's HIV status to various role-players were influenced by stigmatisation and discrimination related to HIV and AIDS; iii) primary caregivers' challenges when caring for a child living with HIV; and iv) the mobilisation of resources by primary caregivers to assist them in caring for a child living with HIV. Findings were contextualised by implementing a literature control and recommendations were made to promote their mental health.

Conclusions

Primary caregivers who cared for children living with HIV in this study were mostly elderly women who were related to the children. They took over the care of the children living with HIV after the children's parents had died. Although they were faced with many challenges, their concern for the children's wellbeing made them to give the children loving care. They found strength and support from prayer, faith and hope in God. The primary caregivers also appreciated the support they received from the health care workers at the Wellness Clinic.

Key words: caring, mental health, HIV, children, primary caregiver.

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CHAPTER 1

1.0 BACKGROUND AND OUTLINE TO THE STUDY

1.1 INTRODUCTION

At the moment, the Human Immunodeficiency Virus (HIV) has no cure and it results in a social, cultural and spiritual crisis that leads to problems in the family and community. The health care system is already overburdened and thus the care for people living with HIV is the responsibility of primary caregivers, who are often elderly women who usually take care of the children after the death of their parents (Wacharasin & Homchampa, 2008:385).

This study seeks to explore and describe the experiences of primary caregivers caring for children living with HIV attending the Wellness Clinic at Jubilee Hospital in Hammanskraal. Based on the findings of this study, recommendations will be made to promote the mental health of primary caregivers in order to enable them to provide quality care that will enhance the quality of life of the children living with HIV.

This chapter discusses the background, rationale, problem statement of the study, research questions, research aim and objectives, theoretical assumptions and the overview of the research design and methods.

1.2. BACKGROUND AND RATIONALE OF THE STUDY

Global understanding of HIV has been changing, as HIV is no longer seen in terms of being another medical condition, but an epidemic within other social epidemics of injustice and a huge developmental crisis. It affects the cultural, spiritual, economic, political, social and psychological wellbeing in South Africa (Parry, 2008:25).

The Joint United Nations Programme on HIV and AIDS (UNAIDS) estimated that 33 million people were living with HIV worldwide in 2007 (Human Science Research Council (HSRC), 2009:1). Southern Africa has 35% of the infections occurring in this region (HSRC, 2009:1). South Africa is the country with the largest number of HIV infections and the biggest paediatric HIV pandemic. In 2009, 5.21 million people were living with HIV in South Africa, and of this number, 280,000, were children under fifteen years (Eley, 2010:41). In South Africa, an estimated 1.8 million people have died of AIDS-related diseases since the start of the epidemic (UNAIDS, 2008:3,4). The aftermath of HIV/AIDS related deaths is an increase in the number of orphans (Parry, 2008:25, 29).

As more parents die from Aids-related diseases, so too, will the number of orphans continue to rise until a cure that is affordable and accessible to everyone is found (Parry, 2008:71). According to South African National AIDS Council (SANAC) (2007:34)'s estimation, orphans will comprise 9-12 % of the population by 2010. The general household survey conducted in 2008 in South Africa indicated that of the 48.7 million people in South Africa, 18.7 million of them were children. Approximately 3.95 million were orphans, respectively: 13% paternal, 3% maternal and 5% double orphans (Eley, 2010:97,102).

In 2007, (SANAC) developed an HIV & AIDS and Sexually Transmitted Infections (STI) National Strategic Plan to deal with this increase of HIV infection. The National Strategic Plan's primary aims were to reduce the rate of new HIV infections by 50% by 2011, as well as reduce the impact of HIV and AIDS on individuals, families, communities and society by expanding access to appropriate treatment, care and support to 80% of all people living with HIV and their families by 2011 (SANAC, 2007:10).

HIV is transmitted predominately through heterosexual sex and mother-to-child transmission. This means that a child is born in a family where the HI virus has already had a devastating impact on the health, income, productivity and quality of care. As its victims are mainly younger adults, this means that one or both parents die from AIDS related diseases while the children are still young. The loss of a parent not only affects the children emotionally, but it also puts a financial burden on the surviving family members (Parry, 2008:29).

In most Sub-Saharan African countries, tradition emphasizes the responsibility of extended families, kin and communities to take care of orphans and vulnerable children. Families are the best places for children to grow up in (Meintjes & Hall, 2010:102; SANAC, 2007:34, 39). The children who have lost their parents due to HIV/AIDS, and are themselves living with HIV, need a lot of support and to be made to feel safe and secure in an environment with familiar people (Meintjes & Hall, 2010:102; SANAC, 2007:34, 39). Studies in several South African districts have revealed that most orphans are cared for by grandparents and family members, or they live by themselves (Meintjes & Hall, 2010:102; SANAC, 2007:34, 39).

The provision of antiretroviral treatment (ART) to HIV patients enables children to grow into adolescence. At the end of 2008, more than 57000 children in South Africa were on antiretroviral treatment (Eley, 2010: 41). For the antiretroviral treatment to be effective, the children living with HIV need to comply when taking ARTs. The children's compliance to antiretroviral treatment can be managed with the help of primary caregivers in the families. The primary caregivers will assist in ensuring that the children living with HIV are compliant to ART, to avoid drug resistance and complications (Moody, Margello, Gerits & Byrd, 2009:344).

The caregivers of orphans due to HIV are often elderly persons who had started by initially providing care to their own children living with HIV/AIDS and had continued in this role by caring for their grandchildren after their parents had died. Some of these children may be infected with HIV (Boon, Ruiters, James, Van der Borne, Williams & Reddy, 2009:374; Chitando, 2007a:11; Kipp, Tindyebwa, Rubaale, Karamaji & Bajenja, 2007:857; Ssengonzi, 2009:309).

Most of the caregivers are women and the role was begun during early childhood and it was continued throughout as daughters, mothers or wives. In some situations, any member of the family, irrespective of gender or age, takes over the care giving role, even though males would mostly get involved only when there are no women to fulfill the role. Although recent studies indicate that men are increasingly being involved in care giving, the bulk of the burden of care continues to be carried by women (Hejoaka, 2009:874; Ssengonzi, 2009:310; Kipp et al., 2007:861).

According to Chitando (2007a:48), it is critical that men begin to play a more prominent role in giving quality care to children even when women are around in order to assist these women in carrying the burden of care. Chitando (2007a:48) suggests that churches and society need to challenge the rigid gender role that associates care giving with women. Men should be encouraged to take an active role in providing care for the sick. Challenges posed by the HIV epidemic, demands that men develop a caring attitude that will enable them to meet both instrumental and financial needs of orphans and vulnerable children, and make a difference in the children's lives (Chitando, 2007a:48,49).

According to literature findings, caregivers experience a number of problems in providing care for people living with HIV, such as: lack of knowledge; own physical burden; sleep deprivation; anxiety; depression; stress; feeling of inferiority; hopelessness; restrictive freedom; rejection and loss of income as well as stigma and discrimination. The caregivers are also faced with inadequate resources including financial limitations (Boon et al., 2009:374; Kang'ethe, 2009:24; Makoe & Jubber, 2008:374; Pallangyo & Mayers, 2009:482,490).

In order to meet the basic needs of the family, elderly caregivers rely on the monthly old age grant which is however insufficient to cover all the financial needs of the family (SANAC, 2007:33). According to South African Security Agency (SASSA), 2010: n.p.), the old age grant is R1080.00. The Foster care grant, of R710.00 per month, is also increasingly used to provide financial support to orphans. The foster care grant is available to foster parents who have a child placed in their care by an order of court (Hall, 2010:108; (SASSA), 2010: n.p). The caregivers of children with severe disabilities or a chronic illness that is disabling, and

who thus require permanent care, are given, a care dependency grant, of R1080.00, per month. Caregivers of children under sixteen years of age, living in poverty and who are not receiving any other grant, are eligible to a monthly child support grant of R250.00 (Hall, 2010:109; SASSA, 2010:n.p).

People living with HIV who are disabled due to the disease, after the submission of a medical report confirming their disability, qualify for a disability grant of R1080.00 (SASSA, 2010:n.p.). However, the caregivers have to wait for a long time before receiving these grants due to a backlog that is caused by a shortage of social workers and an increase in the number of people with disabilities, orphans and vulnerable children (Proudlock & Jamieson, 2008:39).

The two yearly reviews of the grants by the social workers and the court make the financial difficulties experienced by the caregivers worse, as the system is complex and time consuming. SASSA determines the time for the review of the grants in order to ensure that the grants are given only to deserving and qualifying people. The caregivers are notified three months before the date of the review (SASSA, 2010:n.p.). During the review period, the primary caregivers struggle to make ends meet as they also have to provide for the educational needs as well as the health needs of the children (Hall, 2010:109).

Caregivers indicated in studies by Boon et al. (2009:374); Kang'ethe (2009:24); Makoe and Jubber (2008:374) and Pallangyo and Mayers (2009:482,490), that despite the challenges they are faced with when caring for children living with HIV, they nevertheless carry the responsibility of caring for children living with HIV willingly and with love as the duty to take care of their next of kin is a priority.

It is not only important for caregivers to have an understanding of HIV, its mode of transmission, physical effects, management and treatment issues, it is equally important to understand its impact on the individual, family and society. The social and economic circumstances must also be improved, stigmatisation, discrimination and injustices must be challenged (Parry, 2008:29).

Children are also affected by stigmatisation and discrimination associated with HIV. At times the caregivers attempt to protect the children by not disclosing their HIV status. The issue of nondisclosure leads to lack of support and stress. Although it is difficult to disclose the child's status, it is nevertheless important to do so in order to gain the support of other members of the family to ensure the children's compliance with their ARTs treatment. If the children know their HIV status they will understand the importance of taking medication and they will be involved in their own care and will cooperate with the caregiver. The affective component of

care-giving is as important as attending to physical needs and giving medication (Pallangyo & Mayers, 2009:482; Soul Buddyz, 2006:31).

Research findings suggested that the stigmatisation and discrimination against people living with HIV, is a major contributor to destroying families, communities and societies around the world. This is because of the silence surrounding this disease and the South African government as well as governments of other countries not doing enough to deal with those stigmatising and discriminating against people living with HIV and their caregivers (Wacharasin & Homchampa, 2008:386).

The understanding of the care giving of children living with HIV requires that research should emphasise the experiences of caregivers of children living with HIV by allowing the caregivers to share their experiences within the context in which they live (Hejoaka, 2009:870; Parry, 2008:35). Thomas, Nyamathi and Swaminathan (2009:994) indicated a need for research on parenting behaviour, mental- wellbeing, family support and social networking. These authors state that skill building in the coping mechanisms of caregivers and problem solving need to be taken into consideration.

Research should also be done to develop social policies that assist as well as support primary caregivers in their efforts, as they struggle with the demands of caring for children living with HIV. Research should also emphasize the experiences of both caregivers and children. (Hejoaka, 2009:874; Mendez-Luck, Kennedy & Wallace, 2009:233).

The rationale for the current study was that the mental health of caregivers needs to be taken care of as this will in turn lead to effective and efficient care of children living with HIV without compromising the physical and mental health of the primary caregivers themselves (Hejoaka, 2009:874; Mendez-Luck, Kennedy & Wallace, 2009:233). Increased understanding of the phenomenon of caring for children living with HIV will benefit not only the primary caregivers who participated in this study, but all those who find themselves in a similar situation whether in Hammanskraal or other places will also gain.

Thus a study was conducted that allowed the primary caregivers of children living with HIV in a resource limited area of Hammanskraal to explore and describe their experiences of care giving.

1.3 PROBLEM STATEMENT

As highlighted in the background, the HIV pandemic produces many challenges for caregivers as it is clouded in secrecy and many children need care in the homes as hospitals are overburdened. The care of children living with HIV has been taken over by caregivers

who may be household members, neighbours or friends (Pallangyo & Mayers, 2009:481). Furthermore, HIV is a chronic illness, which requires long term physical and psycho-social care and support, as well as adherence to treatment.

When the researcher was interacting with primary caregivers accompanying children to the Wellness Clinic at Jubilee hospital Hammanskraal, they told her that they experienced numerous challenges when caring for children living with HIV. The researcher was curious about what these challenges were. In the busy clinic, these challenges often go unseen or unexplored as the primary focus is on physical care and treatment of the children living with HIV. Holistic and comprehensive care which includes services rendered to the primary caregivers is also required. The mental health of primary caregivers should be attended to as the challenges of caring for children living with HIV affect the primary caregivers' physical, psychological, social and spiritual selves (Boon et al., 2009:374; Kang'ethe, 2009:24; Makoae & Jubber, 2008:374; Pallangyo & Mayers, 2009:482,490).

Furthermore, the extents to which care giving aspects differ according to cultural settings are not known. Experiences of caregivers caring for children living with HIV differ from those who care for adults because children need special care which may depend on their developmental stage (Mendez- Luck et.al. 2009:228).

In order to achieve some level of understanding of their care giving experiences, it was important to acquire such information from the people directly affected, within the circumstances and context in which they live. It is thus important for health professionals and researchers alike to change their mindset from trying to control but rather to facilitate, listen to, and involve people who are affected by HIV. In this study the people affected were primary caregivers caring for children living with HIV attending the Wellness Clinic at the Jubilee Hospital in Hammanskraal.

1.4 RESEARCH QUESTIONS

The research problem, gave rise to the following research questions:

- What are primary caregivers' experiences in providing care for children living with HIV who attend the Wellness Clinic at Jubilee Hospital, Hammanskraal?
- What recommendations can be made to assist nursing personnel at the Wellness Clinic in promoting the mental health of primary caregivers caring for children living with HIV?

1.5 RESEARCH AIM

The aim of the study was to promote the mental health of primary caregivers who provide care for children living with HIV attending the Wellness Clinic, at the Jubilee Hospital in Hammanskraal.

1.6 RESEARCH OBJECTIVES

The objectives of the study were to:

- Describe the biographical data of primary caregivers who provide care for children living with HIV;
- Explore and describe the experiences of primary caregivers who provide care for children living with HIV; and
- Make recommendations which are based on the findings of this study in order to assist the nursing personnel at the Wellness Clinic in the promotion of the mental health of primary caregivers.

1.7 THEORETICAL FRAMEWORK

The Theory for Health Promotion in Nursing (University of Johannesburg, Department of Nursing Science, 2009:4) will be used as the framework for this study. This theory focuses on the whole person with body, mind and spirit as well as on the parameters of nursing service, beliefs concerning patient, health, environment and nursing (University of Johannesburg, Department of Nursing Science, 2009:4). The theoretical framework will be described with reference to its purpose, assumptions and operational definitions as applied to mental health and this study.

1.7.1 Purpose

The purpose of the theory is the promotion of the mental health of the individual, family, group and community (University of Johannesburg, Department of Nursing Science, 2009:4).

This study explores the experiences of primary caregivers caring for children living with HIV with the aim of making recommendations, based on the findings, which will assist nursing personnel at the Wellness Clinic in promoting the mental health of primary caregivers.

1.7.2 Assumptions

The following assumptions are applicable within the Theory of Health Promotion in Nursing (University of Johannesburg, Department of Nursing Science, 2009:4):

- The primary caregiver is seen holistically in interaction with the environment;

- The environment includes an internal and an external environment;
- Mental health nursing is an interactive process which facilitates the promotion of the mental health of the primary caregivers and their families;
- Mental health nursing interactions indicate a mutual involvement between the nurse and the primary caregiver;
- The mental health nurse is a sensitive therapeutic professional who demonstrates knowledge, skills and values to facilitate the promotion of the mental health of primary caregivers caring for children living with HIV;
- Mental health is an interactive dynamic process in the primary caregivers' environment;
- The relative status of the mental health of primary caregivers is reflected by the interactions in the primary caregivers' environment; and
- The promotion of the mental health indicates the mobilisation of resources by the primary caregivers and nursing personnel in order to maintain and restore the mental health of primary caregivers.

1.7.3. Theoretical Statements

The following theoretical statements are derived from the theoretical framework through deductive reasoning (University of Johannesburg, Department of Nursing Science, 2009:4).

- The primary caregiver is a whole person who embodies dimensions of body, mind and spirit, and functions in an integrated manner with the environment (University of Johannesburg, Department of Nursing Science, 2009:5).
- Mental health is a dynamic process in the primary caregiver's environment. This interaction contributes to or interferes with the promotion of physical health and mental health (University of Johannesburg, Department of Nursing Science, 2009:5).
- Environment includes internal and external environments. The internal environment consists of the dimensions of body, mind and spirit. The external environment consists of physical, social and spiritual dimension (University of Johannesburg, Department of Nursing Science, 2009:5).
- Nursing is an interactive process where the nurse as a sensitive therapeutic professional facilitates the promotion of mental health through the mobilisation of resources (University of Johannesburg, Department of Nursing Science, 2009:4).

1.7.4. Operational definitions

The operational definitions for this study are:

- **Assist** means to help someone (Waite & Hawker, 2009:50). In this study assist refers to the primary caregivers' support for the child living with HIV so as to meet the basic needs of the child living with HIV.

- **Caring** is the process of looking after, and protecting, someone or something (Waite & Hawker, 2009:129). In this study, caring refers to the primary caregivers looking after the children living with HIV in order to ensure that the children's social, educational, financial, health, physical and emotional needs are met.
- **Child:** Child refers to a person under, the age of 18 years. (Children's Act, 38: 2005). For the purpose of this study it refers to children living with HIV between and including the ages 7 to 12 years; thus referring to primary school age children.
- **Experience** is defined as an event which affects a person in a certain way (Waite & Hawker, 2009:327). In the context of this study, experience refers to the things or events that have occurred to primary caregivers and which influence the way they think, feel and behave.
- **Hospital** is a large building where people who are sick or injured are given treatment and care (Waite & Hawker, 2009:448). In this study, hospital refers to the Wellness Clinic at the Jubilee hospital in Hammanskraal.
- **Living with HIV:** HIV is an abbreviation which stands for Human Immunodeficiency Virus – a virus that causes weakening of the immune system and can cause AIDS (Waite & Hawker, 2009:441) and living with HIV is when a person has tested positive for the HIV virus.
- **Mental health** is defined by Varcarolis and Halter, (2009:12), as successful performance of mental functions, resulting in the ability to engage in productive activities, enjoy fulfilling relationships, and cope with adversity. Mental health is also being able to solve problems, fulfill one's role for love and work, deal with crisis with the support of family or friends and maintain a state of well-being by enjoying life, setting goals and limits and becoming independent, interdependent or dependent as the need arises without losing one's independence (Shivers, 2008:8).
- **Orphan:** for the purpose of this study an orphan is a child whose mother or father or both biological parents have died. **Double orphan** for the purpose of this study refers to a child where both the biological parents have died. **Maternal orphan** for the purpose of this study is a child whose mother has died but whose father is alive. **Paternal orphan** for the purpose of this study is a child whose father has died but whose mother is alive (Meintjes & Hall, 2010:102).
- **Primary caregiver:** Primary means "of chief importance, main, foremost." (Waite & Hawker, 2009:725). Caregiver means any person other than a parent or guardian who actually cares for a child (Children's Act, 38:2005). For the purpose of this study primary caregiver refers to any person who lives with a child living with HIV on a fulltime basis and

ensures that the child's educational, emotional, financial, health, physical and emotional needs are met.

- **Promotion of mental health:** Promoting mental health, as defined by Varcarolis and Halter (2009:12), means assisting people to recognise feelings, readily deal with them, and learn from the experience. For the purpose of this study promotion of mental health will be the mobilisation of individual, family and community resources by the primary caregiver in order to maintain and restore the mental health state (University of Johannesburg : Department of Nursing Science,2009:4).

1.8 RESEARCH DESIGN

A qualitative, explorative, descriptive and contextual research design was used to explore and describe the experiences of primary caregivers who provide care for children living with HIV (Burns & Grove, 2009:24-25; Polit & Beck, 2008:20-21; Terre Blanche & Durrheim, 2002:331,398).

The research design will be discussed in more detail in chapter 2.

1.9 RESEARCH METHOD

The research method of the study entails the setting of the study, the population, sampling, data -collection, data-analysis and literature control.

1.9.1 Setting

The setting for this study was the Wellness Clinic at Jubilee Hospital in Hammanskraal in the Gauteng Province of South Africa. The setting will be discussed in more detail in Chapter 2

1.9.2 Population

The population for this study was all the primary caregivers who accompanied children living with HIV to the Wellness Clinic at the Jubilee hospital in Hammanskraal.

1.9.3 Sampling

Sampling refers to the sampling procedure and the sample size. A purposive, sampling procedure was implemented to choose the sample for this study (Polit & Beck, 2008:355).The inclusion criteria for the study were primary caregivers who: were living with the child, in the same home and were taking care of the child; were eighteen years and older; and cared for a child between 7 to 12 years who is living with HIV.

The exclusion criteria were caregivers who did not consent to participate in the study and those whose children did not feel comfortable with being separated from the primary

caregivers during the duration of the interview. The sample size for this study of eight primary caregivers was decided on based on the saturation of data evidenced by the repetition of themes (Polit & Beck, 2008:357; Richards & Morse, 2007:231) and confirmed by the independent coder and the researcher's supervisors.

Sampling will be discussed in more detail in chapter 2.

1.9.4 Data collection

Data collection was done by means field notes (Polit & Beck, 2008:405) as well as unstructured interviews which were conducted in Setswana, which is the language in which the primary caregivers were proficient and which the researcher can speak fluently (Greef, 2005:287).

As suggested by Richards (2009:84), the first interview done as a pilot study, was included in the data, as qualitative interviews do not have instruments that require testing. Data collection will be discussed in more detail in chapter 2.

1.9.5 Data analysis

Data analysis was an ongoing process involving continuous reflection on the data. Tesch's descriptive method was used to code the data (Creswell, 2009:186). The independent coder was consulted and consensus was reached after discussion with the researcher. Data analysis will be discussed in detail in chapter 2.

1.9.6 Literature control

A literature control was done after data analysis to explain the findings in relation to what other researchers had found when studying the phenomena of experiences of primary caregivers caring for a child living with HIV, find support for findings and to claim new contributions (Terre Blanche & Durrheim, 2002:18).

A literature control was included in the description of the study findings in chapter 3.

1.9.7 Recommendations

Recommendations based on the findings of the study and those that were grounded in literature were made to assist in the promotion of the mental health of primary caregivers who care for children living with HIV.

Recommendations will be discussed in detail in chapter 4.

1.9.8 Methods to ensure trustworthiness

Trustworthiness of the data was ensured through authenticity, credibility, confirmability, dependability and transferability as discussed by Lincoln and Guba in (Bloomberg & Volpe,

2008:76-78; Lincoln & Guba 1985:289-327; Lincoln & Guba in De Vos, 2005:346-347; Polit & Beck, 2008:539-550) and authenticity (Polit & Beck, 2008:540).

Methods to ensure trustworthiness will be discussed in detail in chapter 2.

1.10 ETHICAL CONSIDERATIONS

The following ethical principles were ensured in the study to protect the rights of primary caregivers: beneficence, non-maleficence, autonomy, confidentiality and anonymity, justice and sound research (Brink, 2006:31-40; Muller, 2009:62-63; Richard & Morse, 2007:235-239).

Ethical considerations will be discussed in detail in Chapter 2

1.11 CHAPTER OUTLINE

The outline for the chapters of this study are as follows:

Chapter 1: Background and outline to the study

Chapter 2: Research Design and method

Chapter 3: Description of findings and literature control

Chapter4 : Conclusions, recommendations and limitations of the study.

1.12 SUMMARY

In this chapter the background and rationale of the study, the problem statement, research question, research aim and objectives as well as the theoretical assumptions underlying this study were discussed. In chapter 2 the research design and method will be discussed in full.

CHAPTER 2

2.0 RESEARCH DESIGN AND METHOD

2.1 INTRODUCTION

The focus of this chapter will be on the description of the research design and method that the researcher used in the study, with reference to: research design; research method; setting; population; sampling; data collection; data analysis; methods to ensure trustworthiness; and ethical considerations.

2.2 RESEARCH AIM AND OBJECTIVES

The aim of the study was to promote the mental health of primary caregivers who provide care for children living with HIV attending the Wellness Clinic, at the Jubilee Hospital in Hammanskraal.

The objectives of the study were to:

- Describe the biographical data of primary caregivers who provide care for children living with HIV;
- Explore and describe the experiences of primary caregivers who provide care for children living with HIV; and
- Make recommendations which are based on the findings of this study in order to assist the nursing personnel at the Wellness Clinic in the promotion of the mental health of primary caregivers.

The objectives, as outlined above, will be achieved by means of the research design as detailed hereunder.

2.3 RESEARCH DESIGN

A research design is a plan for a particular piece of research that includes the decisions from broad assumptions to detailed methods of data collection and analysis. For the purpose of this study, a qualitative, exploratory, descriptive, contextual research design was used in order to explore and describe the experiences of primary caregivers who provide care for children

living with HIV. (Burns & Grove, 2009:24; Creswell, 2009:3; Polit & Beck, 2008:21; Terre Blanche & Durrheim, 2002:331,338).

A **qualitative design** was used to analyse so as to understand phenomena deeply and in detail from the perspectives of the participants (Richards & Morse, 2007:30). People were studied by observing and interacting with them in their natural environment. The emphasis was on quality and depth of the information, with the intention of developing and understanding the meaning of the phenomena as experienced by the participants (Nieuwenhuis, 2007:51).

A qualitative design was appropriate for this study as the experiences of primary caregivers caring for children living with HIV attending the Wellness Clinic at the Jubilee hospital in Hammanskraal were explored by the researcher. The meaning that the primary caregivers hold about their experiences when caring for children living with HIV was the main focus of the research study.

This is an **exploratory study** as it investigates the full nature of the phenomenon of the experience of caring for children living with HIV, the manner in which it was manifested and the factors to which it was related. The researcher's objectives were to become conversant with the experiences of primary caregivers as explained by the participants (Fouche & De Vos, 2005:106; Polit & Beck, 2008:21). The study explored how primary caregivers made sense of their experiences, and described how they perceived, felt, judged, remembered or talked about caring for children living with HIV. In order to achieve this, the researcher asked primary caregivers an open ended question permitting them to describe their experiences in their own words (Bloomberg & Volpe, 2008:11; Brink, 2006:119; Patton, 2002:104; Thomas & Pollio, 2002:5). The experiences of primary caregivers caring for children living with HIV is an area where not much research was done so the study increased understanding in this area (Denzin & Lincoln, 2008: 107; Thampanichawat, 2008:201). The researcher explored the experiences of primary caregivers caring for children living with HIV attending the Wellness Clinic at the Jubilee Hospital in Hammanskraal.

This is also a **descriptive study** as it aims to describe the dimensions of phenomena, their importance and 'ordinary experiences' of people as they experienced these phenomena (Burns & Grove, 2009:25; Polit & Beck, 2008:19). The researcher focused on what was happening in the lives of the primary caregivers, what was important about their experiences, and what alterations could be made in their daily activities (Thomas & Pollio, 2002:5). The researcher gained new knowledge from the primary caregivers' description of their experiences in caring for children living with HIV.

The shared experiences of the eight caregivers who were interviewed enabled the researcher to understand the meaning of caring for a child living with HIV. To achieve this understanding, it was important for the researcher to suspend all she knew or thought about the phenomena and listen respectfully to the caregivers as they explained their confidential experiences (Patton, 2002:106; Polit & Beck, 2008:227; Thomas & Pollio, 2002:7).

A contextual study is concerned with understanding primary caregivers' experiences within the background in which they occur and from their point of view. Human experience cannot be understood without understanding the people's culture, language and history (Terre Blanche & Durrheim, 2002: 338). This interaction with the environment contributes, to or interferes with, the promotion of both physical and mental health. This environment consists of the internal and the external environment (University of Johannesburg, Department of Nursing Science, 2009:5).

The context of this study was the Wellness Clinic at the Jubilee Hospital in Hammanskraal. This will be discussed in more detail under the setting of the study.

As discussed previously, the experiences of the primary caregivers will be understood better if described in the context in which the caregivers live. This will be discussed in the following section on the research method.

2.4 RESEARCH METHOD

A discussion of the research method for this study follows with reference to the setting, the population, sample, data-collection, data analysis and literature control.

2.4.1 Setting

According to Burns and Grove (2009:35), and Creswell (2009:174), a setting refers to a place in which a study is conducted. It can be natural, partly controlled or fully controlled. The setting for this study was a natural, uncontrolled real life setting. In the setting, the researcher had face to face interaction with the primary caregivers (Burns & Grove, 2009:35; Creswell, 2009:174). The setting for this study was the Wellness Clinic at the Jubilee Hospital in Hammanskraal.

Hammanskraal is an area, north of Tshwane. It is in the Tshwane Metsweding Region which is part of Tshwane district, one of the six districts in the Gauteng Province, South Africa. Hammanskraal covers an extensive geographic area which includes several villages and settlements, including the following locations: Ramotse, Marokolong, Kanana, Temba, Majaneng, Bosplaas and Makapanstad. It has a total population of approximately 150000

people (Jones, 2010:6). Hammanskraal has diverse ethnic groups, with cultural practices associated with rural South Africa. Hammanskraal experiences challenges with resources which includes access to water and electricity. It is estimated that 66% of the adults are unemployed and are not involved in any means of earning a livelihood (Jones, 2010: 6). Jubilee hospital caters for the health care needs of the communities in the areas mentioned above.

Jubilee hospital serves a large area, not just Hammanskraal, but the entire Gauteng Province as it is a secondary referral hospital from the rural clinics. Due to the increase in the number of people living with HIV in the Hammanskraal area, there was a need to open a Wellness Clinic in the hospital (Jubilee hospital, Wellness and antiretroviral treatment (ART) Clinic, 2010:n.p.).

The Wellness Clinic is a government primary health care antiretroviral therapy facility which began in 2005, and it offers HIV and AIDS related services. These services include: awareness; care and support; children services; community support and development; counseling; information provision and referral services; nutritional support; organisational support; palliative care and treatment; and voluntary counseling and testing. The ratio of male to female clients that it caters for is 40% to 60%. Approximately 10% of the health care users are children. The clients, who are not employed, are given nutritional supplements (Jubilee hospital, Wellness and ART Clinic, 2010: n.p.; Jones, 2010:7).

The following population for this study was accessed in the setting described above.

2.4.2 Population

Burns and Grove (2009:343-344), Polit and Beck (2008: 337-338) and Strydom (2005:194) describe the population as the entire people, events or any sampling units which consists of elements with which the research problem is concerned. The target population is the entire set of individuals who meet the sampling criteria (Burns & Grove, 2009:343; Polit & Beck, 2008:338). The accessible population is part of the target population to which the researcher has reasonable access (Burns & Grove, 2009:338; Polit & Beck, 2008:338). The accessible target population for this study comprised primary caregivers who accompanied children living with HIV, to the Wellness Clinic at the Jubilee Hospital in Hammanskraal.

As only a limited number of the total population of primary caregivers was required and accessible for the study, and they needed to be selected for certain specific qualities, a nonprobability purposive sampling method (Polit & Beck, 2008:355), was implemented to select suitable participants for the study .

2.4.3 Sampling

The researcher will explain the sampling procedure appropriate for this study, and the inclusion and exclusion criteria and the sample size in the subsection that follows.

2.4.3.1 Sampling procedure

Sampling refers to the process of selecting a portion of the population to represent the entire population so that inferences can be made about the population (Polit & Beck, 2008:339). Non probability, purposive sampling (Polit & Beck, 2008:355) was used for the purpose of this study. Non probability sampling occurs when the researcher selects participants who are more knowledgeable about phenomena under study and who will be able to explain to the researcher all aspect related to it (Gillis & Jackson, 2002:184; Polit & Beck, 2008:355). Primary caregivers were recruited for the study by the researcher with the assistance of health workers working in the clinic, as they attended to them on every visit and knew them well.

As primary caregivers who care for the children living with HIV were purposively selected according to the inclusion criteria, they were able to share very important information about their experiences as they were knowledgeable about this issue.

After being granted permission by the regional director of health and the chief executive officer of Jubilee Hospital, the researcher was introduced to the operational manager of the Wellness Clinic which served as the setting for the research study.

The researcher was introduced to the caregivers by a professional nurse employed at the clinic. The researcher addressed the caregivers and explained to them what the study entailed. The researcher requested for caregivers who complied with the inclusion criteria to volunteer to participate in the study. This was done on Tuesdays as it is the day when most of the caregivers bring their children to the clinic.

The primary caregivers had to meet the stipulated criteria to be participants in the study.

2.4.3.2 Inclusion and exclusion criteria

The inclusion criteria for the study comprised primary caregivers who were:

- Living with the child full time, in the same home and are the ones actually taking care of the child;
- Eighteen years and older; and
- Caring for a child between 7 to 12 years of age and who is living with HIV.

The exclusion criteria comprised caregivers who did not consent to participate in the study and those whose children did not feel comfortable with being separated from them during the interview.

The primary caregivers had varied socio-demographic characteristics and these will be discussed in chapter 3.

As not all the primary caregivers participated in the study, a sample size of the participants will be discussed.

2.4.3.3 Sample size

In qualitative studies sample size will depend on data saturation, which refers to sampling to the point where new ideas do not emerge. Data saturation was determined by the quality of information collected from the participants when they reported their experiences (Polit & Beck, 2008:357; Richard & Morse, 2007:231). Data saturation was reached after a sample of eight primary caregivers had been interviewed. The point of saturation and the sample size were decided on and confirmed by the researcher, supervisors and the independent coder after the data was analysed and consensus about saturation and the identified categories and subcategories had been reached.

After the primary caregivers were chosen data were collected.

2.5 DATA COLLECTION

Data were collected by means of unstructured interviews, which were conducted in Setswana as it is the language that the primary caregivers were comfortable with and in which the researcher is fluent. The researcher has also acquired research methodology and training in interviewing and communication skills and has implemented these skills in providing care for the patients where she is employed.

2.5.1 Unstructured interviews

Biographical information was collected before the interviews (refer to Annexure E) Unstructured interviews were used as a data collection method as they are the predominant mode of data collection in qualitative research (Greef, 2005:287). This method allowed primary caregivers to share their experiences of caring for children living with HIV freely with the researcher (Patton, 2002:341). Unstructured interviews allowed the researcher to find out what was in and on the participant's mind in order to gain the perspective and meaning of the phenomenon of caring for children living with HIV (Greef, 2005:292-293; Patton, 2002:341; Terre Blanche & Durrheim, 2002:128).

The researcher asked primary caregivers open ended questions which offered them an opportunity to respond in their own words and express personal perspectives in order to

explain their experiences of caring for children living with HIV. The researcher asked questions which were: neutral, singular, clear and comprised of words that made sense to the primary caregivers in order to improve the quality of data obtained during the interviews (Patton, 2002:348). The unstructured interview was conducted by the researcher in the Wellness Clinic. It was done for 30 to 45 minutes depending on the needs of the primary caregiver and the child living with HIV (Richard & Morse, 2007:65).

With the caregivers' and the children's permission, the children were left in the care of the researcher's colleague, a registered nurse, during the interview to allow the caregivers to share experiences freely without the children's interference. This was done also to protect the children from potential harm that might be caused by the caregivers' disclosing information about the children and with which the children were not comfortable. This way it was also possible for the caregiver not to lose their position in the queue, where they were waiting to be seen by a health care practitioner.

The central question asked was: **“Tell me about your experiences when caring for a child living with HIV.”** Probes were used to get clarity and to enable the primary caregiver to elaborate more on matters during the sharing of the lived experiences. Probes were non-leading but were only clarifying and exploring in nature; for example: “you spoke about...;” “please tell me more about that” or “I wonder what you mean by...?”

No interview schedule was set as this is not the purpose of unstructured interviews using the phenomenological approach. This approach enables the researcher to enter the interview without preconceived ideas and an agenda, but allows the caregiver who participates to share lived experiences in an open and unbiased manner (Creswell, 2009: 13).

2.5.1.1 Setting up the interview

The researcher asked the operational manager in the Wellness Clinic for a private room where there would be no distractions, to ensure privacy and confidentiality during the interviews. The digital recorder was tested before the commencement of the interviews (Terre Blanche & Durrheim, 2002:129).

The researcher explained to the primary caregiver that notes would be taken during the interview, starting with their biographical data. The biographical data included: the primary caregiver's age, gender, ethnic group, level of education, employment status, relation to child, time- frame caring for the child, number of children in the family, family income and age, gender, education level as well as treatment taken by the child. The biographical data were elicited in the participants' mother tongue and then written down by the researcher on the response form.

2.5.1.2 Phases of unstructured interviews

The following phases of the interview were followed:

i) Preparing for the interview

The researcher prepared herself emotionally by setting aside all emotional concerns that might have had an impact on the relationship with the primary caregivers and by writing self-reflective notes (Burns & Grove, 2009: 545). She also prepared the environment in order to minimise distractions by selecting a room that was free of noise and switching off cell phones. The researcher ensured that all materials and equipment needed were available and within reach of the researcher so as to prevent distractions during the interview (McClan & Woodside, 2010:17-18; Schurink, 1998:301).

ii) Becoming acquainted: The initial relationship

The researcher introduced herself to the primary caregiver and asked how he/she would like to be addressed as this would enable him/her to feel respected and part of the whole process. This relationship was built on respect, unconditional acceptance, empathy, openness, sincerity and modesty (Poggenpoel in Rossouw, 2003:144). The researcher listened attentively to what the primary caregivers were saying and this made them realise that the researcher was taking what they were saying into consideration, and thus they were encouraged to open up and share more of their experiences with the researcher.

The researcher adopted an open posture, maintained eye contact, looked relatively relaxed and showed interest in what was being said. She told the caregiver that the information shared was of great value. The primary caregiver was allowed to talk freely without any interference from the researcher (McClan & Woodside, 2010:23; Schurink, 1998:302), except for probing and clarifying questions.

iii) Establishing a contractual relationship

The informed consent form signed served as a contract between the researcher and the primary caregiver. This informed consent form also included the information that the interview would be audio taped. The researcher ensured that there were no ulterior motives to conducting the study and this was done by being honest with the caregivers. Honesty was ensured by the researcher to maintain a trusting relationship with the primary caregivers. The researcher did this by honestly disclosing all the details of the study and informing the primary caregivers that there would be no incentives for participating in the study (Poggenpoel in Rossouw, 2003:144; Schurink, 1998:307).

The needs of the primary caregiver were taken into consideration by conducting the interview at the time that he/she and the child were waiting to be seen by the health care worker. The primary caregivers were allowed to terminate the interview at any time, or when the child required their attention (Schurink, 1998:302-303).

iv) *Establishing a relationship of trust*

A relationship of trust was established and this enabled the primary caregiver to cooperate and willingly share confidential experiences with the researcher. The researcher honestly described the purpose of the interview and the role of the primary caregiver in the interview. The researcher also told the caregivers that all the information that they were sharing would be kept confidential and their names would not be used in the documents. All information and identity of the primary caregivers were kept confidential by using codes on the research reports, and all documents with the primary caregivers' personal information were locked away in a safe place. As the primary caregivers were assured of confidentiality, they were able to open up to the researcher and divulge information freely. Interviews were conducted in Setswana as it is the language that the primary caregivers were well conversant with and which the researcher is able to speak fluently (McClan & Woodside, 2010:25; Schurink, 1998:303).

The researcher showed unconditional positive regard for the primary caregivers by accepting them as they were without judging them. The researcher did not become emotionally involved with the issues that were raised and she referred the primary caregivers to the relevant health worker, for continuity of care. This was done with the primary caregivers' consent (Poggenpoel in Rossouw, 2003:144; Schurink, 1998:305-306).

v) *Terminating the interview*

The researcher terminated the interview when the child requested the attention of the primary caregiver as agreed with the caregiver before the commencement of the interview. In the case when the interview was not interrupted by the child, but when the primary caregiver looked tired and was repeatedly saying the same thing, the researcher summarised the content of the interview, and clarified it with the primary caregiver to ensure credibility of the information obtained. The researcher asked the primary caregivers if there was anything they would like to add or any question they would like to ask before thanking them and terminating the interview (Schurink, 1998:303-304). The researcher explored how the primary caregivers were feeling after the interview and offered referral to the social worker or the psychologist, with the primary caregivers' consent for those primary caregivers who experienced any emotional discomfort.

The researcher applied the communication skills which follow below during the interview in order to facilitate effective and respectful interviewing.

2.5.1.3 Communication skills

Communication is a two way process which assists the researcher to listen and respond appropriately to the primary caregivers (Kneisl & Trigoboff, 2009:206; Okun & Kantrowitz, 2008:30). Communication involves both verbal and nonverbal messages and responses. The following communication skills were used:

i) Active listening

The researcher listened attentively to the primary caregivers during the interview. This led them to see that the researcher had interest in what they said and regarded it as being important. The researcher responded verbally and nonverbally to encourage the primary caregiver to elaborate on the discussion (Kneisl & Trigoboff, 2009:207).

ii) Verbal response skills

Verbal response skills indicated to the primary caregivers that the researcher was actively listening and understood their point of view.

The following verbal communication skills, as suggested by Okun and Kantrowitz (2008: 76-78) and Greef (2005: 289-290), were used during the interviews:

- Paraphrasing, the researcher repeated what the primary caregiver had said in her own words to confirm what was said;
- Reflecting was used by the researcher to enable the primary caregiver to get in touch with feelings experienced during the interview;
- Open ended questions were used to enable the primary caregiver to describe in full the experiences of caring for the child living with HIV;
- Clarifying was the skill that the researcher utilised when what the primary caregiver had said was not clear and the researcher needed more information to understand it;
- Probing was used by the researcher to obtain more information from the primary caregiver by urging the person to say more about a particular issue;
- Silence from the researcher gave the primary caregiver an opportunity to consider what was said and to elaborate on it; and
- Summarising was done by the researcher to highlight main ideas and to verify with the primary caregiver the accuracy and completeness of the information as well as the researcher's interpretation of the interview content.

Verbal communication was captured by means of audio tape recording by the researcher and she also wrote field notes during the interview.

Non-verbal responding include: nodding of the head, smiling, eye contact, facial expression, leaning forward, enabled the primary caregiver to realise that the researcher was listening attentively and understood what was being said. (McClan & Woodside, 2010:27-28).

2.5.2 Field Notes

Field notes represented the researcher's account of things seen, heard, experienced and thought about during the interview that was not captured on the audiotape. It included primary caregivers' nonverbal behaviour, feelings, emotions and tone of voice. The researcher's feelings, preconceptions, expectations and attitude towards the participants as well as environmental distractions were also reflected in the field notes. The researcher also included what the primary caregiver had said after the recorder was switched off (Polit & Beck, 2008:405). Descriptive and reflective notes were written by the researcher. Descriptive notes are descriptions of observed events and conversations, actions, dialogue and context (Polit & Beck, 2008:406).

Reflective notes are about the researcher's personal experiences, reflections and progress. Methodological notes were about the strategies and methods used in the research study. Theoretical notes were the researcher's thoughts about how to make sense of what had transpired during the research study. Personal notes were comments about the researcher's own feelings and were written in the researcher's journal (Polit & Beck, 2008:406-407).

2.5.3 Pilot study

The pilot study was carried out in exactly the same manner as described in the data collection of the sample above. The researcher conducted a simulated unstructured interview in the presence of peers and supervisors, where she was corrected in order to refine her interviewing skills. An additional interview was conducted at the Wellness Clinic with one primary caregiver. The data from this interview were included in the overall data as suggested by Richards (2009:84), that if the pilot study were to be included in a qualitative study, then the data obtained at this stage need not be discarded as qualitative studies generally do not have a pilot stage in which instruments are tested.

2.6 DATA ANALYSIS

Data analysis was an ongoing process involving continual reflection about data (Creswell, 2009:186). Audiotapes were transcribed verbatim by the researcher, translated into English and organised for analysis (Creswell, 2009:186). This enabled the researcher to gain more understanding of the lived experiences of the primary caregivers and enabled her to code the data with ease.

All translations of transcripts were reviewed by a second person who was also the independent coder, as she is well conversant with Setswana. Differences were discussed and the researcher reached a consensus with the independent coder. The English versions of the transcripts were used for coding the data.

Manual coding of the transcriptions and field notes was done continuously as data were being collected, using a coding process, namely, open descriptive coding as per Tesch's method (Creswell, 2009:186). The researcher and the independent coder independently coded the transcripts as follows:

1. Reading and rereading through all transcripts carefully to get a sense of what the primary caregivers were saying and wrote down ideas that emerged from the data;
2. Picking one transcript at a time, read it with attention to the topics that answered the research question and wrote down underlying meanings on each one;
3. Making a summary of each transcript;
4. Making a list of all topics from all transcripts and grouped similar ones into categories or themes;
5. Finding suitable words to describe the topics, and placed topics that occurred in all or most of the transcripts in one list to make a list of all important topics;
6. Grouping all information belonging into each category in one place as subcategories according to their content;
7. Putting the categories in alphabetic order;
8. Analysing grouped themes.

The independent coder was provided with a protocol for coding the data (refer to annexure G).

The researcher compared her categories and subcategories with that of the independent coder. Discrepancies were discussed resulting in agreement on themes, categories and subcategories to be included in the description of findings in order to enhance the trustworthiness of the study. The researcher's supervisor checked the themes, categories and subcategories to ensure that they answered the research question and reflected the point of view of the primary caregivers.

The analysed data were discussed and described in full to explain the essence of the lived experiences of primary caregivers when caring for a child living with HIV. The research findings were substantiated by studies done by other scholars through a literature control.

2.7 LITERATURE CONTROL

Literature control was done after data analysis for appraisal of the study findings, to compare them with studies already done in the same area, to find support for the findings and to claim new contributions that will augment the significance of the study (Creswell, 2009:25; Terre Blanche & Durrheim, 2002:18). Thus the researcher used information gathered from the literature to compare the findings of the study with what is already known about primary caregivers caring for children living with HIV in order to obtain comprehensive findings for the study.

The literature control was included in chapter 3 with the findings of the study. The findings enabled the researcher to make recommendations for the promotion of mental health of primary caregivers caring for children living with HIV.

2.8 RECOMMENDATIONS

Based on the findings of this study, the researcher made recommendations for: nursing practice; nursing education; and nursing research. These recommendations were made to assist the nursing personnel at the Wellness Clinic in promoting the mental health of primary caregivers caring for children living with HIV.

Recommendations will be discussed in detail in chapter 4.

Throughout this process, the researcher made sure that the methods to ensure the trustworthiness of the study were adhered to.

2.9 METHODS TO ENSURE TRUSTWORTHINESS

Trustworthiness is a method used by qualitative researchers to evaluate the quality of the study (Polit & Beck, 2008:196). Strategies used to achieve rigor in this qualitative study will be explained, by referring to the five criteria for trustworthiness by Lincoln and Guba (1985:289-327). These criteria are: credibility, transferability, dependability and confirmability (Bloomberg & Volpe, 2008:76-78; Lincoln & Guba (1985:289-327); Lincoln & Guba in De Vos, 2005:346-347; Polit & Beck, 2008:539-550) and authenticity (Polit & Beck, 2008:540).

2.9.1 Credibility

Credibility was used as a measure to test the truth-value of data collected and findings accordingly (Bloomberg & Volpe, 2008:77; Lincoln & Guba in De Vos, 2005:346). The

following activities that increased the probability that findings would be credible were implemented in this study:

2.9.1.1 Prolonged engagement

The researcher spent sufficient time with the primary caregivers to build a relationship of trust and consciously bracketed preconceived ideas that might have influenced the collected data. A trusting relationship was built to ensure that the researcher was accepted by the primary caregivers, enabling them to freely share their experiences of caring for children living with HIV. The researcher also had a prolonged engagement with the data by reading and re-reading the data (Lincoln & Guba in Bloomberg & Volpe, 2008:77).

2.9.1.2 Triangulation

Triangulation is a strategy used to increase the quality of the study. The researcher ensured triangulation of data by using more than one form of data, namely recording verbatim transcribed unstructured interviews with the primary caregivers and by writing personal notes, observational notes, methodological notes and theoretical notes (Polit & Beck, 2008:406-407). Furthermore, eight participants were included in the study. Triangulation of was ensured further by having an independent coder and the researcher analysing and interpreting data collected and thereafter comparing it to find out if the results obtained were similar. The researcher's supervisor, who is competent with qualitative data analysis also continuously evaluated the data to confirm the credibility of the study results (Lincoln & Guba in Bloomberg & Volpe, 2008:77).

2.9.1.3 Member checking

The researcher ensured that the primary caregivers confirmed that the data captured reflected their viewpoint. Member checking was continuous during the interview to allow correction of mistakes and to clear misinterpretation and misunderstanding between the researcher and the primary caregivers. At the end of the interview a summary of the conversation was made in order to check with the primary caregivers whether what the researcher had heard was what they had meant. This ensured that the results were a true reflection of what the primary caregivers had shared with the researcher (Holloway & Wheeler, 2010: 305; Lincoln & Guba in Bloomberg & Volpe, 2008:77).

2.9.1.4 Credibility of researcher

The researcher is a registered nurse in general, community, psychiatry and midwifery with 15 years' working experience. The researcher has also acquired research methodology and training in interviewing and communication skills and has implemented these skills in providing care for the patients where she is employed. The researcher's supervisor and co-

supervisor are experts in research methodology and they supervised the researcher throughout the study (Polit & Beck, 2008:550).

2.9.1.5 Peer debriefing

The researcher discussed the research process with the supervisor, co-supervisor and an independent coder. Possible bias was probed and the meaning and interpretation of data were clarified. Peer debriefing assisted the researcher to deal with feelings and emotions that could have interfered with the credibility of the study (Lincoln & Guba in Bloomberg & Volpe, 2008:77).

2.9.1.6 Referential adequacy

The researcher recorded the interviews on an audiotape and will keep the cassettes for audit of the study if necessary. The researcher included quotes from transcripts when describing the findings of the study in chapter three (Lincoln & Guba, 1985: 313).

2.9.2 Transferability

Transferability, which is parallel to external validity in quantitative research is used to determine whether the study results can be transferred to other settings or groups (Bloomberg & Volpe, 2008:78; De Vos, 2005:346; Lincoln & Guba in Polit & Beck, 2008:539;), although qualitative researchers do not intend to generalise the study findings to other settings. The researcher provided a detailed description of the primary caregivers' shared experiences and their demographic data. Purposive sampling of the primary caregivers ensured that the data collected had rich information about the experiences of caring for children living with HIV. The researcher described the research methodology in full to allow others to check if a similar process can be applied to other settings (Bloomberg & Volpe, 2008:78; De Vos, 2005:346; Holloway & Wheeler, 2010: 310; Lincoln & Guba in Polit & Beck, 2008: 539).

2.9.3 Authenticity

Authenticity determines if the researchers' report reflects the participants' experiences from their point of view and not the researcher's opinion. The researcher confirmed with the primary caregivers that the information recorded in the field notes corresponded to what was said during the interview (Polit & Beck, 2008:540). The strategies used for this study were authentic as they allowed the primary caregivers to understand their situation and were eager to improve it.

The researcher kept a reflective journal to write personal feelings, values and perceptions related to the study and that could have affected data collection, analysis and interpretation

(Holloway & Wheeler, 2010:311). The primary caregivers' actual words were reflected in the description of the data.

2.9.4 Confirmability

An audit trail which describes in detail the process of the study was kept to enable anyone who would like to do an audit to follow through all the steps taken by the researcher (Holloway & Wheeler, 2010:310). The following documents are kept by the researcher for the audit trail: field notes, tape recordings, transcripts, condensed notes, themes and interpretations, procedures and research design strategies, study proposal, field journals, information about data collection methods and the researcher's reflective journal. (Bloomberg & Volpe, 2008:87; Lincoln & Guba in Polit & Beck, 2008:539).

2.9.5 Dependability

Dependability is a strategy used to check if the study findings would be similar if the study were to be carried out with similar participants in a similar environmental setting. The researcher will provide an audit trail to enable another person to follow the whole procedure done during the study to check if the result will be consistent, as this will enhance the dependability of the study. An independent coder coded and interpreted the data collected and compared her findings and checked their consistency with those of the researcher. The researcher described in full the research methodology. The researcher was supervised throughout the study (Lincoln & Guba in Bloomberg & Volpe, 2008:78; Polit & Beck, 2008:539).

The researcher is required to consider ethical principles to ensure protection of the rights of primary caregivers.

2.10 ETHICAL CONSIDERATIONS

In order to conduct the study in total adherence to ethical measures, the researcher obtained ethical clearance from the Medunsa Research and Ethics Committee (MREC) before the commencement of the study (refer to annexure A) for a copy of the MREC ethical clearance certificate). The Regional Chief Director of the Department of Health of Tshwane Metsweding Region Research and Ethics Committee (refer to annexure B for the consent letter) and the Chief Executive officer of Jubilee hospital gave consent for the study to be conducted in the Wellness Clinic of Jubilee hospital, at Hammanskraal. The chief executive officer introduced the researcher to the operational manager of the Wellness Clinic who took over and assisted the researcher with the recruitment of the primary caregivers for the interviews.

Brink, (2006:31-40), Muller, (2009:62-63) and Richard and Morse (2007:235-239) discuss the following ethical principles which were adhered to throughout this study: beneficence, non-maleficence, autonomy, confidentiality and anonymity, justice and sound research. These were adhered to in order to protect the rights of the primary caregivers as well as those of the children they brought to the clinic.

2.10.1 Beneficence

Beneficence is the obligation to do good or act in another person's best interest. It is also a responsibility to do what benefits a person and ensuring that benefits outweigh the risks. Non-maleficence is an obligation to avoid harming a person (Brink, 2006:31; Muller, 2009:62).

Beneficence and non-maleficence were ensured in this study by:

- Making an effort not to harm the primary caregivers emotionally; by allowing them to refrain from answering questions that they were uncomfortable with;
- Referring caregivers with emotional problems or who experienced emotional discomfort due to the interview for counselling with their consent to the psychologist or social worker who were part of the multidisciplinary team of the Wellness Clinic; one primary caregiver was referred to the psychologist for assistance with disclosure of the child's HIV status.
- Conducting the interview in the absence of the child;
- Having the researcher's colleague taking care of the children during the interview; and
- Ending the interview when the children became upset or required the care of the primary caregiver (Brink, 2006:31; Muller, 2009:62).

2.10.2 Autonomy

Autonomy is respect for the right of individuals to self determination and to be involved in decisions affecting them (Brink, 2006:32; Muller, 2009:62; Richard & Morse, 2007: 237). The researcher ensured this by:

- Informing the primary caregivers verbally and in writing and in their mother tongue about (a) the purpose of the study and the time required to participate; (b) their right to ask the researcher any question related to the study; (c) their right to refuse to participate and to withdraw from the study at any time without negative consequences or any question being asked; and (d) their right to refuse to answer any question (refer to annexure C for the participant information leaflet) ;

- Discussing and clarifying the informed consent, including consent to make audio recordings of the interview before a primary caregiver signed it (refer to annexure D for the participant consent letter) ; and
- Obtaining verbal consent from the primary caregivers who could not write. The researcher obtained verbal consent from one primary caregiver who said that she could not write and was thus not able to sign the consent letter.

2.10.3 Confidentiality and anonymity

Confidentiality is ensuring that all the primary caregivers' information is not shared with anyone who was involved in the study without their consent. Anonymity is making sure that the primary caregivers are not identified by information that can be linked to them (Muller, 2009:63; Richard & Morse, 2007:236).

The researcher ensured confidentiality and anonymity by:

- Conducting one to one interviews in a private room;
- Not using the primary caregivers' names on the documents and by keeping informed consents away from research documents;
- Ensuring that all the people, including the translator who was also the independent coder, who had access to the research documents were made to sign a confidentiality agreement, and
- Keeping audiotapes and other confidential data in a safe locked place for a minimum period of five years after the study and publication of the article (Medical Research Council, n.d: 52).

2.10.4 Justice

Justice is a commitment to ensure equality of treatment and fair distribution of resources (Brink, 2006: 33). This was ensured by:

- Selecting the primary caregivers who could contribute to the study by sharing their experiences voluntarily;
- Not enticing the primary caregivers by giving or promising them incentives for their participation in the study;
- Honouring all agreements made with the primary caregivers; and
- Not disadvantaging in any way the primary caregivers who did not volunteer to participate in the study or who withdrew from the study for any reason.

2.10.5 Sound research

Sound research was ensured by:

- Having the researcher supervised by a qualified supervisor with a PhD in Psychiatric Nursing and extensive experience in qualitative research throughout the study;
- Communicating and sharing the results of the study with the primary caregivers;
- The researcher who was competent to conduct the study as she had completed a course in research methodology;
- The researcher adhering to all standards pertaining to planning, implementation, evaluation and communication of results;
- Ensuring that the study process and results are trustworthy; and
- Honest reporting of findings and reflecting the limitations to the study.

2.11 SUMMARY

A detailed description of the research design, research methods, measures to ensure trustworthiness; ethical considerations were done in this chapter. In chapter 3 a description of the study findings and literature control will be discussed in detail.

CHAPTER 3

3.0 DESCRIPTION OF THE FINDINGS AND LITERATURE CONTROL

3.1 INTRODUCTION

In chapter 2, the researcher discusses the research design and method of the study and also researcher presents the key findings of the study. The first two objectives of the study namely, i) to describe the biographical data of primary caregivers who provide care for children living with HIV and ii) to explore and describe the experiences of primary caregivers who provide care for children living with HIV, will be addressed in the discussion in this chapter.

The findings are discussed, adding details that support and explain each finding. Illustrative quotations from the interviews transcripts are included in the discussions to emphasise the primary caregivers' voice. Findings from other studies done elsewhere and related to this study are included to place this study within the context of what others have found in exploring the phenomena of primary caregivers caring for children living with HIV.

3.2 OPERATIONALISATION OF THE STUDY

The study was done in 2010 with the data collected between the 19th July 2010 and the 6th of October 2010 at the Wellness Clinic at the Jubilee hospital in Hammanskraal. The researcher received ethical clearance from the Medunsa Research and Ethics Committee (refer to annexure A) as well as from the Tshwane Metsweding Region Research Ethics Committee (refer to annexure B). The Chief Executive Officer of Jubilee hospital gave consent for the study to be done in the Wellness Clinic. The operational manager of the unit and the multidisciplinary team members were informed and they briefed the primary caregivers about the study. They assisted the researcher in the recruitment of primary caregivers who met the inclusion criteria.

The researcher was introduced to the primary caregivers, and she explained to them the purpose of the study and requested those who were interested to volunteer to participate in the study. Unstructured interviews were conducted by the researcher in a private room in the Wellness Clinic. Before the commencement of the interview, the researcher gave the information leaflet and/or explained to the primary caregivers the background information

about the study, and answered questions to clear any misunderstandings. The ethical principles as explained in chapter 2 were adhered to before the primary caregiver could sign or give an informed consent. The researcher conducted the interviews in Setswana, in the child's absence to allow the primary caregiver to share their experiences freely. The researcher interviewed the primary caregivers weekly on Tuesdays until saturation of data was obtained. Data saturation was confirmed in consultation with the researcher's supervisors and independent coder.

3.3 DESCRIPTION OF THE BIOGRAPHICAL DATA

Of the eight primary caregivers interviewed, seven were females and only one was male. In studies by (Hejoaka, 2009:874; Ssengonzi (2009:309), the researchers suggested that most primary caregivers were women but men were involved in cases where a female caregiver was absent. This was the case in this current study as the male primary caregiver took over responsibility of caring for the child living with HIV after his wife, the child's grandmother, passed away.

The primary caregivers' ages ranged from 25 years to 79 years. The mean **age** of the participants was 56.9. This meant that 1 was a young adult, 2 were middle-aged adults, and 5 were older adults.

The findings show that most of the primary caregivers in this study were elderly women. A study on the care for children affected by HIV and AIDS (2010:4) and studies by Meintjes and Hall (2010:99) UNAIDS (2004:47) in South Africa, concur with the findings of this study, that most children affected by HIV and AIDS are cared for by elderly women.

The **relationship** of the caregivers to the children was as follows:

- Of the five older adult caregivers who were the children's grandparents, four were maternal grandmothers and one a paternal grandfather;
- One middle-aged adult was the child's aunt and the other the biological mother; and
- The young adult was the child's aunt.

The children living with HIV who were cared for by the seven non- biological primary caregivers were **orphans**, two double orphans and five maternal orphans. However, only one father was maintaining the child even though the child was not living with him. The father of the child whose biological mother was the primary caregiver was separated from the mother, and he was also not involved in the maintenance of the child.

The study by Meintjes and Hall (2010:102) revealed similar findings, which suggested that biological fathers are not actively involved in their children's lives. This leads to the statistics of paternal orphans to seem to be high as the biological fathers are absent and do not maintain their children. A study by UNAIDS, (2006:93) concurred with the findings in this study about the absence of biological fathers, as their report assumed that paternal orphans are more likely to stay with their mothers than for maternal orphans to live with their fathers.

The **level of education** of the primary caregivers ranged from no formal education to grade 12, with two primary caregivers with no schooling, three with primary schooling and three with secondary schooling.

Three participants have completed grade 12, and these were the two middle-aged adults and the young adult. Of five participating grandparents, two had never attended formal schooling, one completed grade three, the other grade six and the last one grade 8.

The **employment status** of the primary caregivers revealed that only one of the primary caregivers was employed as a part-time domestic worker, three were unemployed and four were pensioners. The **family income** of most of the caregivers was from social grants, the child support grant, care dependency grant, foster care grant and old age pension grant. Only one primary caregiver received financial support from the parents who were gainfully employed.

The unemployment status of the primary caregivers, as suggested in the biographical data, concurs with the findings of the studies conducted by SANAC (2007:33) in South Africa and a study in Care for Children Affected by HIV and AIDS (2010:4) which suggested that black women do not usually participate in economic, social and political life because of the discrimination that was based on class, race and gender. The older women's unemployment status lead them to be poor and depend on social grants, the old age grant and the foster care grant to care for a number of children in the household (SANAC, 2007:33; Care for Children Affected by HIV and AIDS, 2010:4). The care giving role also limits the primary caregivers' opportunity of being educated and gainfully employed (UNAIDS, 2006:90) as in the case of the three primary caregivers in this study who have passed grade 12, but were staying at home to care for the children living with HIV.

The number of **other children** in the households being taken care of by the primary caregivers ranged from two to six, which included the primary caregivers' own children and the siblings of the child living with HIV. The primary caregivers mentioned that the other siblings were not sick, so they assumed that they were not living with HIV. The children brought to the Wellness Clinic were the ones whose status was confirmed to be HIV positive.

Six of the children living with HIV were males and two were females. The **ages of the children** were from seven to twelve years, meaning that they were all in primary school. These children were in grade R to grade six. All the children attended the Wellness Clinic once every month for follow- up and treatment refills. All children were already started on **antiretroviral treatment (ART)**.

3.4 DESCRIPTION OF THE FINDINGS

The findings of this study which reflect the experiences of primary caregivers caring for children living with HIV will be described with reference to the central theme, the categories and sub categories identified in the data. The categories and subcategories are presented in table 3.1.

The central theme identified in the data was as follows: Primary caregivers' experiences in caring for a child living with HIV revealed aspects of the self of the caregiver, experiences related to the decision to disclose the child's HIV status, challenges faced by the caregivers and resources they mobilised to assist them in caring for the child living with HIV.

The **self of the caregiver** included the emotional, social cognitive and spiritual dimensions of the self of the caregiver. There were both positive and negative experiences related to the self of the caregiver. The **decision to disclose** was experienced as a difficult task as it had the potential of leading to stigma and discrimination directed against the children living with HIV and their families. The primary caregivers had to disclose the children's HIV status to the child, family and people outside the family.

Caring for children living with HIV was regarded as a challenge by the primary caregivers. Primary caregivers said the **challenges** they faced were related to: financial resources that were needed to meet the basic needs of the children living with HIV; health needs of the children living with HIV and caring for the children living with HIV without the primary caregiver and the family being exposed to HIV infection.

In order to cope with the challenges the primary caregivers **mobilised resources** to cope with caring for the children living with HIV. The resources were: health professionals and the Wellness Clinic; informal social support groups and family; and going to church.

The findings of this study, as indicated in table 3.1, reflect the experiences of caregivers caring for children living with HIV. The discussion of the categories and subcategories of the caregivers' experiences will follow.

Table 3.1 Categories and subcategories of the primary caregivers' experiences in caring for a child living with HIV

Category	Subcategory
<p>3.4.1 Primary caregivers' experiences in caring for a child living with HIV related to the self of the caregiver.</p>	<p>3.4.1.1 Emotions experienced by the primary caregivers when caring for a child living with HIV were:</p> <ul style="list-style-type: none"> a. Sadness, anger and grief related to the death of the parent of the child living with HIV. b. Anxiety related to child's diagnosis and prognosis. c. Fear of dying before the child living with HIV is self-sufficient. d. A deeper sense of compassion and love for the child. <p>3.4.1.2 Decreased social interaction in order to focus on the child living with HIV.</p> <p>3.4.1.3 Empowering self with knowledge for effective care of self and the child living with HIV.</p> <p>3.4.1.4 Spiritual deepening leading to faith, hope and trust in God.</p>
<p>3.4.2 Primary caregivers' experiences related to the decision to disclose the child's HIV status to various role-players.</p>	<p>3.4.2.1 Experiences related to the decision to disclose to the child.</p> <p>3.4.2.2 Experiences related to the decision to disclose to the family.</p> <p>3.4.2.3 Experiences related to the decision to disclose to people outside the family.</p>
<p>3.4.3 Primary caregivers' challenges when caring for a child living with HIV.</p>	<p>3.4.3.1 Challenges related to insufficient financial resources to meet the basic needs of the child</p> <p>3.4.3.2 Challenges related to the health needs of the child.</p> <ul style="list-style-type: none"> a. physical care of a sick child b. dealing with treatment compliance c. prevention of episodes of illness <p>3.4.3.3 Challenges related to caring for child without exposing self and other family members to HIV infection.</p>
<p>3.4.4 The mobilisation of resources by primary caregivers to assist them in caring for a child living with HIV.</p>	<p>3.4.4.1 Primary Caregivers viewed health professionals and the Wellness Clinic as "a life saver" and a source of hope.</p> <p>3.4.4.2 Primary Caregivers found that their informal social support groups and the family were a source of strength and encouragement.</p> <p>3.4.4.3 Primary Caregivers regarded the church as a source of support and comfort.</p>

3.4.1. Primary Caregivers' experiences in caring for a child living with HIV related to the self of the caregiver

The researcher realised that it was not easy for the primary caregivers to share their experiences of caring for children living with HIV as it appeared to bring out painful memories. The primary caregivers revealed that taking care of a child living with HIV was a demanding "full time job" which affected the internal environment, the body mind and spirit, of the primary caregivers.

This therefore meant that the primary caregivers had to commit their time and self to the care of the child living with HIV. As one participant (08) stated: "*...we cared for him since he was young...I accept I have no choice it is God's will...I must accept because I am the one who has to take care of them...it is difficult especially when the mother has passed away*".

3.4.1.1 Emotions experienced by the primary caregivers when caring for a child living with HIV

Interacting with the child living with HIV evoked a lot of emotions in the primary caregivers. As most of the children in this study were orphans, their parents had been cared for by the same caregivers who suffered loss of their own relative or child and instead of mourning found themselves having to care for a child who was also sick.

Emotions that were experienced by the primary caregivers were, sadness, anger and grief related to the death of the child's parent, namely the biological child of the caregiver; anxiety related to the child's diagnosis and prognosis; the fear of dying before the child is self-sufficient, and a deeper sense of love and compassion for the child.

a. Sadness, anger and grief related to the death of the parent of the child living with HIV

The findings from this study appears to reflect that primary caregivers felt sad because the children who were supposed to take care of them in their old age had passed away leaving them to carry on taking care of children who also seemed to have no chance of survival. The other siblings, even though they were not sick, also demanded to be given care. This meant that instead of playing the role of a grandparent or aunt the primary caregivers had to be parents. As the child's late parents' family they also had feelings of sadness and grief related to the death of their loved one.

Caregiver 06 said:" *There is a time when I feel sad...this child's mother kept it a secret. She did not disclose to anyone, it was her own secret. When you keep a secret, it will kill you. If she had disclosed, I could have told her that my child, women takes this route let us go there [to the Wellness Clinic]. Even now she could be alive.*"

Other caregivers said that they were frustrated and felt angry towards their dead family members who did not disclose their HIV status as they thought that the disclosure might have saved their lives.

Caregiver 04, when talking about her feeling towards her late sister, the child living with HIV's mother, said:

"I was angry at her [parent of the child living with HIV], I was angry at her, as from the pamphlets I read and watching television, I realised that if she had tested maybe this child would have been negative. Maybe she could be alive, on treatment, just like these people who are here [persons' attending the Wellness Clinic]...I was angry at her but (pause) I am no longer angry at her I have accepted."

These findings concur with the ones in a study by Ssengonzi, (2007:342) which was carried out to explore the plight of older persons as caregivers of persons living with HIV and AIDS in Uganda and in a study by Vincent (2003:387) about extended families as caregivers in the United States of America. Both of these studies revealed that primary caregivers were deeply saddened by the death of their own children, the children's biological parents, and this took an emotional toll on them as they had no time to mourn and grieve as their attention was immediately to focus on the surviving children, especially the ones who were sick.

To add to the emotional toll of the primary caregivers in the current study, the primary caregivers said that prior to the confirmation of the children's HIV status, these children were not responding to treatment. This made the primary caregivers anxious because they thought that the children would also die, like their parents have died

b. Anxiety related to child's diagnosis and prognosis

Caring for a sick child made the primary caregivers anxious, as the child had frequent episodes of illnesses and the common medical treatment did not lead to improved health. The primary caregivers took the children to clinics and the hospital frequently hoping to find treatment that would lead to the relief of their children's illnesses. When they realised that there was no improvement in the children's conditions despite numerous consultations and treatments taken, the primary caregivers said the health care workers had suggested that the children be tested for HIV.

Caregiver 05 said the following in this regard: *"...at first I did not know that he has a disease such as this [referring to HIV]. After his mother passed away he became sick and I took him to the clinic. I even brought him here to Jubilee but the child continued to have diarrhoea. So they tested his blood and after that they told us what he was suffering from. It was difficult for*

me but I accepted...he was problematic he had fits. If he had an attack, we will all cry, even the small children...when I was not home they will call and say that the child is sick."

Caregiver 07's words were: *"when this child started, his mother did not want to tell us the truth until she died. After her death, it was then that we knew what the child's problem was...I realised that the child did not spend more than two days without being sick. I took him to the doctor. When they tested his blood they found out that he had tuberculosis. They said I should bring him to the clinic for a period of six months. After the six months, they checked him and said that he had to go for an operation. His testes were swollen. I took him to the hospital for the operation. Thereafter he was given a few months and they said that he should come back. They said that it was tonsillitis and they did a tonsillectomy. After the operations he was better, but I continued to bring him to the clinic."*

The blood test result did not bring relief to the primary caregivers as some of them were shocked to learn that their children had died of AIDS without their knowledge. To another caregiver who was the biological mother of a child living with HIV, it meant that she also had to come to terms with the knowledge that she was HIV positive as she had to be tested after it was found out that her child had tested positive.

Caregiver 06 said: *"he was well at first, three years after his mother died, he started having problems. One morning he had a high temperature. I was suprised, he was weak, and was not able to do anything. I tried everything in vain. I then took him to the clinic...they said I should take him to have a blood test...they said he is [HIV] positive...his mother also had this thing, she kept it a secret and did not tell me that she is like this. I only found out recently."*

The biological mother, caregiver 01 said: *"...in the beginning, I was not aware that he was this way, until I found out. I had hope that I may get something that will make him healthy, however I was also afraid that he will not live to a certain age, or I will eventually reach a stage that I accept that he is like this...I realised in 2000 that I have HIV when my child was sick."*

Wiener, Havens and Ng (2003: 374-375) point out that the biological mother of a child living with HIV often learns of her own HIV status at the same time that she discovers her child's HIV positive diagnosis. This challenges her as she has to deal with her own diagnosis as well as the diagnosis of her child. This could compromise her support for her young child at that stage (Havenga, 2011: 3).

The diagnosis of the child brought about relief for some primary caregivers as the child was started on antiretroviral treatment and the symptoms of the opportunistic infections were

relieved. To others the children's symptoms worsened and they were consequently at a loss as to what action to take. However, they continued with the treatment as they needed the child to be better. The primary caregivers prayed hoping that the treatment would work as they had seen that it worked for others who were attending the Wellness Clinic before them.

As suggested by caregiver 03 who said: *"we were not sure that these tablets will be effective. A lot of people were not yet taking this treatment...that time we did not know what made her sick, whether it was the tablets or what was actually happening...we were surprised that she was sick even when taking the tablets (referring to ARVs). So it was what frightened us. Is it the treatment, illness, will she survive?"*

McComsey and Leonard in the UNAIDS (2006:166) report implied in their findings in a study of the metabolic complications in children, that the caregivers of children living with HIV, did not find rest even though the children's HIV status was confirmed as the side effects associated with the antiretroviral treatment were more severe than the symptoms of the disease. In this McComsey and Leonard UNAIDS (2006:166) study, the caregivers were unable to distinguish between the complications of the disease and side effects associated with the drugs used for managing HIV.

Findings from studies by Thampanichawat (2008:203-204) on care giving for Thai children with HIV infection in Thailand, as well as a study by Wacharasin and Homchampa (2008:392) on uncovering a family care giving model in Thailand confirmed that primary caregivers were said to have wanted to know the truth about the diagnosis of their child living with HIV in order to remove the stress and anxiety they had for not knowing what was wrong with their child. They also did not understand why the treatment was not effective even after numerous visits to the clinics and hospitals. This was made worse by the experience they had had with caring for the family members who had died, the biological mothers of the children living with HIV.

As the children's conditions improved, the primary caregivers, in this current study had confidence and hope that the children would be well and were thus less anxious that the children living with HIV might die. Caregiver 03 said: *"...at first we were confused, we thought that maybe she would not make it ...we thought that if her mother passed away we will lose her too...she is now no longer sick, we have put that behind us, as we have realised that we should no longer worry about her as she complies with treatment"*

In a study done by Thampanichawat, (2008: 203-204) and Wacharasin and Homchampa (2008:393) it was also found that, even though at first the confirmation of the child's status as HIV positive came as a shock to the to the caregivers participating in that study, and they

were even in denial, later they began to accept the child's diagnosis and hope that the commencement of antiretroviral treatment would lead to the child's recovery.

The confidence brought about by knowing the child's diagnosis and the effectiveness of the Antiretroviral Treatment in this study, gave the primary caregivers hope that the child would live longer and even outlive them. This evoked feelings of fear for the future of the child in the event that the caregiver should die.

c. Fear of dying before child living with HIV is self-sufficient

The primary caregivers did not trust others with taking care of the child living with HIV, as they thought that these others might not understand the implication of the disease and the importance of compliance with antiretroviral treatment, as well as follow-up care at the Wellness Clinic. This caused fear and stress to the caregivers related to child's wellbeing should the primary caregivers themselves die before the child was self-sufficient. This should be viewed within the context that many of the primary caregivers who participated in this study were older adults.

Caregiver 02 raised these concerns by saying: *"I do not know what will happen to this child if I can die before she can be able to bring herself to the hospital. I do not know if one of her sisters can feel pity for her...when I am not around you find that the child did not have anything to eat...this thing is a problem to me, it stresses me, because this child is their sibling. If a mother can give birth to us [referring to siblings], we are supposed to love one another as siblings, we should not discriminate others. Even if we can fight at times, when I remember that we are a family I will reconcile with them."*

The primary caregivers also reported that they were told at the Wellness Clinic that the children should be accompanied by an adult when coming for follow up care. This led to fear of death because it meant that were the caregivers to die while they were still reliant on the caregiver children for such help, then the children would have no one to accompany them to the clinic for follow up care and treatment refills.

Caregiver 02 also added by saying: *"...when we were talking earlier on she [the child living with HIV] said that you [the primary caregiver] think I am stupid, I can come to the hospital alone if you can give me money. I told her that they will not agree to give you the medication when I am not around."* [The age of this specific child, living with HIV was.12].

Caregiver 07 said: *"...as you realise this disease is incurable. What kind of a disease is this one... if I can die who will bring him to the hospital? Yes it bothers me as I do not have*

another child who can take care of him. They have died because of this disease...do you think his uncles will cope?"

One of the primary caregivers was concerned about the wellbeing of the child living with HIV, as she assumed that the child's sisters did not seem to care about what happened to their younger sister [the child living with HIV]. The primary caregiver mentioned that the sisters enjoyed the food that she bought with the foster care grant of the child living with HIV, but were not happy when it came to caring for their sibling.

Caregiver 02 said: *"...my concern is that she is going to remain with enemies who will misuse her grant...the other sister does not wash this child's clothes, does not cook for her but when this child has received her grant I buy food and they eat"*.

This primary caregiver therefore mentioned that she wished that she could live until the child living with HIV was self-sufficient.

Caregiver 02 said: *"Yes I am bothered by the fact that if I can pass away, this child should be able to take care of herself, and take treatment...I wish I can whisper to God and tell him that I should pass away this week and she the following one, so that we can go together, because she will suffer. This is what I think, but I do not tell her, it is my secret; I do not want it to bother her. God should grant us life, until this child is self-sufficient, that is what I ask."*

The fact that the primary caregivers thought about the future of the children living with HIV was furthermore supported by one caregiver who said that she was investing some of the child's foster care grant for when she [the primary caregiver] would no longer be alive to take care of the child.

Caregiver 06 said: *"...two of them receive the grant...after I have got it I save some of it to assist with their education if I can die. I invest it for them, buy food. I start with the savings so that when I die...If you eat without thinking of the future the children will suffer...yes when the government assist us it is alright. I am almost at the end of the road, so I have to invest for my child. Even if God call me to be with Him, I will have saved for their future."*

The findings from this study are supported by the findings from the study by Thampanichawat (2008:204) which assumed that, the primary caregivers felt that it was their responsibility to protect the child living with HIV from secondary grief that could occur in case the primary caregiver died. This evoked feelings of fear within them, especially because it would have meant that the child would be left in the care of the other siblings who were also not old enough to can take proper care of the child.

In the study by Thampanichawat (2008:204) the findings revealed that caregivers wished that God could make it possible for them to live longer until the children living with HIV could be mature and able to care for themselves.

The primary caregivers in this study said that they felt that the children living with HIV need to be given loving care.

d. Deeper sense of love and concern for the child.

As the children were orphaned, the primary caregivers made an effort to treat them with love and compassion. Some mentioned that it was because the child was related to them (or was family) and was also a consolation as their own child, the child's parent, had died. The primary caregivers' tone of voice reflected the compassion they felt for the children living with HIV when they shared this information.

Caregiver 08 had this to say: *"...even when it is difficult we do everything to care for him because he is the youngest at home. He is our blood, when we see him he comforts us because his father died. We continue caring for him like his grandmother did. We all love him. He started staying with us when he was still small, he was not even walking then. When I remember how we suffered when he was sick, it will be suprising if we can abandon him. My children have accepted him, he is our child, and he is their sibling."*

Caregiver 05's words were: *"I give him love because the parent is not available. I love them all, they are my children, I also love my children. He comes to me for comfort; there is no other one he can go to. I have to give him maternal and grandmotherly love, and also because he is my grandchild, I am supposed to love him because I comfort myself with him, because his mother and brother passed away at the same time."*

This concern and love for the child living with HIV was confirmed in studies by Wacharasin and Homchampa, (2008:390); Ssengozi, (2007:350); and Thampanichawat, (2008:204) where the caregivers said that they were encouraged by the fact that the children they were taking care of, were their blood relatives who lost their mothers and were still young. This meant that the caregiver had to provide parental level attention to the child living with HIV. They also described feelings of love, attachment and sympathy that they had for the child even before the diagnosis was confirmed.

The primary caregivers in this study reported that they gave less attention to their own biological children at times in order to give the child living with HIV the best care possible to ensure their survival. However, the caregivers also felt that the children living with HIV

should not be given preferential treatment as the other children in the family would be negatively influenced by this.

Caregiver 04's words were: *"... this child when his mother passed away ... my child was also small. I realised that I was neglecting mine a little bit because I was busy taking care of this child so that he can grow up. When his mother passed away, mine had to be weaned from the breast. I started this one on the bottle as he was breastfed. My aunt took my child with her until he was weaned off the bottle. They then became my twins."*

The children living with HIV were also attached to the primary caregivers and did not want to be separated from them. Caregiver 06 said: *"... he does not have any worries when he is with me, not at all. If I can be away for two weeks, he asks:" Where is granny, when will she come back?" He does not want to be separated from me."*

One primary caregiver said that she had to move with the child to live elsewhere as the child's older sisters did not take good care of the child. The older sisters complained that the caregiver loved the child living with HIV more than she loved them.

Caregiver 02 said: *"...the two of us live in her [child living with HIV's] [belated] mother's shack [informal semi-permanent housing structure]. We got out of that mess...so I told her to come and stay with me so that they can remain in my house... we do not have any problems. It is okay when we are together. Others complain that I love her more than them. I think they want me to neglect this child...I love this child very much. I do not love her because of the grant that she is receiving, I just love her..."*

In the study by Zebrack (2007:928) on mental health issues in medically ill children and adolescents in Philadelphia and one by Ethier (2009:575) on children who were suffering from chronic diseases, it was suggested that the caregivers worried about the children who were sick and were protective towards these children, and this made the other siblings feel neglected and not worthy of the caregivers' attention.

In the same studies, these siblings were reported to have feelings of anger, guilt and jealousy towards the sick children who were the centre of attention of the caregivers. The siblings were angered because, for instance, they had to take over the tasks of the children who were sick.

In a study by Kipp et al. (2007:865) about family caregivers in rural Uganda, .and in a study by Wacharasin and Homchampa (2008:393), the researchers suggested that as the caregivers did not complain much about their difficulties and challenges, an assumption was

made by the researchers that the primary caregivers were able to provide loving care to the children living with HIV.

The primary caregivers in this study reported that they had to limit their time away from the children living with HIV and thereby decreasing their social interaction.

3.4.1.2 Decreased social interaction in order to focus on the child living with HIV

The primary caregivers mentioned that they needed to ensure that the children living with HIV always receives proper care and attention. As the care of the children living with HIV was a priority they would rather take the children along when going for a visit to their friends or other family members. The children were at times not allowed to visit other relatives, during the weekend or school vacations for fear that the friends or family members would not be able to take care of them.

The words of caregiver 04 were: *"...when I am going somewhere I would rather leave my child (referring to her biological child) behind. When I am going away and am not sure that they will give him treatment. Will they give him the treatment late, or will they forget to give it to him? So when I go away, and am not sure when will I come back, I take him (the child living with HIV who is the primary caregiver's nephew) along, and take his treatment."*

Caregiver 05 said: *"...I do not want him to go anywhere else because others will not give him the medication. He knows, when the school, closes, others go to other places. He remains at home with me or he will say that he is going to visit his aunt, he loves going there."*

When the primary caregivers had left the children living with HIV at home with other family members, they were often called back when the child became sick. The primary caregivers had to also cut their visits short if they had to take the child to the Wellness Clinic for follow-up visits.

As primary caregiver 05 stated, *"...if he [the child living with HIV] could have an attack [referring to a convulsion] when I was not around they [the other children who were temporarily responsible for his care] will call me and I will be met by the other children crying."*

Another primary caregiver's comment (caregiver 06) was as follows: *"I came back yesterday, I was not home having gone to a funeral. When I remembered his treatment...I told them that I will be leaving on Monday, because my child is my first priority. They asked, (the family at the funeral) should you go so soon? I told them that I have to bring my child to the clinic, it is the day for his appointment, it is the 14th, and I have to take him to the clinic tomorrow."*

The findings of this study reveal that it seems the primary caregivers' concern about, and not trusting other people to give proper care to the child living with HIV led them to sacrifice the social commitments that could have taken them away from home.

These findings concur with other studies done on primary caregivers of children living with HIV which found that the caregivers had to adjust their way of living and not to be involved in social activities like parties, weddings and funerals as they did before in order to be with the child as they did not want to leave the child in the care of other people (Ssengonzi, 2007:348; Thampanichawat, 2008:207).

In a study by Zebrack (2007:935) the researchers found that parents had difficulty in balancing their parental role, work and family relationships with other family members as they had to care for the ill child in the hospital.

However some primary caregivers in this study revealed that they at times allowed the child to visit supportive relatives. The primary caregivers would write down instructions related to the care of the child and of the taking of medication. In this way they impart important information to the other members of the family empowering them with knowledge to care effectively for the child living with HIV.

3.4.1.3 Empowering self with knowledge for effective care of self and the child living with HIV

Taking care of a child living with HIV, as experienced by the primary caregivers in this study, was something which occurred without warning or preparation when the parents of the children living with HIV died and the caregivers had to take over as the children's caregivers. To some of them this was the first time that they had to take care of a sick child even though they lacked the necessary knowledge and skills in how to deal with the situation. Even though the healthcare workers at the Wellness Clinic gave health education to some it seemed inadequate. They therefore took it upon themselves to acquire relevant knowledge from other sources to supplement the health education given at the clinics and hospitals. These primary caregivers increased their knowledge by reading pamphlets, books, and watching television programmes on HIV/AIDS. One caregiver mentioned that she even attended a workshop in order to learn more about HIV related issues as she did not have any idea about how to care for a person living with HIV; the child she cared for was the first person she had to deal with in such circumstances.

Caregiver 04 stated: *"...we have to go on with life and assist this child to reach whatever age he can. So this made me to research if you have a child with HIV, how to protect yourself, how to assist him, and how to take care of yourself. You have to wash him when he has*

sores, you feed him and do everything...I attended workshops. When I saw a pamphlet about HIV I picked it up, when I found a book about HIV, I read it wanting to know what is happening. How will I be infected, as I care for him and what should I do? I have done level one of HIV and AIDS, so that I can have knowledge and know what to do...I also like reading and watch television. There is a programme in SABC 1 on Sunday...no Thursday afternoon. It speaks mostly about HIV and AIDS. I make sure that I do not miss it because one is able to implement their advice. Celebrities who disclose their status, books that give advice about HIV.”

She said the knowledge she gained enabled her to know more about the mode of transmission and how to protect herself and others from HIV infection. This knowledge also ensured that the primary caregiver was able to provide quality care for the child living with HIV. This knowledge also empowered the primary caregiver to protect herself from HIV infection when she was involved in intimate relationships.

She stated (caregiver 04) *“I still have a lot to learn in order to know what is happening. Even though I have gained knowledge from the level one workshop that I attended...yes it made me take care of myself better. At times you realised that our heads were unable to say (shaking head from side to side indicating a no), now they are able to. You did not worry about having an affair with a married man. Now you think carefully and before you say yes, you will say mmm...you will then refuse knowing that if you agree you will be tempted. You will realise that that man is involved with another woman, that woman with yet another man and so on...yes it enabled me to take care of myself better than before”*

The other primary caregivers said that the experience they gained from caring for a child living with HIV prepared them on how to care for their own biological children, should they ever be HIV positive. This was an eye opener for the primary caregivers and they were more accepting of people living with HIV because they realised that it could happen to anyone.

Caregiver 03 stated: *“...in fact it had taught me something [experience of caring for the child living with HIV]...I am engaged to someone, and he wants us to have children...when I looked at the situation of this child, I was undecided...I did not have a choice but to accept. It was difficult as I have realised that a lot of people become infected when they fall pregnant...I went to the clinic, for an HIV and pregnancy test, they were both positive...we discussed it [with her partner] and he confessed that he had an affair and he was infected at that time...the experience I had with this child [child living with HIV] was a difficult one...but now as it is going to happen to me, I do not know how will that make me feel...at the moment I have accepted what happened.”*

Caregiver 04's said: "... if he [the child living with HIV] was not HIV positive, I would not be knowing what I know now...I have sons and I need to learn. They are growing up, and will be going around doing all sorts of things. So if he can get burned along the way, how am I going to live with him? Should I discriminate him? Will I reprimand him? ... I will be able to accept them. You see I am not afraid of anything. I know that there is no problem."

The primary caregivers also learnt that it was important to take care of their own health so that they remained healthy and able to care for the child living with HIV. They were advised to do routine checks of their blood pressure, blood sugar, pap smears and HIV test. They realised the importance of knowing their own status and not live in ignorance.

Caregiver 05 had this to say:"...last month I went to the clinic, I had cold. When we were at the clinic, the nurses said we request that you should test. Not only young ones, even you older women ... Pap smear, blood sugar, and HIV. I went to check the pap smear, blood sugar, blood pressure and HIV. I never had any fear. They checked me and found out that it was negative."

The knowledge was shared with other relatives and people who wanted to know more about HIV/AIDS related issues. Furthermore, the knowledge gained about antiretroviral treatment and its effectiveness in controlling HIV gave the primary caregivers hope that the child would recover and outlive them.

Caregiver 04 explained, "...when a person speaks about HIV and AIDS, I tell them not to be stereotyped. When you speak about how you can get infected, you should also know that you can get infected if you have cuts, and abstain but have HIV, having forgotten that you are assisting a person who is HIV positive...the information that I get about the disease, enables me to assist other people. For the person who has a child, I tell them you can get infected with AIDS in different ways, not the ones that you know. You can take care of a child with bare hands, without gloves, but make sure that you do not have cuts on the hands that you are touching the child with. I tell them that hands are the most dangerous parts of a caregiver...so when we are together, they ask me how I cope because they heard that I have attended workshops. When things are this way I will say I did this and this and life will go on."

Wacharasin and Homchampa (2008:390) had similar results in their study where they found that primary caregivers wanted to render quality care to people living with HIV but did not know how to go about it. They made an effort to get this information from many resources such as books, radio, television, and health care workers. Others joined HIV clubs where they shared ideas with others.

Primary caregivers in the present study did not only rely on the knowledge and information about HIV/AIDS to enable them to render effective care for the children living with HIV. They also had faith and hope and put their trust in God as they believed that everything was possible because of Him.

3.4.1.4 Spiritual deepening leading to faith, hope and trust in God

Although it was important for the primary caregivers to realise that the treatment given to the children was making a difference in their lives, and this reduced the stress they were experiencing, and they acknowledged that they could not have managed without Prayer and intervention from God.

Caregiver 02 stated, *"We have to believe in God, because God supports you. We should pray earnestly and the God will support you. A person should not pray without commitment. There are prayers that when you pray you really feel God's power and support."*

The experience of caring for a child living with HIV lead primary caregivers to increased intimacy, hope, faith and trust in God. For many primary caregivers, this relationship with God often became their primary source of support, when they were challenged in caring for the child living with HIV.

Primary caregiver 05 said, *"I comfort myself with the Bible. I comfort myself with it and pray. When he becomes sick, I feel sad but comfort myself with the Bible...maybe a person may not comfort me...God is the one who will help you. If I believe that God will help me He is the one who will help me. So God will help me, he will heal him, he has given him to me."*

This intimate relationship with God enabled primary caregivers to renew their personal strength and lead to their own spiritual growth. Their spiritual deepening also increased their hope that God will make it possible for the child to live longer as according to them He made it possible for the children to make it to the age at which they were at that moment.

This was reflected in what was said by caregiver 02 who said: *"I however put my trust in God and I was patient. I am not the one who is taking care of these children, it is God. And because God takes care of them they have grown up."*

Caregiver 05 also added by saying: *"...after his mother died, he was having fits and a high temperature. I prayed and said that I am placing everything in your hands Lord, if You give him to me, it is only You who knows. I always prayed that You gave him to me, and here he is, from three years and he is ten."*

The findings of this study, that caring for a child living with HIV, led to spiritual deepening and strength from prayer, hope, faith and trust in God, concurs with the results of Pallangyo and Mayers (2009:40) in a study about experiences of informal female caregivers providing care for people living with HIV in Dar es Salaam who stated that primary caregivers regarded prayer as a source of their strength. The findings suggested that prayer helped the primary caregivers to take one day at a time and as each day passed they realised that the children grew stronger and healthier.

In a study by Chitando (2007b:17) on African churches and HIV/AIDS in Uganda and South Africa, religious faith was found to be a powerful source of comfort to many people who are infected and affected by HIV. Prayer was seen as powerful and enabling people living with HIV to feel good and healthy. The people who cared for them were also encouraged and strengthened spiritually. In Chitando's study (2007b:17) people were relieved to receive in their homes or hospitals Christians who prayed for them.

Even though the primary caregivers of children living with HIV in this study were encouraged and strengthened by their hope and trust in God, they were reluctant to disclose the child's HIV status.

3.4.2 Primary Caregivers' experiences related to the decision to disclose the child's HIV status to various role players

HIV and AIDS remains a disease that is clouded in secrecy even ten years after an eleven year old boy, Nkosi Johnson, boldly stood courageously to speak, at the world AIDS conference in Durban in 2000, against the stigma and discrimination against people infected with HIV (Ramphela, 2005:5). He together with his caregiver experienced stigmatisation and discrimination at school after the disclosure of his HIV status. He said: "I want people to understand about AIDS- to be careful and respect AIDS. You cannot get AIDS if you touch, hug, kiss, hold hands with someone who is infected. Care for us and accept us, we are human beings. We are normal, we have hands, we have feet, we can walk, we can talk, we have needs just like everyone else don't be afraid of us – we are all the same."

Primary caregivers in this study, were challenged by how and what to disclose to the children themselves, the family, the school educators and to the community. This difficulty to make a decision was influenced by the stigma and discrimination towards people living with HIV and their caregivers.

3.4.2.1 Experiences related to the decision to disclose to the child

The primary caregivers explained that they were encouraged by the healthcare workers to disclose the children's HIV status, after the results of the HIV tests revealed that the children were HIV positive. Primary caregivers were reluctant to do this as they were not sure about how the children would react to the news. In this regard, caregiver 05 said: *"Last time in...I do not know what month it was. Here at the Wellness Clinic, we were told that we should tell these children what they are suffering from. These children come to the clinic they are given tablets, but they do not know what they are suffering from. 'Please tell them tell them what the problem is.' So I explained to him but he does not understand that this disease [pause]...it can... [Pause] he does not know that this disease is the one that killed his mother and what its effects are."* [Child aged 10 years]

Caregiver 03 said, *"... it was difficult of course. This illness is a difficult one. We did not know how she was going to take it how she was going to feel. But she got used to it since we explained to her. She is free now and it does not bother her."* [child aged 12 years]

The role of the healthcare workers in encouraging the primary caregivers to disclose the children's diagnosis is shared by Lara, Vaz, Maman, Tshikandu and Benets (2010:254) who in their study on telling children they had HIV in Kinshasha, suggested that health care providers should take the initiative to tell the caregivers to disclose to the children what the diagnosis of their illness is.

However, and contrary to what the above caregivers have said, some caregivers in the current study said that they were told by the health care workers to tell the children about their HIV status only when they were older.

This was suggested by what caregiver 08 said: *"...no we are the only ones who know. His grandmother said she was told at the hospital that they will disclose to her because she is taking care of the child, but she should not tell him. He will know when he is older."*

As the children were too young to understand the implication of the disease, there was a concern that they might tell others about their illness and that these people might discriminate against them or isolate them. The child also might be discriminated against playing with other children due to their status being HIV positive. The other reason the caregivers gave for not disclosing the child's status to the child was that they wanted to protect the child from psychological distress.

Caregiver 01's words were: *"...it is difficult for me to tell him because I am trying to protect him. I think that I may cause him to be disturbed psychologically. I do not know how this*

thing will affect him. I protect him from knowing, to me he is still young. I protect him from psychological distress. He will say eish I am like this and that... whereas a child does not know what kind of a disease this is, he will say I am like this, saying it from lack of knowledge. You may find that this thing make other children to oppress him or whatever. I do not know but that is my viewpoint."

Caregiver 08 said: *"...we thought that he should grow up first. Thereafter we will take the step of telling him. He is still young, he will tell others at school. The neighbours will say do not play with him he will infect you. That is the reason why we are afraid of telling him."*
[Child aged 9 years]

The evidence from studies by Bogart, Burton, Cowgill, Ryan, Murphy, Elijah and Schuster (2008:245) on HIV related stigma among people with HIV and their families in the United States of America; Nehring, Lashley and Malm, (2000:10-11) on mothers' views on disclosing the diagnosis of paediatric HIV infection in the United States of America and a review of literature by Steele, Nelson and Cole (2007:63) on psychosocial functioning of children with HIV and AIDS infection, suggest that primary caregivers did not disclose to the children living with HIV as they wanted to protect the children from the bad news of hearing that they were HIV positive. The primary caregivers reported that the children were too young to cope with the diagnosis of being HIV positive. They were also concerned that others would discriminate against their children.

A study by Steele et al. (2007:63) suggests that the age of children determines when the caregivers will disclose the HIV status of the children. It suggests that disclosure to children of ages 4 to 5 is due to the desire of the family to be honest and the frustration of the caregiver that could result in unintentional disclosure to the children living with HIV. In children who are aged 6 to 10 years, caregivers disclose when the children start to ask the reasons that are related to their disease, or when the caregivers realise that disclosing the children's status will lead to cooperation in taking the treatment.

Primary caregivers in the current study said that the children asked them treatment related questions forcing them to disclose the child's status.

Caregiver 03 said: *"...she was suprised by the monthly follow-ups and what kind of illness is she suffering from that does not heal, and she had to collect treatment every month. Other children take tablets, when they have flu or stomach ache. They take them, get better, and then stop taking them. So why should she come to take treatment and be examined every month...we explained to her, my mother and me. The nurses at the clinic also urged us to tell*

her. As she is mature, it is important that she understands what kind of an illness this is, what will happen to her, she is also supposed to take her treatment. She understands.”

Studies by Steele et al. (2007:63) and Hejoaka (2009:873) on care and secrecy of a mother of a child living with HIV in Burkina Faso support the findings of this present study because the primary caregivers in their studies said the children had asked about their illness and treatment, and the caregivers realised that this could lead to the children refusing to continue with the treatment, so they told the children about their HIV status. This brought about a positive response from the children as they co-operated and took their medication.

Nehring et al. (2000:10-11) and Steele et al. (2007:64) suggest in their respective studies that it was not easy for biological parents to disclose their own HIV status to the children as it meant that they had to answer difficult questions from the child about the transmission of the virus. This made them to hold on to their resolve not to disclose the children's HIV status to them. The findings also suggested that telling the children that they are suffering from an “acceptable” illness was used to protect the children, rather than to tell them lies deliberately.

This was shared by the biological mother in this study: (caregiver 01) *“...he came and asked me:” Why am I taking this treatment?” It is difficult for me to tell him. At times when I tell him to take his treatment, he asks: until when am I going to take the treatment? One thing that encourages him, it does but it is not right. When he started understanding that he was sick, he had fits and he was taking treatment here in Jubilee...I do not know how this thing will affect him. This thing that he is HIV positive and he got the infection from me...I am waiting for him to be matured before I can explain to him what kind of a disease is he suffering from...and I should be ready to answer any questions that he will ask me.”*

The primary caregiver also said that it was difficult for her to give the child treatment as he sometimes refused to take it and asked how long he was going to take the treatment. The mother said that she was at times driven to tell the child that he would die if he did not take the treatment as prescribed.

Evidence from studies by Bikaako-Kajura, Luyirika, Purcell, Downing, Kaharuza, Mermin, Malamba and Bunnell (2006:589) on disclosure of HIV status and adherence to daily drug regimens among HIV infected children in Uganda, and a study by Hejoaka (2009:873), suggest that nondisclosure led to the children taking medication reluctantly, as they did not understand the reason for taking treatment even when they did not have any symptoms. This lack of understanding frustrated the caregivers as they had to force the children to take the medication, or even threaten them with death that would result from noncompliance with treatment requirements

According to the experiences of the primary caregivers in the current study, the reaction of the children to the disclosure of their HIV status was expressed differently. Some children were quiet, others did not show any reaction, while other children were sad, surprised and frightened.

Caregiver 02 explained the child's reaction as follows: *"...it is two years now but it does not seem to bother her. She is happy like any other child. I am happy when others come to play with her...she also goes to play with them at their homes."*

Caregiver 03 confirmed this when she said: *"She was surprised and frightened...we did not understand her reaction because she was quiet. She then asked how she was infected. We explained to her that the infection was transmitted from her mother...at first she was sad but she is used to it now and she knows that she is sick and have to take treatment. She understands..."*

These findings concurred with the literature where the findings of a study by Zebrack (2007:928) of children with cancer suggested that children reacted to disclosure in either a negative or a positive manner. The children felt sad, worried, relieved or had no reaction. Others were comforted after being given an explanation of the disease by their caregivers.

The primary caregivers were required to disclose the children's HIV status to the other family members and the community as well.

3.4.2.2 Experiences related to the decision to disclose to the family

Although it was not easy for the primary caregivers to disclose to the children, they explained the HIV status of the children living with HIV to the older family members. Even though this saddened the family members, they were supportive towards the children and assisted the primary caregiver in taking care of these children living with HIV in the absence of the primary caregivers.

Caregiver 03 said: *"... at home everybody knows. If I am not around my sister brings her to the hospital. We assist each other to bring her for treatment...we take turns in taking care of her, we make sure that there is always someone to keep an eye on her. They have accepted...they have accepted that the child is sick."*

Even though the primary caregivers would disclose to the older family members, they would not tell those they did not trust to keep a secret for fear of them breaking the confidentiality or even ridiculing the children living with HIV.

Caregiver 04's words when explaining the reason why she did not disclose to her younger child who was almost the same age as the child living with HIV that she was taking care of, were: *"...I am afraid to explain to him, because he talks too much. When he is with his friends he will tell them that this one has got AIDS, and they will tell the other children who play with him, because he does not understand. People has still got stigma, they still discriminate, and they will tell him not to play with their children. That is what I am thinking about, people are not the same."*

Caregiver 07 said the following about not disclosing the child's status to his older brother:

"I did not tell him...I am afraid to elaborate. When they quarrel the other one will say it is because you have HIV. I am afraid of that...it is just what I think because the older one at school... (pause) he finds things difficult, this one (the child living with HIV) is intelligent. When he is angry he says to his brother it is because you cannot manage at school. I think that if I explain to the older brother, he will use it against this one (the child living with HIV) and hurt him...that is why I am afraid to tell him. I am afraid to tell his brother because when they quarrel, when this one teases him, that one will tell him your problem is AIDS."

Disclosure of the children's HIV status by primary caregivers in the study by Steele et al. (2007:64) to families and network of friends, led to the family members and friends giving support in caring for the children living with HIV, self-competence and fewer behavioural problems of the children living with HIV. However, evidence from the study by Thampanichawat, (2008:206); Wacharasin and Homchampa, (2008:391) suggest that the primary caregivers did not disclose the children's HIV status to family members because they feared that the family members would discriminate against the children living with HIV and break the confidentiality.

Ethier (2009:590) suggests that it is important that the primary caregivers discuss the child's disease with the other siblings before they are told by any other person to avoid making them anxious due to not knowing what is happening with the sick child. The study by Zebrack (2007: 931) explains the importance of disclosing the child's disease to the siblings of all ages. He suggests that the children are curious to know about the condition of their sick sibling but are usually not told. This makes them feel frustrated or guilty that they are not sick and they consequently ignore the sick child in response to feeling left out.

Primary care givers in the current study rarely disclosed the children's status to the community for fear that the people in the community would stigmatise and discriminate against the children living with HIV and the family. Such discrimination was experienced by primary caregiver 05 who shared her experience as follows: *"It happened...when I say that*

they will discriminate against him. Our neighbour, whose son is a friend of my child [the child living with HIV]...my child had sores, she said do not play with him he has sores. Somebody told me that she overheard them saying that he has HIV and AIDS. I did not take it well."

The primary caregiver reacted to the discrimination against the child living with HIV with anger and even sent people to the neighbour to intervene. The primary caregiver feared how the stigma would affect the whole family, but the children were not even aware of what was happening and they remained friends.

Caregiver 05 said: *"I called my sister-in-law, my husband's sister. I told her to go to my neighbour and speak with her or we will stop speaking to each other...she denied having said that. She called her mother-in-law, who apologised to me...the children are good friends, it did not affect them."*

The study by Thampanichawat (2008:207) about care giving for Thai children living with HIV concurs with the findings of the current study, as the findings of the study revealed that the caregivers did not take kindly to the neighbours' discriminating behaviour and ridiculing of the children, and their need to protect the children led them to confront the perpetrators with aggression.

In this study, another primary caregiver said that they were forced to keep quiet to protect the child and the family from stigmatisation and discrimination. She said that she had the experience when one of her children was HIV positive and the community members were discriminating and stigmatising the family.

Her words were: (caregiver 06) *"...hee... (pause) some people ridicule others because of the disease. When they talk they will say, this thing that have AIDS. They do... someone said it to his uncle, that is why we are afraid that these words will hurt him. There is nothing wrong with the disease... it is no longer a secret. It was a secret before, now it is not. When you tell a child, he tells his friends. When he [the child living with HIV] is with them, they will tell him that you are suffering from this [referring to HIV]."*

The researchers in the study about family experiences of home caring for patients with HIV/AIDS in Limpopo found that primary caregivers were concerned that the ridicule and ostracism that the children living with HIV would be exposed to would make them sad (Tshililo & Davhana-Maselesele, 2009:139)). As a result, the primary caregivers continued to live in secrecy and not openly discuss the diagnosis with the children living with HIV themselves and other people outside the family. This was done to avoid the gossip that would have affected the children and the family.

However, and contrary to the above findings, other primary caregivers such as in this study, said that the reason they kept the child's HIV status a secret was that they had been told by the healthcare workers to keep the news to themselves and not tell it to other people.

Caregiver 08 said: *"...they said that it was our family secret. Even the other children at home just know that he comes to the clinic, we did not tell them what is wrong with him...no we were told that this is a rule. When you tell us something we abide by the rules. One of my sons was also sick; they also told him the same thing. They said it is your secret. He said father I am only telling you so that you will know what was the cause of my death. They said it has to be my secret...it is a secret because the hospital says that it should be like that. Yes they say it is for us to know we should not tell other people."*

He was supported by Caregiver 02 who said: *"...this thing that she is suffering from, they said we should not divulge it to others. It is our family secret."*

The findings from studies by Nehring et al. (2000:11) and Vincent (2003:375) support the findings of this study with regard to the stigmatisation and discrimination against people living with HIV and their caregivers. They claim that even though a lot of effort is taken to deal with the stigmatisation and discrimination against people infected and affected by HIV, there are still people who treat the people so infected and their families badly.

In order to ensure continuity of care when the child was at school, and to gain support of the educators, the primary caregivers said that it was important to tell the educators about the child's disease.

3.4.2.3 Experiences related to the decision to disclose to people outside the family

As the children had to be absent from school on follow-up days, primary caregivers felt that it was important to inform the educators about the children's HIV status. Some caregivers did this voluntarily while others waited for the educators to ask about the children's absence from school.

Caregiver 05 said: *"...they know because I report [the child's HIV positive status] in every class. Every grade that he attends I report to the class teacher. They know that he goes for a check-up every month, so that they should not hit him and say that he was absent from school...if he passes and goes to another grade, I go and explain that they should not be surprised if he does not come to school, once every month. When he is sick, I report to them. If he stays away two, three days, they know that he is sick, but if it is one day, they know that he has gone for a check-up."*

Caregiver 07 said: *“They called me and told me that they are surprised because the child is absent from school every month. I said when this child is absent from school it is because he has a problem, he has HIV. I had to take him to the hospital. They said it is okay.”*

However, other primary caregivers insisted that the children’s HIV status should remain confidential. Primary caregiver 08 said that he used deception when asked about the child’s disease at school. He reported that he was following the rules of the healthcare workers who had told them that the child’s HIV status should remain a family secret.

Caregiver 08 said: *“He tells them he has an appointment at the hospital. They know that every month he comes to the hospital. They just know that he comes here. They will not ask questions...my wife told me that it is for us to know what is wrong with our child...at his school they at times ask us to write on the forms what the child is suffering from. We do not write the right thing, we just write anything that suits us.”*

The study by Thampanichawat (2008:206) supports the above findings as the findings in their study suggested that most caregivers did not disclose the children’s infection to the others outside the family, including educators, as they were not sure of their reaction and were thus afraid that they would discriminate against the child.

The primary caregivers in the current study realised that disclosure to the educators was a positive step as the educators appreciated the efforts of the primary caregivers and commended them for sharing the information. The educators were supportive and were able to grant leave of absence to the scholars to attend the Wellness Clinic on appointment days. The educators also monitored the progress of the children at school and worked together with the primary caregivers to assist the child with academic work.

Caregiver 06 said the educators’ response was: *“...when he is absent they know that I have brought him to the clinic...they took it well. One of them said, granny we need people like you. A lot of people keep their children’s disease a secret. If a child is sick, even if it is any disease and not this one, when you take him to school you must tell them what he is suffering from.”*

Caregiver 03’s response was: *“Today she was supposed to have gone to school, they know, as well as her follow-up dates...they know that she is sick and she is supposed to take treatment...we have explained to them...at her school they do not have stress, they take care of her, and they love her very much. They make sure that she does not mix up with others and end up doing silly things. They take care of her and keep us updated. There is a teacher who comes at home to update us on her progress. I also go to school when they have called*

us in to report her progress...if her performance is not satisfactory they explain this to us as they know her to be an active child. We will then think that maybe she is not comfortable about something, and we will ask her what the problem may be.”

Evidence from studies by Steele et al. (2007:64) and Vincent (2003: 375) support the findings of this study, namely that disclosing the child's HIV status to the educators has a positive result as it provides additional resources for assistance with medicine adherence, social support and monitoring of the child. This leads to the child being competent and having fewer behavioural problems.

This evidence of support by educators after the disclosure of the children's chronic illness was also supported by a study of children with cancer done by Zebrack (2007: 930). The findings of their study suggested that the caregivers' decision to inform the educators about the children's illness was based on the need to gain support from the educators so as to promote the children's education and monitor their health.

However, another caregiver reported that the educators took the news negatively at first and even punished the child when her progress was not good at school. Caregiver 02 said: *“...at her school they are aware that the child is on treatment, and what her condition is. Others beat her at first. One of the teachers said: do not beat this child, she is sick. If you beat her you will confuse her. “*

The primary caregivers in this study did not see the need of disclosing the children's HIV status to the learners as they felt that they were too young to understand. This was expressed by the words of caregiver 03: *“...well the learners are not aware of her status [the child living with HIV]. It is a primary school, most of the children do not understand anything as they are still young. They see her as a normal child, they are not even aware that she is sick. The educators are the ones who know...she [the child living with HIV] understands because she is sick and she is on treatment.”*

The opinion of Ethier (2009:594) on this issue differs with the findings of this study by suggesting that the learners, especially the sick children's classmates, should be given an explanation of the children's disease, especially if it causes physical changes in the children.

Besides having to deal with the stigma and discrimination of caring for children living with HIV, the primary caregivers had to deal with many challenges that were inherent in caring for the children living with HIV.

3.4.3 Primary caregivers' challenges when caring for a child living with HIV

Caring for a child living with HIV poses a challenge to the primary caregivers, as most of them are elderly women and unemployed. These challenges are related to insufficient financial resources to meet the basic needs of the child, challenges related to the child's health care needs, and challenges related to caring for the child without exposing themselves and other family members to HIV infection.

3.4.3.1 Challenges related to insufficient financial resources to meet the basic needs of the child

Every family needs adequate money for it to survive and to be able to meet its basic daily needs. For primary caregivers this problem was compounded by the fact that the children living with HIV had special needs that need to be met in order to acquire and maintain the health status that will enable them to be asymptomatic. Money was also needed to take the child living with HIV to the health care facility when it is sick or for follow-up attention. Some of the antiretroviral treatment needs to be taken after meals and at times there was no food in the house. The children living with HIV were not the only ones who needed care but the primary caregivers' families and the children's siblings also required a share of the meagre finances of the primary caregivers.

The elderly primary caregivers were using their old age grants of R1080.00 per month (SASSA, 2010:n.p). They also supplemented their finances with the foster care grant of R710.00 that they received on behalf of the children living with HIV under their care (SASSA, 2010:n.p).

Even those primary caregivers who were young and could still be gainfully employed were unable to do so as they had to be home to ensure that the children were well cared for and that they were available when needed.

The studies conducted by other researchers made similar findings with the findings of this study, as they revealed that the primary caregivers' limited education, advanced age and need to be committed and focused on the sick person left them with no time to be gainfully employed (Pallangyo & Mayers, 2009:488).

The primary caregivers in this study were of the opinion that the children's biological fathers were not interested in maintaining their children financially, as some of them made empty promises to the primary caregivers. Even though they were not living with the children, the primary caregivers indicated that the fathers had to assist them to care for their children and to relieve the caregivers of their financial burden. It was difficult for the primary caregivers to meet the needs of their families due to the inadequate financial resources available to them.

Caregiver 05 said: *“His father is still alive, but after the funeral, [of child living with HIV’s mother] he never came again. He said that he will buy the child school uniform and I said that it was okay...when I meet him when doing shopping, he will say that I will come to see the child. He came this year and the child is already ten years, he was gone for long and this child loved him...he gave the child ten rand and said that he will come back during the weekend, he never did...he only came and gave him ten rand. He said he will come and buy him school uniform, he never did.”*

Caregiver 07 responded to the question asked about the income in the family as follows: *“I get an old age pension grant...I have to force it to. I take some of it to pay funeral societies, water, services and to buy this and that. I also save some of it for pocket money, and for something for them to eat after school.”*

Another one (caregiver 08) said: *“at home there are...I have two children and two grandchildren, they are four...when I include this one they are five. They are all attending school. I get the pension grant of R1000, 00. I use it to pay funeral societies, school fees because some of them pay school fees.”*

A study by Defilippi (2003:164) on dealing with poverty in South Africa and a study by Thampanichawat (2008:207), suggests that money was needed to care for the sick child, and to take the child to health care facilities which were most of the time far from their homes. The caregivers relied on the old age pensions to cover these costs. They also had to stretch the money to pay school fees for the children and their siblings.

The suspension of the foster care grant (R710.00 per child per month, SASSA, 2010:n.p) and the care dependency grant (R1080.00 per child per month, SASSA, 2010:n.p.) that the caregivers were receiving on behalf of the children made matters worse, especially because the caregivers were not informed in advance of the suspension. They reported that they were surprised when they arrived at the pay points and were told that the foster care grant was suspended and that they needed to reapply for it to be reinstated. They were not sure how long it was going to take for the applications to be processed.

The primary caregivers had this to say about the whole process:

Caregiver 05 had the following to say about this: *“...they suspended the grant. Since June I did not get it, even in July it was suspended. When I asked them why the money was suspended, they said that I did not come for them to check him. They said I was supposed to go to them twice or thrice a year, so that they can ensure that the child is still alive.”*

Caregiver 07 said: *"...their foster care grant. It has been suspended for long. It was R1420, 00. They suspended it in February. They said that they were going to renew it. I last got it in February, till today. ...I went there three times and asked them."*

The slow procedure followed to process the applications, which was seen to be inconsistent, and the documents required for application for the grant, frustrated the caregivers who were not well conversant with the process and thus had to be sent from one office to another. At times they had to resubmit the applications as they were told that their papers were lost and this meant a long wait for them.

Caregiver 05 said: *"...we went to the social workers. I had photocopies of all the documents so they were able to assist us. The schools were still closed for the winter vacation, and they said that they want his school report...when the school reopened; I went to request for it...I did not find the person who assisted me, but others were present so I gave it to them. They said my file was available and they will give the responsible person the report and she will call me. Last month I called as they did not call me. They said that she was not in and they will give her my contact details. I called again last week, and they said that she was still no available, but my name appeared on their computers and she will call me. However I did not get the grant in July."*

Her experience was confirmed by another (caregiver 07) who said: *"...when I go to the social worker they say that they have forgotten, they have lost my papers. I went there three times and asked them. They put them aside...last week I asked them, they searched all over, then said I should bring along the children. There are some forms that they are supposed to sign. The children have to sign. They told me to go home and they will call me so that I can go to court, to date I am still waiting. I manage them with my grant."*

At this period of waiting the primary caregivers had to make ends meet with the old age grant. The government did not offer any emergency financial assistance or food supplements to see the caregivers through this challenging period.

This was no problem to those caregivers who were fortunate to have adequate finances, as they were able to provide the child with the basic needs. Another primary caregiver had to ask the older children for assistance, however at times they were not able to do that and they had to manage without electricity for that time.

One caregiver 07 who had had enough of the whole situation said: *"...I do not care about not coping. They are the ones who are supposed to know because they have suspended the children's grant. They are the ones who are unable to make it possible for the foster care*

grant to be continued. Whatever they get is okay, there is nothing that I can do, because R1000.00 is not enough. I make payment for the societies, water and services.”

Despite the financial difficulties faced by the caregiver during this period the foster care grant of the children was managed properly. One primary caregiver said that even though the grant might not be sufficient, she made sure that she put it to good use when it was available.

Caregiver 05's words were: *“...his grant is for his needs...it covers his school needs. He travels by a special transport to school. I make lunchbox for him. Like the other children, some days he wants fruit or any other delicacy. When he requests that I buy anything for him, I do it. They have a school trip, they paid R150.00. I asked his grandfather to give me the money. They are going in September. If I do not get the grant, I will ask the money for the provision from his father. We also use it for coming here for the treatment. When he coughs, I need to take him to the clinic. I buy him clothing. At the moment he wants a bicycle.”*

Literature cited in a study by Tshililo & Davhana-Maselesele (2009:141) and a study by Defilippi (2003:166), support the findings in this study, namely that the family members were frustrated because the social workers delayed in processing and assisting them in applying for the grants. It took a long time for the whole process to be completed and for the foster care grant to be paid out. In the meantime the primary caregivers had to experience financial hardships, which made it impossible for them to meet the needs of the child living with HIV, and those of the other family members.

A study by Defilippi (2003:166), suggests that problems were worsened when the foster grants were suspended without warning. It is not easy to access the foster care grant, because of various reasons including: work overload, demotivated civil servants and social workers, long queues and poor service delivery in Government departments.

Even though primary caregivers in this study had financial difficulties, they did their best to give the children living with HIV the best care to ensure that their health needs were met.

3.4.3.2 Challenges related to health needs of the child:

The challenges of caring for a child living with HIV were not only financial, but also being faced with a sick child who was not showing any improvement took its toll on the caregivers as well. It is challenging to take care of children living with HIV, as they require a special kind of care due to the chronic nature of the illness. It takes patience and commitment to care for

these children and also involves physical care of a child who is ill, dealing with medicine compliance and prevention of episodes of illness.

a. Physical care of a sick child

The children living with HIV suffered from opportunistic infections at times. The primary caregivers reported to have had sleepless nights when this occurred. The kinds of illnesses they often had to deal with were: diarrhoea, vomiting, oral thrush, pyrexia, tuberculosis and convulsions. Daily visits to the clinic and numerous consultations which involved various health care providers were challenges that the primary caregivers had to face. The care of the sick child was not left to the primary caregiver alone, because the other members of the family had to assist to make sure that the child was cared for well.

Caregiver 04 said: *"...we only found out when this child was two years old. He did not gain weight, coughing and he was sick. I took him to the doctor time and again. I did not have knowledge about this disease as we never experienced it at home. I did not know what was happening if the child was that way. Traditionally we think that the child's problem is "tlhogwana". You take the child to a healer, and they will give him an enema, he will have diarrhoea then you will end up not knowing what to do..."*

Caregivers had to deal with long travels to other hospitals to have the children treated for one or other condition before the Wellness Clinic at Jubilee hospital in Hammanskraal, started operating. The primary caregiver who had to take care of a child living with HIV with persistent diarrhoea, caregiver 02 said: *"...when she first came to the hospital, she was having diarrhoea. I was washing her linen with 'dip' as it had an offensive smell. If you can come to our bedroom now, it smells nice. I am no longer using 'dip'. We just use stasoft to wash our linen so that it can smell nice...before we came here we went to a private doctor, who gave us medication and said that we should bring her back if she was not better. When we went back, she was worse. She was vomiting after every meal. She also vomited the medication we were given at the clinic."*

Findings from the study by Thampanichawat (2008:203), suggest that the primary caregivers struggled with finding relief for the children living with HIV's abnormal symptoms, which did not respond to treatment. These led the primary caregivers to have the child tested for HIV, which revealed that the child's HIV status was positive. The diagnosis enabled the child to be put on antiretroviral treatment

Findings from the work of Wacharasin and Homchampa (2008:390,391) confirmed the findings of the current study of attending to the needs of the children living with HIV without

being offended. The primary caregivers in the study by Wacharasin and Homchampa (2008:390-391), indicated that the people living with HIV did not offend the primary caregivers as they understood the children's problems and needs. The primary caregivers were polite and continued to perform activities with the children living with HIV. The primary caregivers also realised that the children needed not only physical support but also needed mental support from their families.

Caring for children living with HIV, became easier for the primary caregivers when the children were diagnosed and were put on antiretroviral treatment.

b. Dealing with treatment compliance

The primary caregivers said that they were relieved after the blood tests done revealed that the children were HIV positive and the children were started on antiretroviral treatment (ARV) at the Wellness Clinic. The primary caregivers stated that it did not take long after the children were started on antiretroviral treatment that the children's condition improved. The primary caregivers realised that the treatment was effective. The effectiveness of the treatment depended on full compliance. This posed a serious challenge to the primary caregivers as it meant that the children would require constant supervision to make sure that they took the treatment as prescribed.

This challenge is expressed by caregiver 03 as follows: *"... at first she was problematic but now she is not. She is taking her treatment well and she is no longer sick, she only have cold at times...it is because ... children are difficult. [Laughs] they are problematic especially when it comes to taking their tablets. Even this one was tricky saying that she drank her tablets when she did not. So we discovered that because when we checked the tablets, we could realise that she did not. She did not take her treatment, but now she does. She knows that she will live."*

The primary caregivers said that some children took the treatment willingly but others had to be forced to do so as they at times refused to take it. The primary caregivers stated that the refusal of the children to take treatment frustrated them and at times they had to threaten the children with death.

For instance, caregiver 04 said the following in this regard: *"... I show him the tablets. I open them and put them on the table. He will take them and drink them one by one; lastly he will take the multivitamin. If I will be not home for the weekend ... when I come back on Sunday I will ask if he did take the tablets. They will say you know that he is able to take the treatment by himself. I will ask him what tablets do you take in the morning, and he will say, a small one and a yellow one, they are the ones that he takes in the morning. He knows that he*

does not take multivitamin, I like giving it to him at night. He knows that he takes four at night and two in the morning ...it makes my task easier.”

Caregiver 01 said: *“At times when I speak with him he listens, but other times when he refuses to take medication I become irritated and asks him: do you know what this thing is?...he says I will stop taking this treatment. I say to him you will die, even if I know that I use a wrong thing to threaten him.”*

To make her monitoring and pill counting easier one primary caregiver made use of a seven days pill container. Caregiver 04 explained it thus: *“...when I arrive home I have containers. I put in tablets for seven days every Sunday night...Sunday night all containers are supposed to be empty. If I open the containers and find that they are not empty and I was not home, I will ask them, why are there tablets remaining? Which day did you not give him his tablets, or I will ask him: why did you not take your treatment?”*

The other issue mentioned by the primary caregivers in the current study, was the importance of adhering to the schedule when giving treatment to the children living with HIV. The caregivers implemented different methods as reminders to alert them and the children of the time for taking treatment. They used cell phone and watch alarms to remind them. Another caregiver reported that the child used the end of a daily television programme as a cue to remind them that it was time to take medication.

Similar strategies used as reminders for the children to take treatment were also found in studies by Hejoaka, (2009:873) and Wacharasin and Homchampa, (2008:391). The findings of these studies show that the primary caregivers used alarms clocks, mobile phones, and television programmes to make sure that they did not miss the time for giving antiretroviral treatment to the children living with HIV.

The primary caregivers in the current study also emphasised the importance of giving the children food before giving them the treatment.

Caregiver 06 said: *“...he is not problematic. He is not like the others who when you give them tablets, they swallow them one by one. I put them in his hands and he put them all in his mouth and drinks water. When you give him the tablets without first giving him food, he asks, why are you not giving me food? You are supposed to give him food first. I usually give him morvite.”*

The primary caregivers in the current study stated that the treatment improved the children's health and gave them a new lease on life. Therefore the primary caregivers did not want to take chances as far as compliance with the taking of treatment by the children living with

HIV was concerned. The primary caregivers did not allow the children living with HIV to visit relatives who would not give them treatment as prescribed.

Caregiver 05 had this to say: *"... his father is still alive ... one day he asked to take him to his place. I told him that I will agree that he visit him, but I do not know if you will be able to give him the treatment. I let him go for two days. When the child came back he was not given his medication...they explained that there should be no mistakes. He said that he will give him the medication. I told him that he takes this medication in the evening and in the morning. He did not give him medication."*

A UNAIDS (2006:161) study on promoting treatment adherence confirms the above findings as it shows that the primary caregivers were responsible for ensuring that the children living with HIV complied with treatment. The primary caregivers reported that health care workers explained to them that adherence of 90% to antiretroviral treatment by the children living with HIV is required to suppress the HI virus in the blood of a person living with HIV, as well as to decrease drug resistance.

Hejoaka (2009: 891) suggests in a study that concern around adhering to the time of taking treatment made primary caregivers to arrange their day to fit in with the child's times to take medication, as they did not entrust the task to other family members who they believed might not be aware of the time and nutritional needs or constraints of the child.

Even though some of the primary caregivers in the current study had a challenge with family members who did not give the children treatment as prescribed, other primary caregivers relied on the siblings of the children living with HIV and other members of their family to supervise and remind the children to take treatment in the primary caregivers' absence.

Caregiver 05 said: *"... his aunt is the one who always assists me ... when he goes to visit her, I write a note for him indicating the directions of taking the treatment. She is also used to the schedule, she sets the clock."*

Caregiver 06 said: *"...yes I explained to them that he should not miss a day without treatment. He should not miss the time. They told me here in the clinic...he should take his treatment as prescribed, I will explain all the details...food should be ready so that he can eat first before taking his treatment"*.

A study by Thampanichawat (2008:205) concurs with the findings of this study, by suggesting that when the responsibility of compliance with treatment is shared among the child, caregiver and family members, it becomes easier as they assist one another to remind the child to take treatment. So it was important for the primary caregiver to disclose the

child's status and explain the importance of strict adherence to treatment as prescribed by the doctor. The caregiver also explained the correct dosage and scheduling and allowed all people concerned to have access to the storage place of the medication.

According to caregiver 04, it is important to supervise the child to ensure compliance as the child could otherwise not be relied on to take treatment in the absence of the caregiver. Caregiver 04 said: *"...next time I will just tell him that it is seven and he will have to run to get the tablets. I will continue monitoring him, because...he may say that my mother does not see me and not take them. I will have to watch him take the tablets, and check that none falls and I will check them"*.

Thampanichawat (2008: 207) and Wacharasin and Homchampa (2008: 391) in their studies confirm this finding by suggesting that though the children were taking the treatment voluntarily, the primary caregivers explained that it was important for them to supervise the children to prevent any temptation to throw the treatment away. Another important factor was the accompaniment of the child to the clinic or hospital for follow-up and medication refills.

In the study by Thampanichawat, (2008:205) the results revealed that other caregivers did not take the child for follow-up treatment regularly as they sometimes did not have money for transport, or when they thought that the child looked better. However they would realise that they had made a mistake when the child's condition became worse.

In the present study the caregivers made sure that they did not miss the appointments for follow-up treatment, irrespective of the circumstances in which they found themselves; they would rather cut short their visits, ask for transport money or ask other family members to take the child to the Wellness Clinic. They reported that they did not want to go back to the emotional distress that they had experienced when the child had previously been sick.

Caregiver 06 said: *"... when I have to go somewhere, their aunt, and his brother knows that they have to bring him here. I do not want to have any problems with him."*

It is important to comply with antiretroviral treatment to prevent episodes of illness, as noncompliance also leads to drug resistance. However there were other measures taken by the primary caregivers to prevent the children living with HIV from being ill.

c. Prevention of episodes of illness

Primary caregivers maintained a clean environment and ensured that the child had a balanced diet in addition to taking treatment so that the child is able to attain and maintain a good and healthy status. The stress that the caregiver experienced when the child got sick

was something they did not want to experience repeatedly, so they made sure that they told the child to avoid cold food as according to them, it made the child sick. Another caregiver said that she did not allow the child to clean cold floors as she was afraid that it would make the child sick.

Caregiver 02 said: *“I prefer to be her cook for her, and give her food to eat. When we do not have meal I borrow from my neighbours, cook for her so that she can eat. I am happy when she eats, because she is sick, and when she does not I become upset...I do not allow her to clean the floor or to use cold water.”*

It was important for the caregivers to encourage proper nutrition, personal hygiene, environmental hygiene, taking of medication, and avoidance of certain food or activities that would predispose the child living with HIV to opportunistic infections or make their condition deteriorate.

Caregiver 03 said: *“...if she can be sick...she is naughty, she is not supposed to eat cold food. We were told that she is not supposed to eat or drink them. At times when she is at school, she will buy ice or something cold. When she arrives at home, she will start coughing. This will frighten us.”*

A UNAIDS study (2006:170) and a study by Wacharasin and Homchampa (2008:391) concurred with the findings of the current study about the importance of good nutrition in children living with HIV. The studies found that caregivers of children living with HIV realised the importance of providing a balanced diet to the children. The primary caregivers realised that good nutrition would assist in the maintenance of the immune system of the children and in keeping the children living with HIV active and healthy. They did this because they regarded the children as being vulnerable to illness and needed to be protected from opportunistic infections.

It was not only important to keep the child healthy but the family also needed to be protected from accidental HIV infection when taking care of the child living with HIV.

3.4.3.3 Challenges related to caring for the child without exposing self and other family members to HIV infection

The primary caregivers were educated on how to protect themselves and others from being infected by the HI Virus. They in turn taught the family universal infection prevention measures that in turn would not let the children living with HIV feel that they were discriminated against by being treated differently from others. However, one of the primary caregivers went to the extent of telling the child living with HIV not to wash dishes if she had sores or a cut.

She (caregiver 02) said: *"... it is just that I tell her that if you have sores don't, or if you are bleeding, do not touch the dishes ... it is just that here in the hospital they warned us that if she can get injured, do not allow her to touch anything because you will all become sick ... if she can get injured do not let her spill the blood all over because if it can touch food, you are all going to be sick"*.

They knew that they were not supposed to touch the blood with bare hands especially when their hands had injuries or cuts. One primary caregiver said that a person's hands were a potential danger to primary caregivers and need to be checked for cuts or injuries before handling any excretions or blood from a child living with HIV.

The children living with HIV were taught at school about the mode of transmission of the HI Virus so they also did not allow the primary caregivers to touch their blood with their bare hands. Primary caregiver 04 reported that the child had said: *"... mama do not touch my blood, they told us that we should not touch others' blood. He will also say do not touch my blood let me wipe myself."*

The findings in this study, namely that, the primary caregivers made sure to avoid the risk of exposure to the HI Virus are supported by a study by Hejoaka (2009:872) in which the primary caregivers stated that they were careful when they carried out their care giving tasks to avoid being infected by the HI Virus. In the same study, the findings suggested that even though the primary caregivers reported that they were not offended by the children living with HIV, they felt that they needed to protect themselves and other family members from being infected by the HI virus from the children living with HIV. They avoided exposure to blood and the children's vomitus by not touching the excretions with naked hands, especially when they had cuts or injuries. The primary caregivers also made sure that the whole family had their own toothbrushes, washing rags and razor blades (Hejoaka, 2009:872).

Despite the risk of the transmission of infection, the primary caregivers in the current study did everything in their power to show love and affection to the children by not using gloves when bathing them even when they had sores. They said that by wearing gloves it would seem to the children that the primary caregivers were repulsed by them.

Caregiver 05 said: *"...his grandfather shaves the child's head with a razor blade. He shaved him yesterday. When he bleeds, he will continue with the shaving, saying that as long as he does not have a cut or an injury it is not a problem."*

The study by Thampanichawat (2008:206) concurs with the findings in this study that the primary caregivers did not wear gloves when washing the children living with HIV. The

findings stated that some caregivers were not worried about being infected from care giving activities, as they were taught about the mode of transmission by the healthcare workers. To the caregivers in the same study, giving their children living with HIV loving care was their first priority and this overrode all the fears of being infected with HIV (Thampanichawat, 2008:206).

The primary caregivers tried to meet the needs of the child living with HIV and they received support from different sources to cope with the task of caring for the children and to render quality care to them.

3.4.4 The mobilisation of resources by primary caregivers to assist them in caring for a child living with HIV

The primary caregivers did all in their power to render quality care to children living with HIV. They realised that it was important to accept and find support so that the wellbeing of the children living with HIV would be ensured as well as to strengthen themselves psychologically and spiritually. The resources used by the primary caregivers included health professionals, informal support from family and support groups and spiritual resources.

3.4.4.1 Primary Caregivers viewed health professionals and the Wellness Clinic as a “life saver and a source of hope”

In order to address the HIV and AIDS epidemic, it is imperative to have a well-functioning health sector. As reflected from the discussion of the findings of this study, the caregivers revealed that they viewed the Wellness Clinic as a lifesaver and source of hope. This was because of the improvement of the children after their diagnosis and referral to the clinic where they were started on ART.

The Wellness Clinic at the Jubilee hospital opened its doors to people living with HIV in Hammanskraal and surrounding areas in 2005. The people welcomed this with open arms as before they had to travel long distances in order to access the antiretroviral drugs, or watch sadly as their loved ones died.

This was said by caregiver 01:“...before I came here to Jubilee, I started by taking bactrim and multivitamins until the time when we got ARVs here in 2005. We started with those others. We were praying when we heard that there were other hospitals that had ARVs. Hospitals like, Baragwanath, Kalafong and the others. I wished that if it was possible, I could get a transfer or go there to receive them. I wished that we could get ARVs. But at the moment I have hope that I am going to live, we are going to live.”

Caregiver 02's words were: *"I said Jubilee hospital is good and gives lives...yes she [the child living with HIV] regained her life and she is no longer problematic. When I brought her here she was having enuresis, her pants were always wet. I realised that she was not getting better when we were taking her to the clinic. Since we came here she is fine, she started walking, and no longer wets her pants."*

The caregivers reported that the care rendered at the Wellness Clinic was the best and that all the health care professionals at the clinic did their utmost to treat the people with respect. Primary caregivers appreciated the care rendered at the Wellness Clinic. For example, Caregiver 05 observed and remarked during the public servant strike when they did not expect to find any assistance at the clinic: *"...when we came here this morning, I remembered that it was said that there is going to be a strike. I was not sure that we will find them. They are here and we appreciate their help."*

When the children living with HIV had minor ailments, they were taken to local clinics and given treatment for these minor ailments. The primary caregivers also went there when they suffered from any disease. The primary caregivers were however not satisfied with the behaviour of some of the health professionals at the local clinics. The behaviour of the healthcare professionals at a local clinic was described as follows by caregiver 03: *"...our clinics are different from the others and this hospital [referring to Jubilee hospital]. It is difficult for me to ask some questions, as the nurses at our local clinic are not approachable as those who work here [referring to the Wellness Clinic] and other clinics. In our clinic...the nurses are rude one cannot talk to such a person."*

The result of a study by Jones (2010:10) on access to ARV medication and the politics of scale conducted at the Wellness Clinic at the Jubilee hospital in Hammanskraal, confirmed what the primary caregivers shared in this study. The results suggested that the participants regarded Wellness clinic staff as providing a better level of care than the staff in the main hospital and wards.

However not all the participants in the study by Jones (2010:10) expressed their satisfaction with the health care personnel at the Wellness Clinic. Other participant in the study said that they at times experienced problems of long waiting periods at the Wellness Clinic, as the clinic catered for many people. Participants also said that they waited a long time for their files and they were also given wrong appointments date. The other concern of the participants was the nursing staff and the receptionist who gossiped about people living with HIV when they were not present.

The findings confirmed in the same study conducted by Jones (2010:7), that a code was previously used at the Wellness Clinic to identify people living with HIV. The community voiced their dissatisfaction with the use of the code by health professionals and it was no longer used.

A primary caregiver in the present study said that she experienced the use of a discriminatory AIDS code by the health professional at the local clinic. She mentioned that she was also treated badly by the personnel in the local clinic.

Caregiver 02: *"...I had my blood tested...the nurse wrote 2 [paused in deep thought] there is a word that is written when one is positive, it is a number or code, I do not know whether it is 2880 or what...I at times worked with caregivers and I read books and I knew that there was a number that referred to people who are like that. Have you ever heard a person telling you that "it cannot be your child who is like this"...she published it on my file, this thing is not right..."*

In the current study primary caregivers appreciated that the Wellness Clinic had all services under 'one roof'. Therefore, referral to any member of the multidisciplinary team was done depending on the primary caregivers' and the children's needs. Caregiver 4 reported that when she felt that she could not cope with the pressure of caring for the child in her care living with HIV, and she had stress, she went to the social workers for counselling.

She said: (caregiver 04) *"...if I feel upset and something is worrying me, there are social workers, as well as counsellors who I will go to in order to talk to them. I will talk, cry, then come back home and everything will be back to normal. Life goes on."*

Although the social workers at the Wellness Clinic were helpful, this could not be said of those who worked at the welfare offices and assisted the caregivers with the application for grants. This was stated by caregiver 07 when she said: *"...social workers. They come at home and check how we use the grant, whether we buy clothes and other things for the children. They also check the grocery, even what we have in the refrigerator. They want to check how we spend the money. They do not say anything. They just get in and start writing. They do not help us with anything."*

The primary caregivers in this current study were only full of praise for all the healthcare workers working at the Wellness Clinic, and were grateful for their care and support.

The social workers at the Wellness Clinic were available to offer counselling and support to the primary caregivers, even though some caregivers also went to support groups for psychological support as these were in the areas nearer the caregivers' homes.

3.4.4.2 Primary Caregivers found that the informal social support groups and the family were a source of strength and encouragement

Although there was support groups referred to as care groups in the villages, this service was not utilised as a source of support by most caregivers in this study. However, those who went to the support groups reported that they were assisted by the counselling that they received from the people that were there. Caregiver 01 said: *"...experiences of taking care of this kind of a child is difficult...I was strong because I was going to care groups...they advised me and gave me courage until I told myself that I have to accept this thing that I have."*

Steele et al. (2007:62) suggest in their study that even though some caregivers in their study went to care groups to receive counselling for psychosocial problems, most of them relied more on passive coping strategies than on problem-focused active strategies like seeking social support. Thus their findings concur with the ones in this study.

The commitment of the family to assisting in the care of the child living with HIV led to most primary caregivers relying more on their families for support in caring for a child living with HIV.

Primary caregivers realised that they could not manage everything alone, because besides it being a challenge to care for a child living with HIV, they were at times forced to go somewhere to attend to other issues and as a result leave the child in the care of family members. The family of the caregivers were willing and supported the caregiver without complaint to the extent that when the child was sick and they were at work they came back home to offer their support.

Caregiver 03 said: *"...they usually call us. They are at work; they come home at month end. I am the one who stays with her at home. When they are not around, they will call on her follow-up date. They called this morning, reminding us that it is her follow-up date, we need to get up and not forget to go to the hospital...the family support her and do not treat her differently as she is like all the other children...when she is sick, everyone comes back home to support us. Even those who will be at work, request permission from their employers."*

To indicate the importance of family support, a male primary caregiver who took over the care of a child living with HIV after his wife passed away, had his older children, who were already living in their own homes, come over to his house to assist with the chores in the home. The primary caregiver's older children also assisted him with money to take care of the basic needs like school fees and food of the child living with HIV.

Caregiver 08 (male primary caregiver) said: *“the older ones...are the ones who assist me at home. When I talk to them, they come and help me. Yes I have people who help me when I cannot cope. But it is difficult especially when the mother is not around. It is not easy, because at times when they also cannot assist you find that we do not even have electricity.”*

According to Kipp et al. (2007:865), male primary caregivers were finding it hard to care for people living with HIV. Assistance from family members was a welcome relief to the male primary caregivers. The other family members of the male primary caregiver not only provided financial support but assisted with instrumental care of the person living with HIV.

Another caregiver 05 said the following about her relative who gave her support in caring for the child: *“His aunt is the one who always assisted me. She will ask how the child is. She used to accompany me to all the places that I took him to [when the child living HIV was sick].”*

The results from other studies concurred with the results in this study as they show that the support from family members in caring for a child living with HIV relieved the primary caregivers of emotional and material burdens. This also ensured continuity of care, treatment and follow-up which led to improved wellbeing of both the child and the caregiver (Hejoaka, 2009:873).

Even though the family relied on these other support systems, it did not forget the importance of going to church to worship with other church members.

3.4.4.3 Caregivers regarded the church as a source of support and comfort

Primary caregivers in this study seemed to not only depend on health care professionals and family as their source of support, but they also believed that everything that happened to them was the will of God who was also the one who gave them strength to see them through everything that they did and also healed the child living with HIV. They realised the importance of going to church to be with other members of the congregation.

Caregiver 02 said: *“...we have to believe in God because God supports us...we should also go to church.”*

The children also enjoyed going to church and this gave them hope for the future as caregiver 02 said: *“...we should also go to church. After the church service, she will be excited, saying that the service was inspiring, and she enjoyed the dancing. If I can just be committed to the hospital and to God, He will bless me and heal this child...if she is able to say...I am also going to be married to a man that is a Christian. I do not want someone who*

does not attend church. I can realise that she is mature, she says that she wants to be married to a priest.”

One of the caregivers reported that she was comforted by going to church and enjoyed the teachings that were offered. The words of caregiver 07 were as follows: “... *we cope because we go to church. Going to church where we are taught. They read the Bible for us and tell us how we are supposed to find comfort and to have faith. They say that we have to accept everything that comes our way”.*

The studies discussed below concur with the findings in this study that primary caregivers regarded attending church as a source of support.

Chitando (2007b:17-18) in a study on African churches and HIV/AIDS and Kipp et al. (2007:867) claim that the church in Africa is seen as a valuable resource in the response to the HIV and AIDS epidemic. Many Christians view prayer as the church’s unique contribution to the overall response to HIV and AIDS. The people believe that the churches must preach a message of love, healing and hope. Therefore it is crucial for the church to continue to emphasise the importance of prayer and spirituality to people living with HIV and those who care for them.

Parry (2008:72), in a study on HIV competent churches in Africa, suggests that it is important for churches to be knowledgeable about HIV/AIDS issues and be places where people will find identity, shared vision and share challenges and become part of a caring community. He said that the church can bring people together and reduce isolation and restore hope, dignity and be of comfort to people infected and affected by HIV. The role played by the church will assist the people to build inner resilience and strength to deal with the crises that they encounter.

Thus it is important for the churches to be places where people, irrespective of their HIV status, can go in times of need without fear of being stigmatised or ostracised (Chitando, 2007a:25).

The church must embrace everyone and assist people living with HIV and their families to regain hope and move out of doom and desolation in order to regain new life and be healed of their broken hearts (Chitando, 2007a:47).

3.5 SUMMARY

In this chapter the researcher presented the main findings of this study. These findings were organised according to categories and subcategories. The categories were: primary caregivers’ experiences in caring for a child living with HIV related to the **self of the**

caregiver; primary caregivers' **decision to disclose** the child's HIV status to various role players; primary caregivers' **challenges** caring for a child living with HIV; and the **mobilisation of resources** by primary caregivers to assist them in caring for a child living with HIV. The categories are supported by quotes from the unstructured interviews, as well as the studies from the literature.

In chapter 4, conclusion, limitations and recommendations based on the study findings are discussed.

CHAPTER 4

4.0 CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

4.1 INTRODUCTION

This chapter focuses on the conclusions that the researcher was able to arrive at based on the findings of the study. The third objective, namely, to make recommendations which are based on the findings of this study in order to assist the nursing personnel at the Wellness Clinic in the promotion of the mental health of primary caregivers, will be addressed in this chapter with reference made to nursing practice, nursing education and nursing research.

4.2 CONCLUSIONS

The aim of the study was to explore and describe the experiences of primary caregivers who provide care for children living with HIV and attending the Wellness Clinic at the Jubilee hospital, in Hammanskraal in order to make recommendations that will assist in the promotion of their mental health. In this study, five of the primary caregivers interviewed were elderly women. In a study by Meintjes and Hall (2010:99) UNAIDS, (2004:47) it was found that most of the children affected by HIV and AIDS are cared for by elderly women. The role of being caregivers also limit the primary caregivers' opportunity of being educated and gainfully employed (UNAIDS, 2006:90) as in the case of the three primary caregivers in this study who passed grade 12 but were staying at home to care for the children living with HIV.

In addition to their families, the primary caregivers had to take care of the children living with HIV and their own children as well as the other children who are the siblings of the children living with HIV. This might have led to an increase in the financial burden experienced by the primary caregivers. The primary caregivers claimed that the biological fathers of the maternal orphans living with HIV were not actively involved in the maintenance of their children living with HIV, thus the primary caregivers relied mostly on the social grants to meet the financial needs of the families. This meant that the primary caregivers had challenges to meet the basic needs of the children living with HIV, especially when the grants were suspended for renewal by the department of social services and no alternative means of income was provided to the primary caregivers.

The primary caregivers' experiences of caring for children living with HIV seemed to evoke both negative and positive emotions. The primary caregivers seemed not to have had time to grieve and mourn members of their families, the parents of the children living with HIV, as immediately after the death of the children's parents, they were faced with caring for the sick children.

The primary caregivers' sadness and worry about the health of the children living with HIV seemed to make them determined to get the necessary knowledge and skills that could lead to the diagnosis and recovery of the children. However the anxiety seemed not to affect the loving care that the primary caregivers gave to the children living with HIV. Furthermore the primary caregivers seemed to sacrifice their time of attending to other social activities to be with the children living with HIV.

The primary caregivers seemed reluctant to disclose the HIV status of the children living with HIV to the children, themselves, but found it easier to disclose the children's status to the family and educators. The reluctance to disclose the status of the children living with HIV was attributed to fear of stigma and discrimination against these children and the primary caregivers were the children to disclose their HIV status to others outside the family. The disclosure of the children's HIV status to the family and educators seemed to have had a positive response, as the primary caregivers were given support by the family members and educators. Primary caregivers revealed that they experienced mixed messages from health care practitioners about disclosure to others outside the family.

The Wellness Clinic at the Jubilee hospital in Hammanskraal was regarded as a "life saver" by primary caregivers of children living with HIV, as it appeared that after the children living with HIV had been referred to the Wellness Clinic and were given antiretroviral treatment, their symptoms were relieved and their health improved. It appeared that the healthcare workers were committed to assisting the primary caregivers in meeting their physical, social and psychological needs as well as those of the children living with HIV.

The primary caregivers seemed to regard the family support as more valuable than the support groups that were available in the community. However, this might have been due to the fear of stigma and discrimination. The support of the church seemed also to be a source of strength, courage and hope for the primary caregivers and the children living with HIV.

Based on the findings of the study and above conclusions, the researcher made the recommendations that will assist the nurses in the promotion of the mental health of the primary caregivers.

4.3 RECOMMENDATIONS

Recommendations will be made to meet the purpose of the Theory for Health Promotion in Nursing (University of Johannesburg, Department of Nursing Science, 2009), which is the promotion of the mental health of the primary caregivers and their families. The recommendations will be aimed at assisting the nursing personnel at the Wellness Clinic to mobilise resources in order to render holistic care to primary caregivers who will facilitate the promotion of their mental health and that of their families. Furthermore a holistic approach where both the internal (physical, psychological and spiritual) and external resources such as health, welfare, educational sectors, the church and nongovernmental organisations are mobilised will be discussed. Promoting the mental health of primary caregivers will enhance their ability to be effective and efficient caregivers for the children living with HIV. The professional nurse as a sensitive therapeutic agent in the Wellness Clinic will assist caregivers to mobilise these resources. Further recommendations about education and future research will also be made.

4.3.1 Recommendations for nursing practice

As the findings of this study suggest primary caregivers experienced negative emotions as well as positive emotions when caring for children living with HIV. Thus in order to meet the needs of the primary caregivers' internal environment, the researcher recommends that the nursing personnel at the Wellness Clinic should take history which also focuses on the primary caregivers physical, psychosocial and spiritual needs and identify primary caregivers who cannot cope with these emotions and refer them to the psychologist or the social worker for psychotherapy. The nursing personnel should acknowledge the role played by prayer and the church in the psychological and spiritual health of primary caregivers.

As the findings suggest, the primary caregivers seemed to continue with the silence surrounding the disclosure of the HIV status of the children living with HIV to the children themselves, to avoid stigmatisation and discrimination against the children and the primary caregivers. The nursing personnel should therefore support these primary caregivers who are not ready to disclose the HIV status of the children, and assist them in disclosing this information as it will free the primary caregivers from psychological distress, which might result from keeping a secret regarding this.

Naeem-Sheik and Gray (2005:48) recommend the following: the primary caregivers be counselled by knowledgeable nursing personnel about disclosure to the children living with HIV themselves; the counselling be done continuously; the children's cognitive ability, age, clinical status and social circumstances be considered; the children's fears, reactions and

misconceptions should be addressed; the process of disclosure be done after assessing the children's knowledge about HIV and their ability to cope with the disclosure; disclosure should be done in the presence of the nursing personnel if the primary caregivers are uncomfortable about doing this alone; role playing with the primary caregivers will enable them to prepare for answering the questions of the children living with HIV, and to offer support if the children were to react negatively to the disclosure.

The nursing personnel should refer the children and the primary caregivers to social workers or psychologists for further individual or family therapy should the family not cope after the disclosure and counselling by the nurses.

The nursing personnel should be advocates for the primary caregivers by working in collaboration with other departments and sectors to educate the community about how HIV is transmitted and the rights of children living with HIV in order to eradicate the stigmatisation and discrimination related to HIV. The primary caregivers should be encouraged by the nurses to report any experiences of stigmatisation and discrimination, and they should be referred to the social workers who will assist them to get legal resources to address the challenges and to deal with the perpetrators.

To assist the primary caregivers in meeting their social needs, the nursing personnel should encourage the primary caregivers to mobilise resources in the form of support groups. The support groups may benefit the primary caregivers psychologically and physically as well as assist them to deal with life challenges following from taking care of children infected with HIV and them themselves being affected by it.

The support groups may meet in churches in the communities as these are normally accessible and within walking distance of the primary caregivers. Support groups will also enable the primary caregivers to share experiences with others who will not judge or stigmatise them. The primary caregivers will also learn from one another new ways of coping with challenges and stressors associated with caring children living with HIV. The primary caregivers will be motivated and have hope when they realise that others do cope in similar situations that they also face. Support groups are also a platform to form fulfilling interpersonal relationships with others (Yalom and Leszcz, 2005:519).

The nursing personnel should encourage the primary caregivers to take time off from being with the children living with HIV, but only if a suitable alternative caregiver is available. The primary caregivers should be encouraged to be able to trust to leave the children living with

HIV in the care of family members who are willing to assist in taking care of these children. This will give the primary caregivers time to relax, to be with friends and to attend to their own interests and hobbies they enjoy doing. Taking time off could enable the primary caregivers to render effective and efficient care to the children without compromising their mental and physical health needs.

To assist the primary caregivers to cope with the challenges of caring for the children living with HIV, the nursing personnel should give health information to primary caregivers so as to increase their knowledge of child rearing and parenting skills. Furthermore the primary caregivers should be educated in universal precautions to prevent infection with the HIV when attending to the basic needs of the children living with the virus. These precautions are: personal hygiene should be maintained; the immediate environment should be clean at all times; food should be prepared in a clean environment and be covered at all times; fruits and vegetables should be washed thoroughly before being eaten or prepared; cuts or open sores and wounds on the skin should be covered with a bandage; hands should be washed with soap and water before and after using the bathroom, before preparing or eating food, after contact with blood or other bodily fluids; cleaning up spills of blood or other bodily fluids with 1:9 part chlorine or vinegar: water solution. Cleaning should be done with gloves or plastic bags on hands; soiled clothes should be washed separately in hot soapy water or be disinfected with a chlorine and water solution before washing; the clothing should be aired and dried in the sun; dispose of water that contain blood or bodily fluids in a toilet; dispose the gloves and infected plastics in the pit latrine or burn it (Ziady, 2003:132).

The nursing personnel at the Wellness Clinic should also educate the primary caregivers in the importance of giving the children antiretroviral treatment (ART) as prescribed to prevent drug resistance. The nursing personnel should also suggest to the primary caregivers to make use of pill boxes which can contain treatment for seven days at a time and can be refilled at the end of each week. The pill boxes will make it easier for the primary caregivers to monitor compliance with treatment and to check if the children have missed any treatment. The nursing personnel should assist the primary caregivers to draw a treatment plan as a means of keeping a record of the children's treatment. The plan should reflect the name of the treatment, dosage, frequency, and dates as well as comments that should include whether the treatment was taken, not taken, taken late or the child reacted badly after taking the treatment (Soul Buddyz, 2006:22).

It is important to include the children in the treatment plan to ensure their compliance and cooperation when they should take their ART. Other family members can also assist the primary caregivers to give the treatment to the children living with HIV. The primary caregivers should be encouraged or educated in the use of a reminder system by, for

example, setting an alarm clock, cellular telephone, or making the taking of the treatment part of the children's daily routine. For example the children may be made to take treatment after brushing their teeth in the morning and evening, and to ensure that they adhere to the same times for carrying out the routine.

In order to relieve the primary caregivers from their financial burden, the nursing personnel should refer the primary caregivers to social workers who will assist them with the processing of applications for social grants or refer them to the relevant departments responsible for such applications. The social workers should assist primary caregivers by providing them with food parcels when the social grants have been suspended. The church should also play an important role in the alleviation of hunger of the primary caregivers and the children living with HIV by identifying members of their congregations who are poor, and provide food or any assistance that will relieve the primary caregivers' financial burden.

The nursing personnel should work together with the department of agriculture and assist the primary caregivers to start vegetable gardens individually at home, or in a group start a community garden. The primary caregivers can be given seeds or seedlings from the department of agriculture and be encouraged to make composts and to use the water they have used for bathing and laundry to water the gardens. The department of agriculture may also assist the primary caregivers with how to get water supply and funding to start gardening activities (Defilippi, 2003:169).

The researcher suggests that continuous health education by the nursing personnel related to how HIV is transmitted and how to take care of children who are suffering from opportunistic infections, might lead to primary caregivers acquiring invaluable information on caring for children living with HIV as well as promote the mental health of the children, primary caregivers, families and communities. The education should also be focused on ways to include the community in the eradication of the stigma and discrimination against children living with HIV and their primary caregivers.

4.3.2 Recommendations for nursing education

The researcher suggests inclusion of child- friendly and community-based care in the training of nursing personnel. Tertiary institutions should emphasise HIV/AIDS issues in the curriculum, including how to assist the primary caregivers in the disclosure of the status of the children living with HIV to the children themselves, the family and the community.

Student nurses should be educated in the importance of advocating for the children living with HIV and their primary caregivers when they experience stigmatisation and discrimination.

The researcher also suggests that the student nurses' curriculum should include training that will enable the students to acquire individual, group and family therapy skills. The skills acquired by the professional nurses will make it possible for the primary caregivers to receive effective and efficient care from the Wellness Clinic.

4.3.3 Recommendations for nursing research

Research that will explore the care giving experiences of biological parents needs to be conducted either in the same setting or in another setting because their experiences might differ from those of primary caregivers who are not biological parents of children living with HIV. The feelings of guilt from the biological mothers may make it difficult for them to disclose the children's HIV status.

Research should also be conducted to explore the experiences of primary caregivers in households headed by children as well as explore the experiences of siblings of children living with HIV. It is also important that research be done to explore the effect of living with HIV on the children's learning needs.

Even though the primary caregivers were able to share their experiences of care giving with the researcher, there were limitations to the study.

4.4 LIMITATIONS OF THE STUDY

Based on the qualitative design of this study, eight primary caregivers were selected purposively. As this is not a representative sample of primary caregivers caring for children living with HIV attending the Wellness Clinic at the Jubilee hospital in Hammanskraal, so the findings of the study cannot be generalised to other settings.

The sample consisted mostly of caregivers who were not biological parents of the children living with HIV. Their experiences might not be the same as those of primary caregivers who are the biological parents of the children living with HIV.

The separation of the primary caregivers from the children during the interview might have led to the primary caregivers terminating the interview prematurely as they wanted to make sure that the children were receiving care and attention.

In spite of the limitations, the study was an opportunity for the researcher to give the primary caregivers a chance to voice their concerns and share their positive and negative experiences of caring for children living with HIV. This study provided information that will lead to further research and the ability to improve the Wellness Clinic services as well as the mental health of the primary caregivers and their children.

4.5 CONCLUSION

In this study the researcher was able to come to an assumption that although it is a challenge to care for children living with HIV, the primary caregivers are committed to caring for these children with love as they are their family members. The study gave the primary caregivers an opportunity to share with the researcher their feelings related to the care of the children living with HIV. Furthermore the availability of the Wellness Clinic in a rural area of Hammanskraal was a relief and gave the community hope for a better life for the children living with HIV.

The recommendations stated above should assist the nursing personnel in the rendering of quality care to the children living with HIV and their primary caregivers in a holistic manner.

In the discussions in the chapters above, the researcher was able to use the qualitative research method in order to enable the primary caregivers to share their experiences of caring for children living with HIV. The researcher was thus able to meet all the objectives as set out in chapter 1. The researcher was able to: i) describe the biographical data of primary caregivers; ii) explore and describe the experiences of primary caregivers caring for children living with HIV and iii) make recommendations based on the findings of the study, in order to assist the nursing personnel at the Wellness Clinic in the promotion of the mental health of primary caregivers.

REFERENCES

- Bikaako-Kajura, W., Luyirika, E., Purcell, D.W., Downing, J., Kaharuzza, F., Mermin, J., Malamba, S. & Bunnell, R. (2006). Disclosure of HIV status and adherence to daily drug regimens among HIV infected children in Uganda. *AIDS behaviour*, 10: 585-593.
- Bloomberg, L.D. & Volpe, M. (2008). *Completing your qualitative dissertation. A roadmap from beginning to end*. London: Sage publications.
- Bogart, L.M., Burton, O., Cowgill, D.K., Ryan, G. Murphy, D.A., Elijah, J. & Schuster M.A. (2008). HIV related stigma among people with HIV and their families: a qualitative analysis. *AIDS behaviour*, 12: 244-254.
- Boon, H., Ruiter, R.A.C., James, S., Van Den Borne, B., Williams, E. & Reddy, P. (2009). The impact of a community-based pilot education intervention for older people as caregivers of orphans and sick children as a result of HIV in South Africa. *Journal of cross cultural gerontology*, 24, 373-389.
- Brink, H. (2006). *Fundamentals of research methodology for health care professionals*. 2nd edition. Cape town: Juta and Company limited.
- Burns, N. & Grove, S. K. (2009). *The practice of nursing research . Appraisal, synthesis, and generation of evidence 6th edition*. St Louis , Missouri. Saunders Elsevier.
- Care for Children Affected by HIV and AIDS. (2010). Available from <http://www.etu.org.za/toolbox/docs/aids/care.html>. Accessed 2010/02/19.
- Children's Act no. 38. Of the Republic of South Africa. (2005). *Government Gazette* (no.38). South Africa: Government printers.
- Chitando, E. (2007a). *Acting in hope. African churches and HIV/AIDS 2*. Geneva: World Council of Churches.
- Chitando, E. (2007b). *Living with hope. African churches and HIV/AIDS 1*. Geneva: World Council of Churches.
- Creswell, J.W. (2009). *Research design, qualitative, quantitative, and mixed methods approaches*. London. Sage Publications.
- Defilippi, K. (2003). Dealing with poverty. In *Home based HIV/AIDS care*. Edited by Uys, L. & Cameron S. (eds) . Cape Town: S.A. Oxford university press.

Denzin, N.K. & Lincoln, Y. S. (2008). *The landscape of qualitative research*. 3rd edition. Los Angeles: Sage publications.

De Vos, A. S. (2005). Qualitative data analysis and interpretation. .In *Research at grassroots for the social sciences and human service professions*. 3rd edition. Edited by De Vos, A.S., Strydom, H., Fouch'e, C.B. & Delpont, C.S.L. (eds.). Pretoria: J.L. van Schaik.

Eley, B. (2010). HIV, TB and child health. In *South African child gauge 2009/2010*. Edited by Kibel, M. Lake, L., Pendlebury, S. & Smith, C. (eds). Rondebosch: Children's institute, University of Cape Town.

Ethier, A.M. (2009). Chronic illness, disability or end of life care for the child and family. In *Wong's essentials of pediatric nursing*.8th edition. Edited by Hockenberry, M.J. & Wilson, D. St Louis Missouri: Mosby Elsevier.

Fouche, C.B. & De Vos, A.S. (2005). Introducing qualitative research. . In *Research at grassroots for the social sciences and human service professions*. 3rd edition. Edited by De Vos, A.S., Strydom, H., Fouch'e, C.B. & Delpont, C.S.L. (eds.). Pretoria: J.L. van Schaik.

Gillis, A. & Jackson, W. (2002). *Research for nurses. Methods and interpretation*. Philadelphia: F.A. Davis.

Greef, M. (2005). Information collection: Interviewing. In *Research at grassroots for the social sciences and human service professions*. 3rd edition. Edited by De Vos, A.S., Strydom, H., Fouch'e, C.B. & Delpont, C.S.L. eds. (2005). Pretoria: J.L. van Schaik.

Hall, K. (2010). Income, poverty, unemployment and social grants. In *South African child gauge 2009/2010*. Edited by Kibel, M. Lake, L., Pendlebury, S. & Smith, C. (eds). Rondebosch: Children's institute, University of Cape Town.

Havenga, Y. (2011). *A model for the facilitation of mental health of young children with HIV in Tshwane, South Africa*. Unpublished Thesis. Johannesburg: University of Johannesburg.

Hejoaka, F. (2009). Care and secrecy: Being a mother of children living with HIV in Burkina Faso. *Social science and medicine*.69: 869-876.

Holloway, I. & Wheeler, S. (2010). *Qualitative research in nursing and health care*. 3rd edition. Oxford: Wiley- Blackwell.

Human Science Research Council (HSRC). (2009). *South African National HIV Prevalence, Incidence, Behaviour and Communication*. Cape town: HSRC.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2004). *2004 report on the global AIDS epidemic. 4th global report*. Geneva: WHO library cataloguing publication data.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2006). Report on the global AIDS epidemic. A UNAIDS 10th anniversary special edition. Geneva: WHO library cataloguing publication data.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2008). SubSaharan Africa AIDS epidemic update. Regional summary. Geneva: WHO library cataloguing publication data.

Jones, P. (2010). *Mind the gap: Access to ARV medication and the politics of scale in South Africa*. Available from <http://www.gautengonline.gov.za>. Accessed 2010/11/01.

Jubilee hospital, ART and Wellness Clinic, (2010). Available from <http://www.AIDSspace.org>. Accessed 2010/11/01

Kang'ethe, S.M. (March 2009). Challenges impacting on the quality of care of persons living with HIV/AIDS and other terminal illnesses with reference to Kanye community home based care programme. *Journal of social aspects of HIV/AIDS*, 6(1): 24-32

Kibel, M. Lake, L., Pendlebury, S. & Smith, C. (eds). (2010). *South African child gauge 2009/2010*. Rondebosch: children's institute, university of Cape Town.

Kipp, W., Tindyebwa, E., Rubaale, T., Karamagi, E. & Bajenja, E. (2007). Family caregivers in rural Uganda. The hidden reality. *Health care for women international*, 28: 856-871.

Kneisl, C.R. & Trigoboff, E. (2009). *Contemporary psychiatric-mental health nursing*. 2nd edition. New Jersey: Pearson Prentice Hall.

Lara, M.E., Vaz, S.M., Eng, E. Maman, S. Tshikandu, T. & Behets, F. (2010). Telling children they have HIV: Lessons learned from findings of a qualitative study in Sub-Saharan Africa. *AIDS Patient Care and STDs* 24(4): 247-256.

Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic inquiry*. London: Sage publications.

Makoe, M.G. & Jubber K. (April 2008). Confidentiality or continuity? Family caregivers' experiences with care for HIV/AIDS patients in home based care in Lesotho. *Journal of social aspects of HIV/AIDS*, 5(1):36-46.

McClan, T. & Woodside, M. (2010). *Initial interviewing: What students want to know*. Australia: Brooks/ Cole Cengage Learning.

Medical Research Council(MRC), (n.d). *Guidelines on ethics for medical research: General principles including research on children, vulnerable groups, international collaboration and epidemiology*. South Africa: MRC.

Meintjes, H. & Hall, K. (2010). Demography of South Africa's children. In *South African child gauge 2009/2010*. Edited by Kibel, M. Lake, L., Pendlebury, S. & Smith, C. (eds). Rondebosch: Children's institute, University of Cape Town.

Mendez-Luck, C.A., Kennedy, D.P. & Wallace S.P. (2009). Guardians of health, the dimensions of elder caregiving among women in a Mexico City Neighborhood. *Social Science and Medicine* .68(2): 228-234.

Moody, A.L., Margello, S., Gerits, P. & Byrd D. (2009). Vulnerabilities and caregiving in an ethnically diverse HIV infected population. *AIDS behaviour*, 13: 337-347.

Muller, M. (2009). *Nursing Dynamics*. 4th edition. Sandton: Heinemann.

Naeem –Sheik, A. & Gray, G. (November 2005). HIV disclosure in children. *The Southern African Journal of HIV medicine*. 46-48.

Nehring, W.M., Lashley, F.R. & Malm, K. (January-March 2000). Disclosing the diagnosis of pediatric HIV infection: mothers' views. *J.S.P.N.*, 5(1): 5-13.

Nieuwenhuis, J. (2007). Introducing qualitative research. In *First steps in Research*. Edited by Maree, K. Pretoria: J. L. Van Schaik Publishers.

Okun, B.F. & Kantrowitz, R.E. (2008). *Effective helping: interviewing and counseling techniques*. 7th edition. Australia: Brooks/ Cole/ Thompson's learning.

Pallangyo, E. & Mayers, P. (2009). Experiences of informal female caregivers providing care for people living with HIV in Dar es Salaam, Tanzania. *Journal of Nurses in AIDS care*. 20(6) 481-493.

Parry, S. (2008). *Beacons of hope. HIV competent churches: a framework for action*. Switzerland: World Council of Churches. Ecumenical HIV & AIDS initiative in Africa.

Patton, M.Q. (2002). *Qualitative research and evaluation methods*. 3rd edition. London: Sage publications.

Polit, D. B. & Beck, C.T. (2008). *Nursing Research. Generating and assessing evidence for nursing practice*. 8th edition. Philadelphia: Wolters Kluwer Lippincott Williams & Wilkins.

Proudlock, P. & Jamieson, L. (2008). The children's act: Providing a strong legislative foundation for a developmental approach. In *South African child gauge 2007/2008*. Edited by Proudlock, P., Dutschke, M., Jamieson, L. Marson, J. & Smith, C. eds. Rondebosch: Children's institute, University of Cape Town.

Punch, K.F. (2005). *Introduction to social research. Quantitative and qualitative approaches*. 2nd edition. London: Sage publications.

Ramphele, M. (2005). HIV/AIDS: The mirror in South Africa's face. *The Southern African Journal of HIV medicine: 5-8*.

Richards, L. (2009). *Handling qualitative data. A practical guide*. 2nd edition. London: Sage publications.

Richards, L. & Morse, J.M. (2007). *Read me first for a user's guide to qualitative methods*. 2nd edition. London: Sage publications.

Rossouw, D. (2003). *Intellectual tools. Skills for the human sciences*. 2nd edition. Pretoria: Van Schaik publishers.

Schurink E.M. (1998). Interviewing. In. *Research at grass roots. A primer for the caring professions*. Edited by De Vos, A.S. (ed.). Pretoria: J.L. van Schaik.

Shivers, L.R. (2008). *Basic concepts of psychiatric- mental health nursing*. 7th edition. Philadelphia: Lippincott Williams & Wilkins.

Soul Buddyz. (2006). *Parents, children and anti-retroviral treatment (booklet)*. Parktown. Soul City: Institute for Health and Development Communication.

South African National AIDS Council (SANAC). (2007). *National Strategic Plan for HIV & AIDS and STI Strategic Plan for South Africa, 2007- 2011*. Pretoria: SANAC.

South African Social Security Agency (SASSA). (2010). *You and your grants 2010/11 (booklet)*. Republic of South Africa.

Ssengonzi, R. (March 2009). The impact of HIV/AIDS on the living arrangements and well-being of elderly caregivers in rural Uganda. *Aids Care*, 21(3): 309-314.

Ssengonzi, R. (2007). The plight of older persons as caregivers to people infected or affected by HIV/AIDS. Evidence from Uganda. *Journal of cross cultural gerontology*, 22: 339-353.

Steele, R.G., Nelson, T.D. & Cole B.P. (2007). Psychosocial functioning of children with AIDS and HIV infections: review of the literature from a socioecological framework. *Journal of developmental & behavioural pediatrics*, 28(1): 58-69.

Strydom, H. (2005). Sampling and sampling methods. . In *Research at grassroots for the social sciences and human service professions*. 3rd edition. Edited by De Vos, A.S., Strydom, H., Fouch'e, C.B. & Delport, C.S.L. (eds.). Pretoria: J.L. van Schaik.

Terre'Blanche, M. & Durrheim, K. (2002). *Research in practice. Applied methods for the social sciences*. Cape Town, SA. University of Cape Town Press.

Thampanichawat, W. (2008). Maintaining love and hope:caregiving for Thai children with HIV infection. *Journal of the association of nurses in AIDS care* , 19 (3), 200-210.

Thomas, B., Nyamathi, A. & Swamithan, S. (2009). Impact of HIV/ AIDS on mothers in Southern India: A qualitative study. *AIDS behaviour* , 13, 989-996.

Thomas, S.P. & Pollio, H.R. (2002). *Listening to patients. A phenomenological approach to nursing research and practice*. New York: Springer publishing company.

Tshililo, A.R. & Davhana-Maselesele (2009). Family experiences of home caring for patients with HIV/AIDS in rural Limpopo province, South Africa. *Nursing and health sciences*, 11: 135-143.

Tshwane Metsweding Region, Hammanskraal. (2010). Available from: <http://www.gautengonline.gov.za> Accessed 2010/11/01

University of Johannesburg, Department of Nursing science, paradigmatic perspective. (2009). *Theory for health promotion*. Johannesburg: University of Johannesburg.

Varcarolis, E.M. & Halter, M.J. (2009). *Essential of psychiatric mental health nursing. A communication approach to evidence-based care*. St Louis Missouri. Saunders Elsevier.

Vincent, C.A. (2003). Nursing care in pediatric HIV infection. In *Medical management of AIDS in children*. Edited by Shearer, W.T. & Hanson, C.I. Philadelphia: Saunders.

Wacharasin, C. & Homchampa, P. (2008). Uncovering a family caregiving model:Insights from research to benefit HIV patients,their caregivers and health professionals. *Journal of the association of nurses in AIDS care* , 19, 385-396.

Waite, M. & Hawker, S. (eds.) (2009). *Oxford paperback dictionary and thesaurus*. 3rd edition. Oxford: Oxford University press.

Wiener, L.S., Havens, J.F. & NG, Y.I.W. (2003). Psychosocial Challenges in Paediatric HIV Infection. In *Medical Management of AIDS in Children*. Edited by Shearer, W.T; & Hanson, C.I. Philadelphia: Saunders.

World Health Organisation (WHO). (2002). *Community home-based care in resource limited settings. A framework for action*. Geneva: WHO publications.

Yalom, I.D. & Leszcz, M. (2005). *The theory and practice of group psychotherapy*. 5th edition. New York: Basic books.

Zebrack, B.J. (2007). Mental health issues in medically ill children and adolescents. In *Lewis's child and adolescent psychiatry. A comprehensive textbook*. 4th edition. Edited by Martin, A. & Volkmar, F.R. (eds). Philadelphia: Lippincott Williams & Wilkins.

Ziady, L. (2003). Infection prevention and control aspects in home-based care. In *Home based HIV/AIDS care*. Edited by Uys, L. & Cameron S. (eds). Cape Town: S.A. Oxford university press.

ANNEXURE A

MEDUNSA RESEARCH AND ETHICS COMMITTEE CLEARANCE CERTIFICATE

UNIVERSITY OF LIMPOPO
Medunsa Campus



MEDUNSA RESEARCH & ETHICS COMMITTEE
CLEARANCE CERTIFICATE

P O Medunsa
Medunsa
0204
SOUTH AFRICA

MEETING: 05/2010

PROJECT NUMBER: MREC/M/91/2010: PG

Tel: 012 - 521 4000
Fax: 012 - 560 0086

PROJECT :

Title: Experiences of primary caregivers caring for children living with Human Immunovirus attending wellness clinic at Jubilee Hospital, Hammaskraal

Researcher: Mrs SM Bejane
Supervisor: H Havenga
Co-supervisor: Prof E van Aswegen
Hospital Superintendent: Mrs D Magano (CEO Jubilee Hospital)
Department: Nursing Sciences
School: Health Care Sciences
Degree: M.Cur Advanced Psychiatric Nursing Sciences

DECISION OF THE COMMITTEE:

MREC approved the project.

DATE: 09 June 2010


PROF. GA-OGUNBANJO
CHAIRPERSON MREC

Note:

- i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
- ii) The budget for the research will be considered separately from the protocol.
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

ANNEXURE B

TSHWANE METSWEDING REGION CLEARANCE CERTIFICATE



Umyango wezempilo no Kuthuthukiswa Komphakathi
Lefapha la Maphelo le Tshebeletso le Ntshetsopele ya Sechaba
Department of Health and Social Development
Departement van Gesondheid en Maatskaplike Ontwikkeling

TSHWANE/METSWEDING REGION

Enquiries: Ms M Mosito

+27795602528

Email: Motlalepule.Mosito@gauteng.gov.za

TSHWANE METSWEDING REGION RESEARCH ETHICS COMMITTEE

CLEARANCE CERTIFICATE

Meeting: 02/2010

PROJECT NUMBER: TMREC 2010/18

PROJECT:

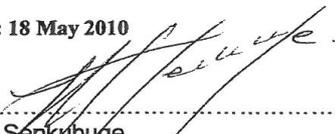
Title: Experiences Of Primary Caregivers Caring For Children Living With Human Immunovirus Attending Wellness Clinic At Jubilee Hospital, Hammanskraal.

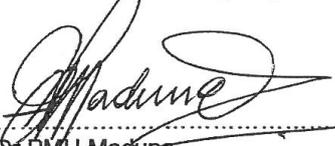
Researcher: Ms SM Bejane
Supervisor: Mrs Y Havenga
Department: University Of Limpopo
Degree: MCur (Advanced Psychiatric Nursing)

DECISION OF THE COMMITTEE

Approved

Date: 18 May 2010


.....
Dr F Senkubuge
Chairperson Tshwane Metsweding Research Ethics Committee
Tshwane Metsweding Region


.....
Dr PMH Maduna
Chief Director: District Health Services
Tshwane Metsweding Region

NOTE: Resubmission of the protocol by researcher(s) is required if there is departure from the protocol procedure as approved by the committee.
ALL CORRESPONDANCE TO INCLUDE PROTOCOL NUMBER

ANNEXURE C
PARTICIPANT INFORMATION LEAFLET

PARTICIPANT INFORMATION LEAFLET ENGLISH

Dear participant

I am currently undertaking a study about: EXPERIENCES OF PRIMARY CAREGIVERS CARING FOR CHILDREN LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS ATTENDING THE WELLNESS CLINIC AT JUBILEE HOSPITAL HAMMANSKRAAL, as part of my post graduate studies in psychiatric nursing science at the University of Limpopo (Medunsa Campus).

- The aim of this research is to promote the mental health of primary caregivers who provide care for children living with HIV attending the Wellness Clinic at Jubilee hospital in Hammanskraal. I would like to hear from caregivers like you, how it is to care for a child who is HIV positive.
- What would I have to do?
 - An interview of about 45-60 minutes with me during the time you are waiting to be seen by the health professional.
 - The interview will be done here in the Wellness Clinic in a private room.
 - I will ask you some questions during this time about how it is for you to care for a child who is HIV positive.
 - I will record the interview and make some notes during the interview.
 - With you and your child's permission, my colleague , a professional nurse , shall take care of him/her by remaining seated in the queue were you have been seated until now. If he/she becomes upset or requires your care, the interview will be stopped immediately.
- Is there any harm for me?
 - No harm to you or your child is anticipated by participating in the interview.
 - I will not make your name or your child's name known and the recording will be heard by my coder, translator, my supervisor and me only.
 - You will not lose your place in the queue so this will take no additional time of yours. I will ask the nurses to call you once it is your turn and we are still busy with the interview.
 - There is no cost for participation in the research, 45 -60 minutes of your time is the only thing requested from the participant.
 - If you have any psychosocial needs with your permission, I will refer you for counselling and to the social worker for further management.
- On request, the research report will be made available to you.
- Participation is voluntary, and you can withdraw from the study at any time. You will not be harmed in any way if you choose not to participate.
- You can call me, the researcher, Ms. S.M. Bejane, for more information, on this cell phone no. 0833475954.

ANNEXURE D
CONSENT LETTER

UNIVERSITY OF LIMPOPO (MEDUNSA CAMPUS) CONSENT LETTER

Statement concerning participation in a Research Project

Name of Project:

EXPERIENCES OF PRIMARY CAREGIVERS CARING FOR CHILDREN LIVING WITH THE HUMAN IMMUNODEFICIENCY VIRUS ATTENDING THE WELLNESS CLINIC AT JUBILEE HOSPITAL, HAMMANSKRAAL

I have read the information and have heard the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurised to participate in any way.

I understand that participation in this study is completely voluntary and that I may withdraw from it at any time and without supplying reasons. This will have no influence on the regular treatment that holds for my child's condition neither will it influence the care that my child receives from the doctor or staff at the Wellness Clinic.

I know that this study has been approved by the Medunsa Campus Research and Ethics Committee (MREC), University of Limpopo (Medunsa Campus) / Jubilee Hospital. I am fully aware that the results of this study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participate in this study and for the interview to be audio recorded.

Name of participant Signature of participant.....

Place..... Date.....

Statement by the Researcher

I provided verbal and/or written information regarding this study.

I agree to answer any future questions concerning the study as best as I am able.

I will adhere to the approved protocol.

.....
.....

Name of Researcher Signature Date Place

ANNEXURE E
BIOGRAPHICAL INFORMATION

BIOGRAPHICAL INFORMATION

Date:

Participant information	
Age	
Sex	
Ethnic group	
Level of education	
Employment status	
Relation to the child and reason for caring for the child	
Time –frame caring for the child	
Number of children in the household	
Family income	

Child information	
Age	
Sex	
Ethnic group	
Level of education	
Treatment taken by the child	

ANNEXURE F
INTERVIEW TRANSCRIPT

TRANSCRIPT OF INTERVIEW AND FIELD NOTES

INTERVIEWER	CAREGIVER	FIELD NOTES
<i>What is the family income?</i>	<i>The only person who is working is my husband. They suspended her grant. Since June I did not get paid, even in July it was suspended.</i>	
<i>What was their reason for suspending it?</i>	<i>When I asked them why the money was suspended, they said that I did not come for them to check him. I was supposed to go to them for them to check him twice or thrice a year, they said they need to ensure that the children are still there.</i>	The primary caregiver sounded frustrated when relating this to the researcher.
<i>Where are you supposed to go for this checking?</i>	<i>At the social workers. I was getting his grant, at our place. So in June, when we went there it was said that the money was not there. We went to the social worker, assisted us before, we did not find her but there was another one. When we arrived they said our social worker was not available but the others were there. Our files were available.</i>	
Ok	<i>We went to the place and found the social worker. I had photocopies of all the documents so they were able to assist us. The schools were still closed for the winter vacations, and they said that they want his report. On the previous occasions, they did not ask for the school report. I said that I will bring his report as soon as the school reopens as I had already signed it and taken it back to the school. When the school reopened I went to request for the report, it was photocopied for me. However I did not find the person who assisted me but others were present so I gave it to them. They said that my file was available and they will give the responsible person the report and she will call me. Last month I called them as they did not call me. They said that the social worker who was assisting us was not in and they will give her my details. I called again last week, and they said that she is not available but my name appeared on their computers and she will call me. I did not get the grant in July.</i>	The primary caregiver's voice was rising as she related this due to the frustration that she experienced as the social workers kept on telling her different things every time she went to their offices. The researcher empathised with the primary caregiver as from her background she understood what having financial difficulties meant.

INTERVIEWER	CAREGIVER	FIELD NOTES
<i>What type of a grant is he getting</i>	<i>The foster care grant of R710.00</i>	
<i>How did this affect you?</i>	<i>It did affect me as he is sick. His grant is for his needs, and my husband's salary is used for our basic needs at home and it is not enough.</i>	
<i>What do you mean when you say his grant is for his needs?</i>	<i>It covers his school needs. He travels by a special transport to school. I make a lunchbox for him. Like the other children, some days he wants fruit, or any other delicacy. When he requests me to buy anything for him I do it. They have a school trip they have to pay R150.00. I asked for the money from his grandfather. They are going in September, so even if I cannot get paid, I will ask his father [referring to the child's grandfather] the provision for the trip. We also use it for coming here for the treatment. When he coughs I need to take him to the clinic. I also use it for his clothing and at the moment he has asked me to buy him a bicycle.</i>	
<i>I understand that it means it helps you a lot in taking care of him?</i>	<i>Yes it helps us a lot.</i>	
<i>I am done with this form. Now I would like you to explain to me in full your experiences of caring for a child living with HIV.</i>	<i>Caring for my child, where should I begin?</i>	The primary caregiver willingly volunteered for the interview and she signed a consent form for agreeing to be interviewed and for the interview to be audio taped.
<i>Start at the beginning and tell me what your experiences of taking care of the child are.</i>	<i>Taking care of this child? At first I did not know that he has a disease such as this one. After his mother passed away, he became sick and I took him to the clinic. I even brought him here to hospital but the child continued to have diarrhoea. So they tested his blood and after that they told us what he is suffering from. It was difficult for me but I accepted it. There was no other way I had to accept it because I am the one who had to take care of him. I willingly accepted it. When I arrived at home I explained to them that the child is sick. I explained to his grandfather that the child is like this.</i>	The experience of caring for the child living with HIV seemed to be overwhelming to the primary caregiver as she seemed not to know where to start in explaining her experience. The researcher put her at ease as she explained to the primary

INTERVIEWER	CAREGIVER	FIELD NOTES
	<p><i>We were hurt but we accepted. I continued to take care of the child. He was problematic, he had fits. If he had a fit we will all cry, even the small children, her sisters' children will cry tears. When I was not home, maybe having gone to a night vigil, they will call and say that the child is sick. I will hurt, especially because his mother passed away due to the illness. We were afraid that he will follow his mother. We accepted it and we are alright. At the moment we even forget what kind of a disease he is suffering from.</i></p>	<p>caregiver before the interview that it will be confidential and she can withdraw from the interview when she feels uncomfortable and she should not answer questions she was uncomfortable with.</p>
<p><i>When did his mother pass away?</i></p>	<p><i>His mother passed away in 2003. When she passed away she was already engaged and staying with the in laws even though she was not yet married legally. So she was sick, and she reported that she is sick. I told her that she should come back home because she was not even yet married. She had oral thrush so I told her to come home. The man that she was staying with did not care. Even the child was having diarrhoea, he was sick. I made an effort for them to come to the hospital. Both of them were attending checkup here. He had a brother who also passed away and followed his mother, the same year, 2003.</i></p>	<p>It was difficult for the primary caregiver to relate this as she sounded sad due to the loss of the loved ones in her family.</p> <p>The researcher allowed the primary caregiver to relate her experiences with minimal interruption.</p>
<p><i>What was wrong with him?</i></p>	<p><i>No he was not infected. He was just close to his mother. When I brought him to hospital they said that he had a liver disease, he had oedema, and they said his liver was swollen. He was also close to his mother. When his mother passed away he was in the hospital. I requested that he be discharged home. After his mother passed away I had to take care of two children, I took care of this child and his brother. I brought them to hospital time and again. After his mother passed away... for five months, his mother passed away in May, [counting with fingers]...August, in October before five months had passed his brother also died. I was sad. I said it is hardly five months, and he followed his mother. It was</i></p>	

INTERVIEWER	CAREGIVER	FIELD NOTES
	<i>difficult here at home but there was nothing we could do.</i>	
<i>When his mother passed away did you know that this child is HIV positive?</i>	<i>This child was not yet tested. We did not know. The hospital explained his mother's disease, after that they were both sick. Both he and his mother were in the hospital. They tested his blood after his mother's death.</i>	
<i>What was wrong with the mother?</i>	<i>She was HIV positive. They told her and asked if she gives consent to them to tell her parents. She agreed and they explained to me. When I arrived at home I explained to them. She was discharged, she never accepted, her diagnosis and it stressed her. She was never okay, she took treatment for a short time and she passed away. I took an effort to continue taking the child for follow-ups and he was tested. They explained to me that he has HIV. I took him to the clinic in the hospital as Wellness was not yet operating. After Wellness was opened they referred us here, until now.</i>	
<i>Did you disclose the child's status to the family?</i>	<i>Yes they know.</i>	
<i>When did you do it?</i>	<i>After they tested him here in the hospital, they told me what was wrong with the child. I explained to them when I arrived at home. I have a boy, one of my sons is sick, so we have accepted. They all know what he is suffering from.</i>	
<i>How did they react to the news?</i>	<i>We love this child very much. If he is sick...that I why I say when he is sick we cry. He was being attended to at the clinic before Wellness started operating. He had fits. If he could have an attack when I was not around they will call me and I will be met by the other children crying. He was not yet getting the foster care grant, we will come to the hospital. The disease made the child to have fits. Now he no longer has fits.</i>	<i>The tone of the primary caregiver's voice changed when she related this and she sounded that she cared for the child living with HIV deeply.</i>
<i>Does he know what disease is he suffering from?</i>	<i>Last time in... [deep in thought] I do not know what month it was. Here at Wellness they told us that we should tell these children what they are suffering from. These children come to the clinic, they are given tablets but they do not know what they are</i>	<i>The primary caregiver seemed guarded when she related this.</i>

INTERVIEWER	CAREGIVER	FIELD NOTES
	<p>suffering from. Please tell them, tell them what the problem is. So I explained to him but he does not understand that this disease...it can...he does not know that his disease is the one that killed her mother and what are its effects. I can infect another person. I sat him down, and said my child, he answered "mama" he calls me mother. You heard that at the hospital they told us to tell you what you are suffering from. These tablets that you are taking every day. When we give him the tablets, he says that I am tired of taking them, but he takes them. This is your life if you cannot take your tablets you are going to be admitted in the hospital. You are suffering from HIV. Do not tell your friends that you are suffering from this disease. This is your disease, and here at home we all know. In time he will understand what kind of disease is he suffering from. So he knows, at times I ask him: "by the way what did I say you are suffering from?" He will say HIV, but he does not understand the effects of HIV even though he knows that he has HIV.</p>	
<p>If they did not say that you should tell them, when were you going to tell him?</p> <p>Mmmm...</p>	<p>I was going to ask...I was prepared to ask the social-worker to tell him. So on the day that they explained to us, the social-worker also said do not send them to us, tell them. If you are not able to manage it is then that you can come to us, to assist you and to counsel you. It did not bother him. I thought that maybe because he is still young and it will worry him.</p>	
<p>According to what you are saying it did not bother him.</p>	<p>Yes it did not bother him. He just takes it like any illness, because he sees us taking the medication, he does not bother what kind of a disease it is. It the one that killed my mother, it kills or whatever.</p>	
<p>You said that you explained to him that his mother passed away, how did he</p>	<p>I...his mother passed away when he was three years, he is now ten years, he knows that his mother is dead, he</p>	

INTERVIEWER	CAREGIVER	FIELD NOTES
<i>take it?</i>	<i>does not forget. He knows that his mother and brother are dead. At that time as he was still small I did not tell him what the cause of her death was.</i>	
<i>May you please tell me more about his father?</i>	<i>His father is still alive but after the child's mother's funeral, he never came again. He said that he will buy the child school uniform and I said that it was okay. One day he asked to take him to his place. I told him that I agree that he should visit you, but I do not know if you will be able to give him the treatment. I let him go for two days. When the child came back he was not given his medication. I was fed-up but I gave him the medication and he was okay. When I meet him at the shops, he will say that I will come to see the child. He came this year, and the child is already ten years, he was gone for long and this child loved him. He came because he met the child's aunt at checkers. When he came he said that the child is afraid of him. I told him that he is supposed to because he never comes to see him. He gave the child ten rand and said that he will come back during the weekend, he never did.</i>	
<i>Does he know what the child is suffering from?</i>	<i>Yes he knows, I told him. When I refused that he should visit him, it was because I was uncertain. When he visits it should be for a day as he takes medication. They explained that there should be no mistake. He should sleep out for only one night, because he knows that this disease is this and that way. He said that he will give him the medication. He takes this medication in the evening and in the morning. He did not give him the treatment.</i>	
<i>Does it mean that he does not assist you financially to take care of the child?</i>	<i>He only came and gave him ten rand. He said he will come and buy him school uniform, he never did.</i>	
<i>Mmmhmm...</i>	<i>I do not know if he is right or not because he does not stay with us. He was staying here but it is said that he has moved to another place.</i>	
<i>I heard you saying that when you disclosed to the child his status you said</i>	<i>Oh what made to say that he should not tell his friends...you know how children are, when they are playing,</i>	

INTERVIEWER	CAREGIVER	FIELD NOTES
<i>that he should not tell his friends, what makes you say that he should not tell his friends?</i>	<i>hei you are like this and that! Or if he can get injured, because they are boys, and bleeds, you are going to infect me with your disease. They will stop playing with him...they will ridicule him. Yes do not touch him, all those things, that is what I think.</i>	
<i>How will it affect you?</i>	<i>It will make me sad if they can ridicule him. Yes it will make me sad.</i>	
<i>Who else did you disclose to?</i>	<i>The neighbours who know are those that knew when his mother's status when she passed away. Others do not know. Those who are near know how his mother died. After that he had sores.</i>	
<i>How do those who know relate to him?</i>	<i>It happened that...when I say that they will discriminate him with words. The woman who stays next door, whose son is a friend of my child, and they play together. My child had sores, she said do not play with him he has sores. Somebody told me that she overheard them saying that he has HIV and AIDS. I did not take it well, I called my sister in law, my husband's sister. I told her to go to my neighbor and speak with her or we will stop speaking to each other. My sister in law asked her if she knows that she will be arrested for saying that a person has AIDS if she can be reported to the police. She denied having said that. She called her mother in law, who apologised to me. They told her that if we are neighbours we should be on good terms. They apologised on behalf of their daughter in law and it ended there. The children are good friends.</i>	The primary caregiver's voice was a bit loud indicating that she may still be angry about the neighbour's behaviour towards her child.
<i>Oh...it did not affect them, it did not involve them.</i>	<i>Yes it did not involve them.</i>	
<i>Please tell me more about your experiences when caring for this child.</i>	<i>About this child and I... [pause] He loves me very much. He is close to me. When he is with me he touches me, he is close to me. He calls me mother. He knows that I am his grandmother. As soon as his mother passed away he started calling me mama, his grandfather is father to him. He has aunts. I love him very much and he loves me too, he is close to me as if he is my lastborn.</i>	
<i>Mmm....</i>	<i>Yes...</i>	

INTERVIEWER	CAREGIVER	FIELD NOTES
Mmmmm...	<i>My lastborn is grown up she does not matter much to me. I am always with this one.</i>	
Okay	<i>I give him love because the parent is not there. I love them all because they are my children. I also love my other grandchildren. He comes to me for comfort; there is no other one he can go to.</i>	
Nods head.	<i>I have to give him maternal and grandmotherly love, and also because he is my grandchild. I am supposed to love him because I comfort myself with him, because his mother and brother passed away at the same time.</i>	
<i>Does the school know that he is sick?</i>	<i>They know because I report in every class. Every class that he attends I report to the class teacher. They know that he goes for a checkup every month; so that they should not hit him and say that he was absent. I report to them right through.</i>	
<i>How did they react?</i>	<i>They took it alright, and accepted it because they said that others do not report.</i>	
Mmm...	<i>Others do not report that the child is sick. And you find that we do not know that the child is sick. The educators like us to explain to them. If he passes and goes to another class, I go and explain that they should not be surprised if he does not come to school each month. When he is sick I report to them. If he stays away two, three days they know that he is sick, but if it is one day they know that he has gone for a checkup.</i>	
<i>When he is sick...?</i>	<i>When he is sick is if he has a cold because the other thing that was problematic was the fits. It really was a problem in the beginning. He started getting treatment and he became alright.</i>	
<i>The treatment helped him?</i>	Yes	
<i>According to you this treatment helps?</i>	<i>A lot he is no longer problematic. His only problem is coughing. When he gets cold it is an ordinary one. If he has cold, he gets to the nearest clinic, they give him medication, and he becomes alright.</i>	
<i>What is your experience of</i>	<i>When we come here they give us the</i>	

INTERVIEWER	CAREGIVER	FIELD NOTES
<i>the Wellness clinic?</i>	<i>ARV's. Here at Wellness they are alright. I am happy.</i>	
<i>Tell me more...</i>	<i>Even the way they have helped us, the way the nurses have assisted us. We have to have treatment that assists us with this type of disease. When I come here, I observe the people, even the older ones. I look at them and could see that they have changed. This treatment helps if you comply.</i>	
<i>It means that their care and treatment are okay.</i>	<i>It is right, it helps a person. You can go and look for a job, get it and work. As long as you comply with treatment.</i>	
<i>Tell me more about your experiences with your child.</i>	<i>After his mother died, he was having fits with a high temperature. I prayed and said that I am placing everything in your hands Lord if you give him to me; it is only you who knows. I always prayed that you gave him to me and here he is from three years and he is ten years. Yes I was carrying him on my back every day going to the clinic. Where are you going today? A certain Shangaan woman will ask, are you going to the clinic again today? We went to the clinic every day.</i>	
<i>And now...</i>	<i>Now we come once a month, it is not the same.</i>	
<i>So it is better now.</i>	<i>Yes it is better, I am proud; I was able to take care of him.</i>	
<i>Nods head</i>	<i>It is better we have accepted. When the schools are closed and he goes to visit, he goes to his aunt. She is the one who knows his medication. She gives it to him. I do not want him to go anywhere else because others will not give him the medication. He also knows when the school closes, others go to other places, he remains at home with me or he will say that he is going where his aunt lives, he loves her.</i>	
<i>What makes him not to go to visit in other places?</i>	<i>Just this thing with the medication. I think that they will not give it to him because they are not used to it. They are going to forget.</i>	
<i>Nods head</i>	<i>His aunt is the one who always assisted me. She would ask how the child was. She used to accompany me to all the places that I will take</i>	

INTERVIEWER	CAREGIVER	FIELD NOTES
	<i>him to. So she is the one who...when he goes there I write a note for him indicating the directions of taking the medication. So she is also used to it and she sets the clock.</i>	
<i>Is he not yet responsible for taking his medication?</i>	<i>He knows that he takes it at seven in the evening and morning. When he watches the television, he will have the cell phone with him and say that mama it is seven o'clock. In the morning as he will be asleep at times I wake him up. During the week when he goes to school, he washes himself; thereafter I give him the tablets.</i>	
<i>He does not have a problem.</i>	<i>He does not have a problem.</i>	
<i>When you feel sad, how do you deal with that?</i>	<i>What comforts me; I comfort myself with the Bible. I comfort myself with it and pray. When he becomes sick, I feel sad, but comfort myself with the Bible.</i>	
<i>So it is your comfort.</i>	<i>Yes it comforts me, because maybe a person may not comfort me so I comfort myself with the Bible. God is the one who will help you. If I believe that God will help me He is the one who will help me. So God will help me, he will heal him, he has given him to me. When I think about his mother, I see that he is like her.</i>	<i>Even though the primary caregiver said that she is comforted she still sounded sad but hopeful.</i>
<i>What about the infection?</i>	<i>Infection, I never think about it. Last month I went to the clinic, I had cold. When we were at the clinic, the nurses said we request that you should test. Not only the young ones, even you older women. Pap smear, blood sugar level and HIV. I went to check the pap smear, blood sugar level, blood pressure and HIV. I never had any fear. They checked me and found out that it was negative.</i>	
<i>You never think about being infected.</i>	<i>I never think about it. I know that I take good care of him, and he never bleeds. They explained to us how one gets infected. I take him like everyone in the home.</i>	
<i>How does he relate to others at home?</i>	<i>Alright, he is okay.</i>	
<i>How does he behave?</i>	<i>Yes, he is naughty, he is just naughty. He does not miss his mother. We think that he does not understand. When his mother passed</i>	

INTERVIEWER	CAREGIVER	FIELD NOTES
	<p><i>away he was three years, but he knows that his mother died. When we show him the pictures he is able to identify her. His grandmother, my aunt, said you should not...how does the child know that...we will say he knows, nobody told him but he knows. He was three years but he knows.</i></p>	
<p><i>He is okay.</i></p>	<p><i>Yes he is.</i></p>	
<p><i>Does he know how he is supposed to look after himself, when he bleeds and other things?</i></p>	<p><i>Yes they tell them at school. The educators say if one of the children bleeds the others should come and inform them. A grownup is supposed to assist.</i></p>	
<p><i>It means that at the moment you are alright.</i></p>	<p><i>Presently I am alright.</i></p>	
<p><i>How would you have cared for him if he was not HIV positive?</i></p>	<p><i>No, to us it would not have made a difference, we could have taken good care of him. He could say they do not take good care of me because my mother is not around. We have to take good care of him, and be happy just like when his mother was around. Give him love. We comfort ourselves with him</i></p>	
<p><i>Am I right to say that you said when you care for your child living with HIV you do not have to use gloves when bathing the child, or assisting him when he is injured?</i></p>	<p><i>Yes for us it is not like that. His grandfather uses a razor to cut his hair. He was shaving him yesterday. Even if he can cut him and he bleeds, he will continue and he will say as long as I do not have a cut there is no problem. After that he will wash his head.</i></p>	
<p><i>It implies that he has warmth at home.</i></p>	<p><i>Yes, he has warmth, we accept him.</i></p>	
<p><i>Are you not afraid that he will tell his friends at school?</i></p>	<p><i>No... [Doubtful], even if he can do it, they should not tell anyone. We are afraid that they will hurt him. His friends will say to each other do not touch him, he will infect you with a disease.</i></p>	<p><i>She was doubtful when saying this.</i></p>
<p><i>Thank you. The information that you have given me is very valuable.</i></p>	<p><i>Thank you.</i></p>	
<p><i>You taught me that when a person takes care of a child living with HIV, even though there are challenges, it is easy if you give the child loving care.</i></p>	<p><i>It is easy if a person can accept.</i></p>	

INTERVIEWER	CAREGIVER	FIELD NOTES
<i>If you can accept.</i>	<i>Exactly.</i>	
<i>Thank you. So this has been a valuable lesson to you too?</i>	<i>It has taught me to accept everything. If you do not you will be stressed. You have to accept. When God says that you have to do this, you need to accept. That is the way God wants it to happen. When you are sick you have to accept. If I went to the clinic to test and they told me that I was infected, I would have accepted because I know that I have been taking care of people living with HIV. When they said that we should get tested, both young and old people, I did not have any fear. They tested my blood, and it was negative. Even if they could have said positive, I would have accepted and started with the treatment. I can see these people who take treatment, and they are healthy. I would have started treatment when I am still healthy, not having lost weight yet. I would have taken the treatment to the point where God wills. So if only the other caregivers can accept like I did. At home we have all accepted.</i>	
<i>You have accepted.</i>	<i>According to me... [Deep in thought] we have forgotten that there is someone who is sick at home. Everybody at home including all the children knows. They have all accepted him.</i>	
<i>They have accepted...</i>	<i>They know that they have to give him treatment when I am not at home.</i>	
<i>You are able to can go out and attend to other matters.</i>	<i>Yes, I can go to church during the weekend. I tell my lastborn child, who is 22 years. I tell her that these ones are for the morning and the others for the evening. She gives him the treatment when I am not at home.</i>	
<i>Mhmm..</i>	<i>They also remind me...what about the treatment? I will tell them that I have not forgotten, it is not yet time. Seven in the morning and seven in the evening.</i>	
<i>It means that if the family knows about the child's HIV status, and have accepted, you are able to assist each other to care for the child.</i>	<i>We are able to support each other to take care of the child. When there is a funeral, Friday night, I tell my daughter that she should not forget to give him his treatment. She gives it to him.</i>	
<i>Does he not have a</i>	<i>No, he knows that he has to take</i>	

INTERVIEWER	CAREGIVER	FIELD NOTES
<i>problem when he has to take his treatment?</i>	<i>treatment.</i>	
<i>The health care workers at the Wellness clinic are available when you need them.</i>	<i>Yes they are. I am surprised that they are here. I heard that there was a strike. When we were on our way here, I did not know if we would find them. They are here; we thank them for their assistance.</i>	
<i>Thank you, mama. I wish you well with your good work of caring for the child.</i>	<i>Thank you very much sister.</i>	
	BIOGRAPHICAL DATA OF THE PRIMARY CAREGIVER	
PARTICIPANT INFORMATION		
Age	51 years	
Sex	Female	
Ethnic group	Tswana	
Level of education	Grade 8	
Employment status	Unemployed	
Relation to the child and reason for care giving.	Maternal grandmother. Child maternal orphan.	
Time-frame caring for the child	2003-2010	
Number of children in the household	04	
Family income	Child's foster care grant. Husband, child's grandfather is employed.	
CHILD INFORMATION		
Age	10 years	
Sex	Male	
Ethnic group	Tswana	
Level of education	Grade 3	
Treatment taken by the child	Antiretroviral treatment	

ANNEXURE G

PROTOCOL TO INDEPENDENT CODER

PROTOCOL TO INDEPENDENT CODER

Dear Dr Temane

Kindly receive the attached documents of the interview transcripts from eight participants. I have translated the interviews from Setswana to English and I will appreciate your input in editing of the translations. I also request you to assist me in the manual coding of the data and to use the Tesch's method as reflected below. I will also be coding the data using the Tesch's method.

1. Reading and rereading through all transcripts carefully to get a sense of what the primary caregivers were saying and wrote down ideas that emerged from the data;
2. Picking one transcript at a time, read it with attention to the topics that answered the research question and wrote down underlying meanings on each one;
3. Making a summary of each transcript;
4. Making a list of all topics from all transcripts and grouped similar ones into categories or themes;
5. Finding suitable words to describe the topics, and placed topics that occurred in all or most of the transcripts in one list to make a list of all important topics;
6. Grouping all information belonging into each category in one place as subcategories according to their content;
7. Putting the categories in alphabetic order;
8. Analysing grouped themes.

Thanking you in advance.

Kind regards

S.M. Bejane (Ms)

ANNEXURE H
LETTER FROM THE EDITOR

Read and Write Assist

P.O. Box 11965

The Tramshed

0126

TO WHOM IT MAY CONCERN

This is to confirm that I have read and edited the dissertation entitled, **Experiences of Primary Caregivers Caring for Children Living with the Human Immunodeficiency Virus Attending the Wellness Clinic in Jubilee Hospital Hammanskraal**, by Ms. Stella M. Bejane.

The dissertation was edited for language use, including such aspects as consistency in tense usage, clarity of expression, and effective and appropriate use of selected vocabulary. Care was taken to suggest reformulations that would make the dissertation meaningful by keeping to plain language usage, while respecting the accepted jargon and concepts as used in the discipline within which the dissertation was written. Ms. Bejane is therefore solely responsible for the content and knowledge area aspects of the dissertation.



Frederick M. Papo

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