

UNIVERSITY OF KWAZULU-NATAL

**UNDERSTANDING THE EXPERIENCES OF CAREGIVERS
OF HIV INFECTED CHILDREN AT A PUBLIC HOSPITAL IN
DURBAN**

By

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in the School of Applied Human Sciences in the College Of Humanities

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DECLARATION – PLAGIARISM

I, Dhashini Ramsamy – student number: 9037050 declare that, the research reported in this thesis, except where otherwise indicated, is my original research. This thesis has not been submitted for any degree or examination at any other university.

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DECLARATION BY SUPERVISOR

This thesis which I have supervised is being submitted with my approval.

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DEDICATION

This study is dedicated to my wonderful husband Rajen and our beautiful children, Tanaya, Kidaren and Talia. You have always been a constant joy in my life. Thank you for being my support and for always believing in me, even at times when I didn't believe in myself.

ACRONYMS AND ABBREVIATIONS

ABBREVIATION	DEFINITION/MEANING
AIDS	Acquired Immune Deficiency Syndrome
ANECCA	African Network for the Care of Children Affected by AIDS
ART	Antiretroviral Therapy
ARVs	Antiretroviral Medication
DOH	Department Of Health
HAART	Highly Active Anti-Retroviral Therapy
HCT	HIV Counseling And Testing
HIV	Human Immunodeficiency Virus
MDG	Millennium Development Goal
MTCT	Mother-To-Child-Transmission
DOH	National Department of Health
NSP	National Strategic Plan
PMTCT	Prevention of Mother-To-Child- Transmission of HIV
UNAIDS	United Nations Joint Programme on HIV/AIDS
WHO	World Health Organisation

ABSTRACT

Globally HIV and AIDS are considered to be a major health and developmental challenge facing humanity. The HIV infection of children is not only an area of great concern for families but for the future of humankind. Caring and nurturing of children generally is considered as a challenging responsibility. Caregivers of HIV infected children are faced with the added responsibility of ensuring that these children have access to life saving health care at all times. Caregivers who are responsible for the health and well being of HIV infected children face constant challenges in their care giving role and this has implications for the quality of care of the child. The needs of HIV infected children are complex and vital to their basic needs is the administration of antiretroviral therapy (ART).

This study aimed to explore, describe and interpret the experiences of caregivers, caring for HIV infected children and accessing services from a public hospital in Durban. Using the ecosystems theory, this qualitative study explored the experiences of thirty caregivers caring for HIV infected children. The data was collected using semi structured interviews with the caregivers. Four main themes emerged from the data analysis; namely: The caregivers' intrapersonal experiences, their perspectives on HIV and ART, their access to health and social services and their coping strategies. This study concludes that caregivers of HIV infected children within the public hospital setting, experience numerous psycho-social and economic challenges on a daily basis. Subsequently, these challenges impacted on the quality of care to the HIV infected child. It was evident that respondents dealt with challenges differently, as the older respondents were more equipped emotionally and psychologically than the younger respondents. Generally, all respondents were negatively affected by poor psychological and socio-economic circumstances that prevented them from ensuring the wellbeing of the child. The challenges that they faced on the micro level (economic and psycho-social experiences), the mezzo (stigma, community and family support) and exo levels (health and welfare services) together with the macro level (DOH strategic plans and childcare legislations) determined how they provided for the care of the HIV infected child. Despite these challenges respondents' resilience and commitment to providing for the health and wellbeing of the HIV infected child

was consistent and remained a priority. Multi-level intervention programmes are required to help caregivers cope with their challenges. As such social work practitioners need to take cognizance of the psycho-social, emotional and material support required by caregivers of HIV infected children.

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CHAPTER ONE

SETTING THE SCENE ABOUT THE RESEARCH

1.1 INTRODUCTION

Children are a vulnerable group in society, more especially those who are infected with the Human Immunodeficiency Virus (hereafter referred to as HIV). HIV has both a physical and psycho-social impact on individuals, the latter often being a neglected aspect of intervention. This follows that HIV infected children experience a range of emotions, often involving fear of medical procedures and health care facilities. Toddlers also typically experience exaggerated separation anxiety and, because they do not understand the disease yet, the fear of being separated from caregivers and parents is more challenging for the HIV infected child (Ross and Deverell 2004).

In addition to the emotional turmoil, HIV infected children are also plagued by physiological challenges like acute “weight loss, failure to thrive, prolonged fever, recurrent thrush, chronic diarrhea and gastroenteritis, tuberculosis, pneumonia, recurrent bacterial infections, dermatitis, neurological abnormalities such as seizures and other Acquired Immune Deficiency Syndrome (hereafter referred to as AIDS) defining conditions”. A further challenge is that HIV infected children are often not as responsive to medical treatment as “non infected children”. As a result, they are likely to struggle with “life threatening complications” (Van Dyk 2008, pp. 59-60).

These physiological and psychological experiences can be frightening and traumatic for the HIV infected child because they could require extensive periods of hospitalization. Thus providing for the health and welfare of HIV infected children can be emotionally and physically draining for their caregivers (Demmer 2011 and Van Dyk 2008).

Proper medical management of HIV infected children however is vitally important for their survival. This follows that it is crucial that their caregivers facilitate the HIV

infected child's access to antiretroviral treatment (hereafter referred to as ART). ART helps to prolong the life of HIV infected children and assists by reducing opportunistic infections, thus preventing serious terminal illnesses and improving the overall quality of life for the HIV infected child (McKerrow, et al., 2006 and Van Dyk 2008).

However, the World Health Organisation (hereafter referred to as WHO), found that only one third of the world's HIV infected children were receiving ART. This finding indicated that there was little cohesion between HIV services and child health services globally, with subsequent gaps in services and thus poor access to ART (WHO 2011). This is an even greater challenge for countries that are struggling with the scourge of HIV and AIDS and lack the proper medical and health resources. Consequently, South Africa bears the brunt of the HIV pandemic and is still struggling to facilitate access to antiretroviral treatment for a substantial number of HIV infected individuals that require treatment (South African History online 2012)

The South African government however strives towards improving the availability of antiretroviral drugs and expanding health and social services in communities. This is perceived as government fulfilling its responsibility to provide for the prevention, treatment, care and support of the vulnerable HIV infected citizens of the country (Department of Health 2011- hereafter referred to as DOH).

By scaling up the access of ART to HIV infected individuals, in line with the WHO's 2011 strategic plan, South Africa acknowledges the importance of treatment access (DOH, 2011 and WHO 2011). However, increasing the number of health care facilities, ensuring that community clinics have antiretroviral treatment and the necessary diagnostic services available, are not sufficient in addressing the issue of access to services. The social barriers need to be considered as well. The HIV infected child who relies on their caregiver for survival, is often confronted by social barriers to accessing treatment and support from health and welfare institutions.

This is supported by Phili's (2009) qualitative study with 42 caregivers from two public hospitals in KwaZulu-Natal. The study focused on the social barriers experienced by caregivers in accessing ART for HIV infected children. The researcher used four groups of caregivers, two groups that were accessing ART for the children in their care, and another two groups that consisted of caregivers that were accessing ART for themselves but not the HIV infected child. Phili's study found that the level of caregiver knowledge on ART, stigmatization, the existence of support at family and community levels, the quality of service at clinics and health legislation, all determined whether caregivers accessed health services for the HIV infected child. It was further suggested that improving the caregiver's knowledge about ART and the re-training of clinic and hospital staff on assisting caregivers with their psychosocial problems, would result positively in increasing the number of caregivers, that accessed paediatric ART (Phili 2009).

The purpose of this current study was to build on Phili's (2009) study by describing the experiences of caregivers of HIV infected children at a public hospital. This study is also unique as it explores the overall care of the HIV infected child, together with the social and structural barriers experienced by care givers in accessing health services. It further discusses various health and child care legislations that impact on the care of the HIV infected child.

This follows that the South African government outlined its priorities regarding child health in the country's fourth Millennium Development Goals (hereafter referred to as the MDGs). Progress reports on the attainment of the MDGs however, state that interventions that address childhood health are still struggling to reduce childhood deaths in South Africa (Republic of South Africa 2010). Thus South Africa's DOH's National Strategic Plan's (hereafter referred to as NSP's) third objective focuses on the improvement of health for all South Africans by reducing the number of deaths by HIV and TB infection (DOH 2011).

In addition to the health needs of HIV infected children in South Africa, there is also policy in place that guards the social wellbeing of the HIV infected child. The Children's Act of 2005 stipulates that the state has a responsibility to ensure the protection of children, through the preservation of families and the development of structural services in the community (Children's Act 38 of 2005).

The Children's Act (2005) and the DOH (2011) NSP merely guides government and other role players in the provision of services to the HIV infected child and their caregiver. In order for legislation to be effective, it has to be combined with sustainable programmes that address the needs of HIV infected children and other vulnerable individuals (WHO 2011). It has therefore become imperative when providing services to the HIV infected child, to consider them and their caregivers within their context of not only their health needs, but also to take into account their social and economic needs.

It is interesting to note that the HIV and AIDS pandemic, which in the past was perceived as a dreaded terminal illness, have progressed today to being viewed as a "manageable chronic disease". Consequently, with the roll-out of ART, the life of the HIV infected child has been prolonged, thus delaying the onset of AIDS (Van Dyk 2008, p.114). Thus the quality of life for the HIV infected child is now a priority and hence the health and social welfare legislations guiding HIV infected children's care have to be explored. This follows that the disease still remains complex in its challenges and its psycho-social implications for caregivers of HIV infected children is still a contentious issue.

With the introduction of paediatric ART and its complexities, it becomes imperative that caregivers are adequately prepared, for the challenges of taking care of a chronically ill HIV infected child. This follows that "In South Africa, it has been postulated that the majority of HIV and AIDS – infected and affected people, will be assisted and absorbed by the extended family network in black families" (Ross and Deverell 2004, p. 207). The authors further contend that despite families taking on the task of caring for the HIV infected person in the early days of the pandemic, the overwhelming spread of the disease has resulted in the "extended family system becoming overburdened" (Ross and Deverell 2004, p. 207).

It is argued that caregivers also often have to provide care and support to their extended families in addition to taking care of the HIV infected child. This can be challenging for them in the face of their own poor psycho social support systems, hence resulting in them experiencing a sense of being overwhelmed or stressed. This is supported by Giese (2003) who argues that governments' stance of

transferring the responsibility of care for HIV infected people, to families and communities, is resulting in the over burdening of the micro and mezzo systems, in the face of the growing HIV pandemic.

Sewpaul (2001) contends that communities were willing to contribute to caring for children, but they were inhibited by the lack of economic and social support provided by government. It is further stated that despite the “extended family” of children, being the “main catchnet of care”, they also experienced challenges in fulfilling their care giving roles, in a resource limited society. The researcher thus suggested that government develop a more conducive “socioeconomic environment, that will support the community” in the caring role (Sewpaul 2001, p. 582).

In addition Giese (2003) and Sewpaul (2001) further urged social workers to take cognizance of the fact that most often it is the women in communities that ultimately become the overburdened, under resourced caregivers of these children (Giese 2003 and Sewpaul 2001). Therefore socio- economic interventions should respond to issues and challenges that face women in particular.

This follows that Raniga and Simpson (2010) corroborates with Sewpaul (2001), when they found that the female caregivers of HIV infected individuals often had to perform a multitude of challenging tasks, in the midst of financial strife and their own ill health. The researchers thus also recommended more economic and social interventions for female caregivers, caring for the HIV infected in South Africa.

This current study therefore aims to explore, describe and interpret the experiences of caregivers of HIV infected children whilst they accessed services from a public hospital. It is envisaged that by understanding the caregiver’s experiences, appropriate interventions may be developed, within the health and welfare sectors, to address their challenges, so that they are able to ensure the well being of the HIV infected child.

This opening chapter commenced with an introduction which is then followed by the outline of the research problem. A discussion of the rationale for the study, the research aim, objectives and research questions then follow. Furthermore, an overview of the ecosystems theory as the key conceptual foundation for this study

is discussed. This is followed by an overview of the value of the study; the clarification of concepts used and finally concludes with a synopsis of the dissertation.

1.2 OUTLINE OF THE RESEARCH PROBLEM

“Our future lies with our children...we should empower our children with the education and life skills, not only so that they can prevent themselves from being infected, but also so that they can learn to become compassionate, caring members of a society that will be dealing with the aftermath of HIV and AIDS, for a long time to come” (Van Dyk 2008, p. 165). This is the ideal that humanity seeks, a world with little to no disease and discrimination, with an ambiance of love, compassion and care from all sectors of society. We are a long way from that perfect scenario, when we consider that HIV infection is still devastating in its rampage of causing the deaths of so many children. Without treatment, HIV infected people, more especially children, are likely to suffer severely from the disease (Van Dyk 2008).

Despite global and national government efforts on making ART more accessible to HIV infected individuals, it was found that there are still barriers to people accessing services and thus still gaps in HIV and AIDS programme implementations. This is of concern as ninety percent of children globally that were newly infected with HIV in 2011, were living in Sub Saharan Africa (United Nations Joint Programme On HIV/AIDS, here after referred to as UNAIDS 2012).

This follows that in South Africa it is reported that in June 2009, 800 000 people were on ART, which comprised forty percent of HIV infected adults and only ten percent of HIV infected children (UNAIDS 2010). Since 2009, South Africa has embarked on further efforts to improving access to ART but challenges still remain in ensuring that all children who need it are receiving it (DOH 2011; DOH 2010 and Republic of South Africa 2010).

HIV infected children are dependent on their adult caregivers for their medical needs to be met and it is therefore a huge concern when these needs are not being met. This study therefore also aims to explore the challenges experienced by caregivers in accessing services for HIV infected children, with the view to making recommendations that would address these challenges.

HIV progress reports indicated that despite improvement in the access to HIV testing and counseling services (hereafter referred to as HCT), there were still many HIV infected people who were unaware of their HIV status in low and middle income countries. This was a barrier to referring the HIV infected individuals for treatment and support, which then also impacted negatively on the further transmission of HIV (WHO 2011).

Other researchers who shared similar findings were Wanyenze et al. (2010) in their research study on a HCT program conducted during the period of 2005 to 2008 in Uganda. This study introduced HIV counseling and testing at a public hospital to assess the benefits of early testing and intervention. The findings were based on data collected with 9 687 children that were admitted to hospital for treatment and 8 990 caregivers. This study identified many children and their caregivers who were HIV infected and unaware of their statuses until the HCT was administered. It was further found that more than fifty percent of the infected children were already at an advanced stage of HIV Infection. Gaps in the HCT programme that prevented early diagnosis and treatment of HIV were issues around consent, counseling, maintaining of children's rights, and the lack of clarity in legislation and policy with regard to testing children for HIV. It was therefore recommended that these gaps be addressed in the future for earlier HIV diagnosis of children in order to facilitate their referral for medical treatment and social support.

In an attempt to explore the problem of early HIV identification in infants, Richardson et al. (2008) conducted serial clinical assessments of three hundred and 62 infants born to HIV infected mothers in Kenya. In the study, Richardson et al. suggested that the presentation of early symptoms such as rash, failure to thrive, and pneumonia in infants could be regarded as indicators of acute HIV

infection. Richardson et al. (2008) concluded that because infants were generally prone to febrile and general illnesses, it was difficult to relate symptoms specifically to acute HIV infection. The paucity of studies that determined the specific symptoms, typical of HIV Infection in infants, created a challenge to health care professionals in identifying HIV related illness at an early stage. This could also be one of the reasons why HIV infected children who were admitted to hospital, were already very ill.

This sentiment is further illustrated in a report by the Committee on Morbidity and Mortality in Children, which is enshrined in the DOH's (2010) strategic plan. South Africa has approximately 60 000 children under the age of five dying each year, with the primary and underlying contributors to childhood deaths being perinatal conditions with HIV and AIDS (DOH 2010).

In 2010, the DOH in South Africa, thus acknowledged the seriousness of the HIV pandemic and its implications for children. This was done by highlighting the importance of community and social factors in addition to perinatal factors that contributed to the plight of HIV infected children (DOH 2010). This study thus included the socio-economic experiences of caregivers of HIV infected children, with the aim of understanding how these experiences impact on child care.

Socio-economic experiences of caregivers, often predetermines their decision to access health care for the HIV infected child. Wingham et al. (2008) in their study found that HIV infected children's adherence to treatment was related to their poor economic circumstances. The researchers found that often a choice had to be made between using money to go to clinic appointments or to buy much needed food. Giese (2003) stated that the HIV pandemic perpetuates social disparity, but more especially it contributes to challenges at the household level. It is believed that disease, death and poor financial circumstances changes the roles in the home, with the need for children to seek employment and the role of care giving being relegated to the aged and frail.

This follows Raniga and Simpson's (2010) descriptive study of grandmothers in KwaZulu-Natal, where it was found that these elderly caregivers experienced socio-economic challenges when caring for sick HIV infected family members and

children. The grandmothers in this study reported to have relied heavily on their meager state pensions to provide for the basic needs of the entire family. It was found that the pensions were insufficient in providing for the needs of the grandmothers, as in most instances, the money was used for the care of their HIV infected relatives.

A further discussion on the impact of HIV and poverty experienced by families is Loewenson and Whiteside (1997) study. The researchers described the economic impact of HIV, firstly at a household level, whereby the costly implications of medicines and treatment for the HIV infected individuals drains the financial resources in the home. It is suggested in this study that HIV infected people would spend money on their health care and will not be able to sustain investments, which ultimately impacts on the economy of the country (Loewenson and Whiteside 1997).

The researcher agrees with the findings in the above studies, that poverty and HIV can have devastating consequences for individuals and families. It is interesting to that Loewenson and Whiteside (1997) noted financial implications in caring for HIV infected individuals, in their mention of costly treatment. This is especially important when one considers caregivers who need money in order to access health care for the HIV infected child.

Other challenges to accessing health care for the HIV infected child would include HIV stigma and discrimination. The caregiver, the community, and the health care system are often influenced by issues of stigma.

This follows that in the researcher's experience as a social worker, it has been noted that many caregivers often did not willingly reveal their difficulties or challenges of caring for the HIV Infected child. This often resulted in the problem/s only being identified when the child was admitted to hospital for the treatment of severe illness. This statement can be supported by Demmer's (2011) study, where it was found that caregivers were sometimes afraid to access much needed medical assistance for the sick HIV infected child, as they were concerned about

people discovering the status of the child and feared possible discrimination towards themselves and the child.

Phili (2009) concurred by adding that parents who were caregivers of HIV infected children were reluctant to test, because a HIV positive test of the child could indirectly reveal their own status. This is further supported in the study by Vreeman et al. (2010) where caregivers who were reluctant to disclose the child's HIV status did not medicate or delayed the administration of medication to the child at the appointed time so as to avoid disclosure. This has serious implications for the HIV infected child, as the caregiver's failure to comply with the treatment plan could result in the child developing a resistance to the antiretroviral treatment, and / or developing opportunistic infections. This adds to the burden of care as the caregiver then has the added stress of taking care of an HIV infected child, whose physical health has now been compromised.

This study may also serve to give caregiver's a better understanding of the reasons why they make certain choices. The aim is to provide them with favorable options and more productive alternatives than possibly the abandonment of the HIV infected child, or unconsciously subjecting the child to neglect because of a lack of knowledge about available resources.

One of the aims of this study is to explore contrasting experiences of caregivers, by focusing on their positive and negative life experiences in the caring relationship with the HIV infected child. Studies that had differing findings and contrasting views regarding caregiver's experiences were reviewed for this study. The qualitative study by Vreeman et al. (2010) on issues of disclosure of children's HIV status in Western Kenya revealed that some caregivers of HIV infected children perceived disclosure of the child's status as having a positive impact on older children's adherence to antiretroviral therapy and the social support received. The same study however, also found that some respondents believed that disclosure was detrimental to the child's emotional health and possibly attracted discrimination and stigmatization for the family as a whole. The caregivers' experiences of stigmatization and HIV disclosure can therefore directly

impact on whether health and welfare services are accessed for the HIV infected child.

Demmer (2011) further stated that adherence to ART is challenging for both the children receiving treatment and their caregivers who are primarily responsible for administering medication. A key objective guiding this study was to explore the challenges experienced by caregivers in ensuring the HIV infected child's adherence to treatment, and thus builds on the findings of Demmer's (2011) study.

Consideration of the caregiver's experiences, and the subsequent impact on their ability to provide for the HIV infected child's care, is crucial when looking at the health and welfare issues of the child. Cluver and Gardner's (2007) qualitative study with children orphaned by AIDS in Cape Town, suggests that it is imperative to conduct a psycho-social assessment of children's home circumstances as the HIV pandemic can often impact negatively on child care, sometimes resulting in the infringement of children's rights.

This study explored caregiver's difficulties in providing for the care of the HIV infected child. Much too often the researcher, in the role of a hospital social worker, has encountered similar situations, where caregivers were unable to provide for the basic needs of HIV infected children. This was often perceived as child neglect, because they did not have and/or were not knowledgeable about the necessary resources.

1.3 RATIONALE AND BACKGROUND

The main purpose of the study was to understand the experiences of caregivers of HIV infected children that were accessing services at a public hospital in Durban.

The researcher is employed as a social worker at this public hospital. During her seven years of employment at the hospital, she had frequent interactions with caregivers of HIV infected children. She found that they experienced many challenges in their role as caregivers. One of their main challenges was their poor

socio-economic circumstances. Caregivers reported that they struggled to provide for the child's and their own basic nutritional needs.

Between 2009 and 2011, psycho-social assessments of the circumstances of 146 HIV infected children who were admitted for treatment, revealed that the caregivers also experienced dire psycho-social problems, which then had implications for the quality of care of the HIV infected child when they returned home. Many of the children that were admitted to hospital for treatment were diagnosed with severe malnutrition and weight loss, in addition to their already compromised HIV status. It was found that some caregivers were experiencing housing crises and often did not even have stable accommodation. The hospital social work department intervened by providing advocacy services towards assisting the caregivers to liaise with government departments when the need arose. However, in most instances pertaining to the child's discharge from hospital, social workers had to refer these cases to the community social worker for further investigation of the home circumstances. This was necessary if there was concern that the child may be returning home to poor socio-economic circumstances that placed them at risk of possible neglect or abuse.

It was also found that caregivers waited too long to access medical treatment for the sick child. In many instances, the children were not tested for HIV infection and were only diagnosed after being hospitalized. A further concern was that some primary caregivers did not accompany the child upon admission, and there was evidence of social neglect of the HIV infected child. It therefore became a concern to try to understand why so many children were being admitted to hospital with severe illness in addition to poor social conditions, like abandonment and neglect. This presented implications for social work intervention at the hospital and within the community. HIV infected children that were abandoned in hospital, were subjected to being drawn into the social welfare system, as per the requirements of the Children's Act (Act 38 of 2005). The Children's Act (2005) guides social work intervention, in terms of children that are found to be in need of care. Radio announcements were conducted by the hospital social worker, in order to trace possible family members of the abandoned child, and referrals were made to non-governmental organizations and the Department of Social Development social workers, to initiate statutory intervention in respect of the child.

A further objective of this study was to gain an understanding of the caregiver's challenges in accessing services for the HIV infected child.

According to Demmer (2011) and Phili (2009), HIV infected children are still not accessing adequate health care and more especially ART that is critical for their survival. They found that the care givers, who play such a vital role in the lives of the infected child, often do not or cannot access treatment for the child due to their poor economic and social circumstances. Other studies that concur with Phili (2009) and Demmer (2011) add that caring for HIV infected individuals is often physiologically exhausting and socio-economically challenging for the caregiver. This negatively impacts on them accessing services for the HIV infected individual and themselves (Raniga and Simpson 2010; Shebi 2006 and Ryan 2001).

A qualitative study that was conducted at the same public hospital by Buthelezi in 2011 focused on the experiences of caregivers of malnourished children who were admitted in the paediatric ward of the hospital. This study found that caregivers experienced many challenges in ensuring that the children in their care had sufficient nutrition. Some of the findings of this study were that poverty and lack of familial support impacted on the caregiver's ability to provide for all the needs of the malnourished child.

This current study is based at the same public hospital, however it is unique, as it aimed to describe the experiences of caregivers of HIV infected children. It further makes recommendations for improvements to, and/or additions to health and social services within the public hospital setting.

1.4 RESEARCH AIM AND OBJECTIVES

1.4.1 Research Aim

The main aim of this study was to explore, describe and interpret the experiences of caregivers caring for HIV infected children and accessing services from a public hospital in Durban.

1.4.2 Objectives of the Study

- 1.4.2.1 To ascertain the caregivers' experiences and the implications for the care of the HIV infected child.
- 1.4.2.2 To explore the caregivers' understanding of HIV and adherence to treatment.
- 1.4.2.3 To explore and describe the existing services, programmes and resources available for caregivers and the HIV infected child.
- 1.4.2.4 To explore the coping strategies of caregivers caring for children with HIV infection.
- 1.4.2.5 To make recommendations for the improvement of services based on findings of the study.

1.5 RESEARCH QUESTIONS

- 1.5.1 What are the physiological, psycho-social and economic experiences of caregivers?
- 1.5.2 What is the caregiver's understanding of HIV and HAART?
- 1.5.3 What are the challenges encountered by caregivers caring for HIV infected children when accessing services at a public hospital?
- 1.5.4 What are the coping skills of caregivers caring for the HIV infected child?
- 1.5.5 How can the services for caregivers and the HIV infected child be improved?

1.6 THEORETICAL FRAMEWORK UNDERPINNING THE STUDY

De Vos et al. (2005) suggest that researchers use paradigms or theories that they are knowledgeable about, in order to ensure clarity and unambiguity in their studies. The use of the ecosystems theory in this study, enabled the researcher to understand how the interplay of the microsystem, the mezzosystem, the exosystem and the macrosystem, impacted the quality of life of the HIV infected child and their caregivers.

Zastrow (2003) explains that the ecological model was adopted by social workers in the 1960s as a practice model, because environmental factors were shown to be as influential as internal factors in causing client's problems.

Thus the ecological model looks at treating the client by assessing the person's relationships with others, be it functional or dysfunctional, and their physical and social interactions within their environment.

The ecological model would always consider that human beings have a reciprocal interaction with their environment and that they do not exist in isolation. Human beings are constantly interacting with the various systems that constitute their living environment. This could include the individual's friends, family, work colleagues, their communities and the broader Welfare and Government institutions (Zastro and Kirst-Ashman 2010 and Zastrow 2003).

Meyer (1983) believed that the General Systems Theory (GST), combined with the ecological model, provided a better understanding of the nature of people's interaction with the various systems in the environment.

This follows that there are various systems that impact on the lives of caregivers. Ryan (2001) suggests that "HIV does not occur in a vacuum", and that the pandemic extends to the systems that are beyond the boundaries of the HIV infected person, thus the ecosystems theory was deemed fit as the key conceptual foundation of this study.

This research study sought to gain insight into the resources, experiences and needs of caregivers caring for the HIV infected child, in relation to the micro system (the HIV infected child, the caregiver and the household), the mezzosystem (family, neighbours, social relationships, the community), the exosystem (employment, the public hospital, clinics and welfare organizations) and the macro system (government, health and welfare policies and economic factors). The current study used the ecosystems framework, to explain the structural and social barriers experienced by caregivers, in accessing services for the HIV infected child.

The ecosystems theory will be further elaborated on in chapter three which discusses child care legislation.

1.7 VALUE OF THE STUDY

This study aimed to enlighten social work practitioners and health care workers about the experiences of caregivers of HIV infected children, and possibly create an understanding of their challenges in ensuring the well-being of the child in their care. The researcher believes that an understanding of the phenomenon under study would enable health care workers to better engage with the people that they serve, specifically HIV infected children and their caregivers. The researcher envisages that this study would also enhance the knowledge of social workers, who are faced with the enormous task of facilitating the health and wellness of HIV infected children in the public health sector. From a public health perspective, this study would add value to service delivery, for both caregivers and children infected and/or affected by HIV and AIDS.

The researcher further envisions that this study's findings would compliment and enrich the findings of other researchers in the complex area of HIV and AIDS, thereby contributing invaluable to the area of social science research.

The study further aims to make suggestions to the provincial health and welfare departments for the improvement of existing services. With specific focus on the needs of caregivers of HIV infected children.

1.8 CLARIFICATION OF CONCEPTS

For the purposes of this study, the key concepts will be clarified as follows:

Caregiver – The Children’s Act (Act 38 of 2005, p. 14) defines a “Caregiver” as any person other than a parent or guardian, who factually cares for a child and includes a foster parent; a person who cares for a child with the implied or express consent of a parent or guardian of the child; a person who cares for a child whilst the child is in temporary safe care; the person at the head of a child and youth care centre where a child has been placed; the person at the head of a shelter; a child and youth care worker who cares for a child who is without appropriate family care in the community; and the child at the head of a child-headed household.” For the purposes of this study, the ‘caregiver’ refers to those individuals, related and unrelated to the HIV infected child, who were living in the same home as the HIV infected child and were primarily responsible for the child’s overall care and ART.

Child - “Child means a person under the age of 18 years” (Children’s Act 2005, p. 14). This study will refer to the “child” as an HIV infected child who is under the age of 15 years, as this was the target age of children that were receiving services at the hospital in the paediatric departments and ART clinic.

Paediatric HIV – This refers to the HIV infected child who is under the age of 18 and is receiving antiretroviral treatment at the public hospital or clinic.

Health systems – A health system “consists of all organisations and individuals whose actions are intended to promote, restore or maintain health. A health system involves a broad range of institutions and individuals; their actions help to ensure the efficient and effective delivery and use of products and information for the prevention, treatment, care, and support of people in need of these services”

(UNAIDS–Terminology Guidelines 2011, p. 14). For the purposes of this study Health systems and facilities will refer to government funded hospitals and clinics.

Mother-to-child-transmission (MTCT) – This refers to the HIV infection of the child from the biological mother during pregnancy, child birth or breastfeeding (UNAIDS Terminology Guidelines 2011, p. 21 and Van Dyk 2008).

1.9 SUMMARY

Chapter one provided an introduction to the purpose and background of the study. Secondly, the HIV and AIDS pandemic and the theoretical framework that guided the study followed. Thirdly, a discussion followed on the value of the study and an explanation of key concepts and abbreviations. Finally, the chapter concludes with a synopsis of the dissertation.

1.10 SYNOPSIS OF DISSERTATION

Literature Review

Chapter two provides a critical review of all relevant literature, with the purpose of examining previous studies, taking into account possible gaps that were evident and how the current study addresses those inadequacies. This will include a global, African and South African overview of HIV and AIDS, the government's response to HIV in South Africa, a biomedical perspective of HIV infection in children and HIV treatment legislation guiding the care of children. This will then be followed by the public health sector's response to the HIV infected child and the caregiver's response to paediatric ART adherence. Chapter Two will conclude with literature pertaining to HIV and the psycho-social health of caregivers.

Chapter three continues the literature review with a focus on the social welfare legislations and policies guiding the health and care of HIV infected children. This

is followed by a discussion on the ecosystems paradigm as the conceptual framework for the study. The ecosystems theory and HIV are elaborated on further. The socio-economic barriers to services for caregivers and HIV infected children are also discussed in detail. The chapter concludes with a discussion on the social worker's role in the context of HIV and AIDS, with special focus on services to HIV infected children and their caregivers.

Research Methodology

Chapter Four discusses the sampling procedure, the research design, the research tools used, the data analysis, ethical considerations and limitations of the study.

Analysis and Discussion

Chapter Five focuses on the factors influencing the care giving relationship. This is followed by a demographic profile of the respondents. Finally the major themes and sub themes that distilled from the data analysis are discussed.

Chapter Six explores the respondents' experiences regarding their access to health and social services. The chapter concludes with findings and discussions on the care givers' coping strategies.

Conclusions and Recommendations

Chapter Seven discusses conclusions and recommendations arising from the study. Recommendations will also be presented for future studies. The chapter concludes with the researcher's recommendations based on the value of the study.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

According to Neuman (1997) the literature review aids the researcher in contextualizing the research project by acknowledging previous research and illustrating how the current study relates to previous studies regarding the same phenomenon. Neuman (1997) adds that the literature review allows the researcher to acquire new knowledge and generates creativity that contributes to the value of the study.

The literature review thus helped the researcher to better frame the study in present literature and guided the selection of areas for investigation in the study, based on the recommendations of similar studies.

2.2 THE GLOBAL RESPONSE TO HIV AND AIDS

The United Nations Joint Programme on HIV and AIDS (hereafter referred to as UNAIDS) argued that because access to ART has increased, more people are 'living with HIV'. In 2011 it was estimated that globally 34 million people were living with HIV; which was a 17 percent increase from 2001 statistics. The report suggests that ART was impacting positively on the reduction of AIDS related deaths worldwide (UNAIDS World AIDS Day Report 2011, p. 6).

Despite global efforts to fight HIV and AIDS by scaling up access to services, UNAIDS reported in 2011 that access to ART for children is still a major concern. It has been reported that only 28 percent of HIV infected children in the world have access to treatment. This has implications for the HIV infected children of South Africa, as the country still leads the HIV pandemic with 5.6 million people living with HIV at the end of 2011 (UNAIDS world AIDS day report 2011 and WHO 2011).

In September 2000, countries and heads of state agreed to take a stance against the HIV and AIDS pandemic. The strategy adopted by the United Nations, was called the Millennium Development Goals. The strategy was to work collaboratively with state organizations and Non-governmental organizations to achieve eight key objectives, namely; poverty alleviation, education for all, promotion of gender equality, the reduction of “child mortality”, the improvement of “maternal health”, the combating of “HIV and AIDS, Malaria and other diseases”, ensuring “environmental sustainability” and the development of “global partnerships” for the purposes of development (Republic of South Africa 2010, p. 13).

This follows that the WHO then developed global guidelines for the strategic management of the HIV and AIDS pandemic, based on the MDGs of the United Nations declaration. The WHO’s strategic plan for the period 2011 to 2015, was based on four core objectives, namely: the achievement of HIV prevention programmes and strategies for all; the diagnosis of HIV so that the disease can be managed at an early stage; treatment of currently HIV infected people and the provision of care and support to HIV infected individuals and their caregivers (WHO 2011).

This follows that the WHO (2011), suggested a global strategic plan comprising of four main strategies that will address the core objectives discussed. Firstly, to focus on prevention, diagnosis, treatment and care, by ensuring that health programmes address these key objectives and are comprehensive and effective. This would require that countries continuously evaluate their health programmes and interventions to ensure that optimum service standards are adhered to.

Secondly, the WHO suggests a collaboration of programmes from the various sectors of health like maternal health, child health, nutrition etc, so that there is a greater coverage of the HIV infected population that is targeted. The researcher agrees with this aspect of the strategic plan, where health care workers are urged to provide services to HIV infected and affected people by considering them and all the systems that they interact with. It is therefore not sufficient to focus only on the medical aspects of dealing with the HIV and AIDS pandemic, but also

necessary to collaborate services within the health sector, to include treatment as well as prevention, care and support (WHO 2011). These collaborations would have to be reinforced and supported in order to deliver the appropriate services and achieve the desired outcome.

Thirdly, countries are urged to strengthen their health systems by ensuring that their systems are able to deliver cost effective, accessible and sustainable health services.

It is fruitless to expand health services by scaling up the access of ART without addressing structural barriers that impact on the HIV population accessing these services. Therefore, the fourth strategic plan focuses on exploring these structural barriers and addressing them so that service access is possible. Thus if countries are able to ensure the human rights and security of the population together with facilitating the access to health services, this would result positively in reducing the risk and vulnerability of those populations that are considered to be more at risk of HIV infection (WHO 2011).

The overall global vision is to have, “zero new HIV infections, zero AIDS-related deaths and zero discrimination in a world where people living with HIV are able to live long, healthy lives” (WHO 2011, p. 7).

Fortunately, the guideline to achieving this global vision is provided by the WHO (2011) however, it is advised that when using the guidelines, countries take into consideration their differing contexts. Governments are therefore urged to be clear about the nature and the extent of the HIV and AIDS pandemics within their own countries and to strategize their health plans accordingly.

The researcher is in agreement with the WHO's (2011) suggestion to examine the extent of the HIV and AIDS pandemic in individual countries. This is based on the belief that all countries are unique in terms of available resources and infrastructure. Thus they would need to consider their strengths and their limitations when planning appropriate programmes that would address the prevention, treatment, support and care for the HIV infected and affected.

2.3 HIV AND AIDS: SUB SAHARAN AFRICA AND SOUTH AFRICA

Sub Saharan Africa accounts for 68 % of the world's HIV infected people, which is catastrophic as the region consists of only 12 % of the total global population. In addition to these statistics, by the end of 2010, the region reflected that at least one million lives were being lost annually since 1998 as a result of AIDS and the HIV pandemic. This meant that the number of people that died as a result of AIDS, in Sub Saharan Africa, contributed to more than half of the total number of AIDS-related deaths worldwide.

It has been stated that in 2010, there was a reduction in the number of new HIV infections globally, with even Sub-Saharan Africa reflecting a decrease in new infections. However, the region is still leading the pandemic with the highest number of new infections in the world. This follows that 70 % of all new HIV infections occurred in this region (UNAIDS World AIDS day report 2011)

A further area of concern is that the global HIV epidemic report by UNAIDS in 2012, found that Sub Saharan Africa still leads the world in accounting for 90 % of new HIV infections in children globally (UNAIDS 2012). This is therefore of concern, as one addresses the health and welfare of these HIV infected children. Thus, South Africa which is situated in the Sub Saharan region, has identified the reduction of child mortality and new HIV infections as key objectives in the DOH's NSP for the period 2010/11-2012/13 (DOH 2010). This commitment to improving child health generally and reducing HIV infection in children is also in keeping with the country's NSP, of improving the access to ART for all HIV infected individuals in South Africa (DOH 2010).

2.4 GOVERNMENT'S RESPONSE TO HIV IN SOUTH AFRICA

As previously discussed the South African government has been supportive of the WHO's (2010) strategic plan and the United Nation's MDGs. This is indicative of the changes that were instrumented in the countries HIV and AIDS treatment

protocol, for the purposes of scaling up antiretroviral treatment, and the provision of care and support for HIV infected people in 2010.

This follows an important statement made by South African president, Jacob Zuma on 1st December 2009, in commemoration of World AIDS day in Pretoria. The President reiterated the country's commitment to joining the rest of the world in efforts to fight the HIV pandemic. President Zuma explained that this would be achieved by implementing the policy changes listed below to HIV and AIDS treatment protocols in South Africa by 1st April 2010:

The launching of the HCT campaign to motivate the nation to test for HIV infection was the first initiative.

Secondly, children under the age of one year, who tested HIV positive, would automatically receive ART and the previous guideline of requiring the CD4 count to be considered before initiating treatment, would no longer apply.

Thirdly, all tuberculosis (T.B) and HIV infected patients would qualify for ART initiation, if their CD4 count was 350 and below. This deviated from the previous guideline which considered patients for ART, only if their CD4 count was below 200.

Fourthly, the policy also ensured that all HIV infected pregnant women would qualify for ART, with CD4 counts less than 350, or if they presented with "symptoms" (AIDS symptoms) then regardless of their CD4 counts, they would be eligible for treatment. The previous policy considered only HIV infected pregnant women with CD4 counts below 200.

Fifthly, the policy also enabled all HIV infected pregnant women to access ART as early as 14 weeks into the pregnancy, in order to decrease the risk of infection to the baby. Previously, ART was administered to HIV infected pregnant women only during the last trimester of their pregnancy. The President also committed to ensuring that all health care facilities in the country would be equipped to provide HIV testing, counseling and treatment to all.

The policy changes in HIV treatment protocol for South Africa in 2010 were received in a favorable light by the nation, considering that the changes were intended to make a positive impact on decreasing infant mortality rates and preventing deaths as a result of tuberculosis amongst HIV infected patients (Zuma 2009).

However, it is argued that at the end of 2010, only 55 % of the 80 % that the government had initially perceived would require ART were actually receiving treatment. Further, only 36 % of HIV infected children in the country that should have been receiving ART, actually had access to the treatment (South African History online 2012)

It is therefore important to understand the structural barriers that are experienced by the caregivers of HIV infected children, in order for health care workers to facilitate their access to ART.

This follows Lazarus and Folkman's (1984) assertion cited in Naidu (2005), that individuals who were economically stable were able to readily access services. These individuals also had more coping choices available than those individuals who struggled financially. This supports the argument that poverty impacts on caregivers' access to health services for HIV infected children. This is corroborated by Phili (2009), where it was found that caregivers in poor households were forced to prioritize the purchase of food and clothing over accessing health care for HIV infected children.

As caregivers are solely responsible for the health and wellbeing of the children in their care, this is an area of concern for social workers in the health care setting, as they strive to ensure the medical and social needs of children are being met. There is currently still no cure for HIV and research has indicated that ART can only help to prolong the lives of HIV infected adults and children (Van Dyk 2008 and Ross and Deverell 2004). Never the less, The African Network for the Care of Children Affected by AIDS (hereafter referred to as ANECCA) contends that access to ART for HIV infected children is a serious health and welfare concern, as children who cannot access ART are more susceptible to developing serious illness and possible death, ANECCA 2006).

This again reflects the importance of this study in exploring the experiences of the caregivers of HIV infected children, as they encounter many challenges in the care giving relationship, many of which impacts on their ability to provide the necessary care for the HIV infected child. Social workers and health care workers therefore need to understand the HIV infected child and their caregivers within their social environments, in order to render the necessary services to them.

2.5 A BIOMEDICAL PERSPECTIVE OF HIV INFECTION IN CHILDREN

HIV and AIDS still pose many challenges to the infected population, especially children who are minors, as they are dependent on a trusting caregiver to nurture and administer medication responsibly (Vreeman et al. 2010). Thus the concern still remains for the psychosocial wellbeing of not only the biological mothers, but also other caregivers of the HIV infected child and their ability to provide comprehensive health and welfare of the child (Demmer 2011).

These areas of concern for the survival of children thus lead to South Africa's support of the WHO (2011) goals to combat HIV and AIDS. The plan is to aim for the reduction in AIDS related deaths and discrimination, as well as achieving a goal of "zero new HIV infections from MTCT" by 2015 (DOH 2011 p. 14 and WHO 2011 p. 7). Of interest is that the DOH (2011) speaks to not only the issues of improving access to ART for pregnant HIV infected women, but also issues of care and support to caregivers of children already born with HIV infection.

In order to plan interventions for and achieve the above goals by 2015, it becomes necessary for health social service providers to understand the phenomenon of MTCT of HIV. Additionally, Van Dyk (2008, p. 42) states that HIV infected mothers could pass the HIV infection to their baby during pregnancy, child birth or breastfeeding. She explains that the unborn child is largely at risk of in utero HIV infection if the mother becomes infected "just before or during pregnancy". The risk of infection for the unborn child is also increased if the mother presents with "AIDS" (which is the latter phase of the HIV infection). This implies that in order for HIV infected pregnant mothers to reduce the risk of HIV infection to their unborn

babies, they need to access health and prenatal care themselves, so that they have access to ART timeously. The ART in this instance serves to reduce the viral load in the breast milk and blood content of the HIV infected pregnant woman, and thus is able to minimize infection risk to the baby (Van Dyk 2008).

Conversely, MTCT of HIV is not the only way that children become infected with HIV, and it is necessary to bear in mind the other modes of infection. The African Network for the Care of Children Affected by AIDS (ANECCA 2006, pp.20-21) thus summarizes some of the other modes of HIV transmission to children as occurring in the following ways:

- Infection can spread through medical procedures such as blood transfusions with HIV infected blood.
- During access to services at health care centers where “non-sterile equipment” is used on the child.
- During the procedures of “male circumcision and scarification” by traditional healers, where non –sterile equipment may sometimes be used.
- A child may be infected with HIV as a result of “rape” or other “sexual abuse” by an HIV infected individual.
- “Child prostitution and sexual initiation practices amongst sex workers”, could also put children at risk of HIV infection.

This study however focused on HIV infected children that contracted the HI virus through mother-to-child-transmission, as the researcher found that this was predominantly the mode of HIV transmission that infected the children treated at the public hospital.

It is important for social workers in the health setting to understand the nature and extent of any problem before actually planning interventions (Turner 1996).

This follows that in an attempt to explain the extent of MTCT of HIV in South Africa, Abdool Karim and Abdool Karim (2005, p. 183) assert that the majority of HIV infected children become infected as a result of MTCT and thus HIV and AIDS significantly impacts on childhood deaths. The authors state that the “overall

transmission rates are between 25 % and 40 % of all children born to HIV positive women in South Africa”.

In contrast to Abdool Karim and Abdool Karim’s (2005) assertion regarding the devastating extent of the problem of MTCT of HIV, the WHO in 2011 argued that the programmes focusing on reducing MTCT of HIV infection have been successful in noticeably reducing HIV infection in children, globally. In support of this statement the WHO’s (2011) statistics projected global MTCT rates of 500 000 in 2001 and then 370 000 in 2009.

Similarly, in South Africa it was found that since the government’s scale- up of the prevention of MTCT of HIV (hereafter referred to as the PMTCT) campaign the number of babies that were born with HIV infection had declined by the year 2010. Thus the national HIV transmission rate in infants for South Africa was reflected as 11 % in 2010 (Republic of South Africa 2010). This finding supports the premise that HIV and AIDS prevention and treatment programmes have made significant headway over the years.

A further concern was that despite the efforts of MTCT programmes to curb MTCT of HIV, there still were barriers to its complete success, as there were still babies being born with HIV (Kasese-Hara et al. 2008). This follows that the United Nations Joint Programme On HIV/AIDS stated in their global HIV epidemic report that seventy percent of HIV infected pregnant women who qualified for ART were still not receiving treatment to prevent MTCT of HIV (UNAIDS 2012).

Blystad and Moland (2009) corroborate with the assertion by Kasese-Hara et al. (2008) when they found that many HIV infected pregnant women are aware of their HIV statuses but lack the ability to prevent the infection to their unborn children. Their study with expectant mothers in a PMTCT programme, highlighted gaps in the programme that impacted on expectant mothers accessing services and resources readily. The researchers stated that HIV infected pregnant women have incongruous perceptions of themselves as mothers. The authors likened these perceptions to being uncertain between their nurturing or life creating roles and the likelihood of them killing their babies with HIV infection through

breastfeeding and the birth process. This has resulted in these HIV infected mothers adopting unconventional coping strategies like the non-disclosure of their statuses and their withdrawal from society. This then often results in them not accessing health care resources like PMTCT programmes that could reduce the risk of HIV infection to their unborn babies.

The authors argue that PMTCT programmes need to take the above perceptions of HIV infected pregnant women into account, in order for the programme to be truly effective. They therefore recommend that present treatment and support services for HIV infected pregnant women, include psychological and supportive services as well to their existing programmes (Blystad and Moland 2009).

2.6 HIV TREATMENT LEGISLATION

AIDS can take 10-15 years to develop in a HIV infected person and it has been found that antiretroviral drugs can slow down the process of HIV progression to AIDS (WHO 2011). ART has been found to facilitate normal growth and development in HIV infected children. It can prevent opportunistic infections and improve and prolong the child's life span (Van Dyk 2008 and ANECCA 2006).

Contrasting arguments state that ART however, can be ineffective in HIV infected individuals that are already in the advanced phase of HIV infection. Research in Uganda found that HIV infected people, who commenced ART at advanced stages of the disease, "were three times more likely to die" than those individuals who started at the early stages of HIV infection (Van Dyk 2008, p. 101). This could be attributed to the effects of AIDS related illnesses in the advanced stage of the disease, which would have weakened their bodies and thus their ability to respond to treatment.

Similarly, the African Network for the Care of Children Affected by AIDS asserts that the late diagnosis and treatment of sick HIV infected children could result in the ineffectiveness of ART for these children, and it is therefore crucial for the early diagnosis of HIV infected children (ANECCA 2006).

This has serious health implications for the HIV infected child, who is reliant on their caregivers to facilitate their HIV testing and access to ART. In fact the transmission of HIV infection to infants is generally dependent on the actions of their biological mothers. This follows that HIV infected pregnant women who access ART for themselves, could prevent MTCT of the virus (Blystad and Moland 2009).

This supports the HIV and AIDS treatment protocols of 2010, where improvement to access to ART for pregnant women was prioritized (Zuma 2009). Furthermore, it is suggested that should the child become HIV infected, despite all of the necessary preventative measures, ART can still be administered to the HIV infected child, in order to prevent opportunistic infections and delay the onset of AIDS (Van Dyk 2008).

A contentious issue regarding the immediate administration of paediatric ART, would be that ART should only be administered to HIV infected children when a suitable caregiver has been identified, who will be committed to administering the treatment to the child (McKerrow et al. 2010 and McKerrow et al. 2006). The authors here contend that in order to ensure paediatric adherence to ART it is more beneficial to wait for a responsible care giver who will manage the HIV infected child's treatment appropriately.

It is argued however that HIV infection progresses differently in children from adults. Children have lower resistance to disease and illness because their immune systems are still developing. This makes them more susceptible than adults, to progress faster to the AIDS phase of the HIV disease, once infected. This rapid progression of the HIV disease in children can be prevented if they have early access to ART (UNAIDS 2000).

Van Dyk (2008) corroborates UNAIDS' (2000) assertion by suggesting that children should be given ART as soon as they have been diagnosed with HIV infection, especially if they are younger than three months old and their mothers have tested HIV positive. Thus the South African government has implemented the Department of Health's National strategic plan to deal with the scourge of HIV

and AIDS, with specific attention to HIV infected children and their caregivers, as will be discussed later in this dissertation.

2.7 PUBLIC HEALTH SECTORS RESPONSE TO THE HIV INFECTED CHILD

Reducing HIV infection rates in children is an on-going challenge in South Africa, despite Government and Non-governmental sector's concerted efforts to implement programmes to address the problem. Public hospitals are still inundated with the growing admissions of very sick HIV infected children.

In keeping with the National Strategic Plan, health care facilities, have been encouraged to extend their programs to provide treatment, care and support of HIV infected children and their caregivers (DOH 2011).

This follows McKerrow, Stephen and Reddy's (2006) guidelines to the clinical management of HIV infected children in the health care setting as involving:

- The monitoring of HIV infected children's "growth" and development.
- Provision of "nutritional and dietary advice" to caregivers - ensuring that HIV infected children are routinely immunized and clinically managed.
- "Vitamin A supplementation"
- Routine treatment of children for worm infestation.
- Dispensing of "Cotrimoxazole prophylaxis".
- Provision of supportive services to caregivers and the child.
- The encouragement of "positive living".

It is perceived that the clinical management of the HIV infected child at health care facilities, together with the involvement of their caregivers promotes paediatric ART adherence, as there is communication and support between the caregivers and the health sector. Wingham et al. in their (2008) study supports this perception when it was found that health care professionals' experiences of the child-centred

approaches to care, with the active involvement of caregivers, proved to be successful in facilitating paediatric adherence to ART.

This follows that in addition to the clinical management of HIV infected children, it is important to also consider the needs of their caregivers.

McKerrow, Stephen and Reddy (2006, p. 3) outlined the following principles to managing HIV Infected children and their caregivers in the public health setting:

- Health care workers are reminded to never “discriminate” against the child and or the caregiver.
- Health care workers are urged to have compassion, empathy and confidentiality towards caregivers.
- It is also suggested that there should be clear channels of communication in all sectors of the health care system (i.e. clinics and hospitals) and the caregiver needs to be present and active in the management of the HIV infected child. There should be total involvement of the multi-disciplinary team (doctors, nurses, physiotherapists, occupational therapists, social workers and dieticians);
- It is imperative that the child’s “quality of life”, is preserved and their pain is managed effectively especially in the latter part of the illness.

In order to render the necessary health and social services to caregivers of HIV infected children, it is important to have an understanding of the caregivers’ level of knowledge regarding HIV and ART. It is suggested that the caregiver understands and is committed to following the child’s ART treatment plan indefinitely, as this impacts on the level of adherence that can be expected. Thus caregivers tend to have a better understanding of adherence, if they relate HIV and its treatment to other chronic diseases like diabetes or hypertension, where “poor adherence is associated with disease progression” (Van Dyk 2008, p. 108).

With the introduction of ART, the disease has become manageable like most chronic illnesses. It is therefore better understood by caregivers, when health care workers liken the disease to the management of a chronic illness, it helps the caregiver to put the disease in context and manage it accordingly. Comparing the disease to a chronic illness could also have benefits, as the caregiver then

becomes less stressed and more empowered. As they realize that they can control, to some degree, the health of the HIV infected child.

Caregivers are often responsible for the ART adherence of children, and it is therefore imperative not only to take into account the medical condition of the child but also the health and psycho-social experiences of the caregiver.

2.8 CAREGIVERS' RESPONSE TO PAEDIATRIC ADHERENCE

McKerrow, Stephen and Reddy (2006, p. 25) discussed the importance of “social criteria” to the success of the paediatric antiretroviral treatment. It is suggested that there should be at least two reliable caregivers who will ensure that the child is supervised and medicated regularly. The caregivers need to ensure that the HIV infected child’s immunisations are up to date and that at “least three scheduled clinic visits” are kept. A supportive home or social environment is important, so that there is another individual in the home who can assist with the child’s treatment, in the event of the primary caregiver being incapacitated for any reason. Caregivers are therefore encouraged to disclose the child’s HIV status to another responsible adult living in the same home. This is especially crucial for the administering of ART timeously to the infected child, and it allows for a second person to ensure ART adherence.

This follows the United Nations Joint Programme on HIV/AIDS (2011) report that the mortality rate of HIV infected children in developing countries is exacerbated as often the infected child succumbs to common paediatric illnesses that could have been managed through early identification of the disease and treatment intervention. Children are reliant on their caregivers to access health services for them and therefore the role of the caregiver in the life of the HIV infected child is vitally important in determining the health of the child.

Thus, Van Dyk (2008) states that the physical and psychological care of the HIV infected individual, can be influenced by the people who are considered to be most important in their lives. In this study it will be the caregiver of the HIV infected

child. It is therefore imperative that this caregiver be counseled on the physical and psychological needs of the HIV infected child and themselves.

MTCT of HIV impacts negatively on the psychological health of mothers of HIV infected children. This follows Demmer (2011) where it was found that perinatal HIV infection of children resulted in the mothers experiencing feelings of overwhelming guilt. Traditionally, the psychological health of caregivers has not received much attention, as the focus has always been on the HIV infected child. Ross and Deverell (2010) thus argued that there is insufficient literature that emphasized the importance of psychosocial approaches to dealing with health issues in South Africa. The Government's National Department of Health Strategic Plan thus corroborates the above statements, when it suggested a multi-sectoral response to South Africa's AIDS pandemic, by focusing on treatment, care and support for 80 % of HIV infected individuals and their caregivers by 2013 (DOH 2010).

2.9 HIV AND THE PSYCHO-SOCIAL HEALTH OF CAREGIVERS

The HIV infected child and the caregiver are constantly relating and interacting with other systems in their lives. It is suggested that these systems, like the socio-economic system (mezzosystem), impacts on the caregivers' actions and their quality of life. Demmer's (2011) exploratory study on caregiver's experiences in KwaZulu-Natal, with 13 female caregivers and 12 professionals who worked with caregivers and HIV infected children, concluded that poverty and stigma impacts greatly on the caregiver's ability to provide care for the HIV infected child. Demmer's (2011) study found that often caregivers would not accept that a child could be HIV infected. This denial of the possible HIV infected status of the child often proved to be life threatening for the child, as the extended family in some cases ignored the symptoms of the child, and only sought health care after the mother of the child died. This study further reported that the medical needs and the frequent hospitalizations of the HIV infected child, resulted in caregivers experiencing fear and anxiety about the child's health. Caregivers in this study cited economic difficulties that impacted on their ability to cover transport costs to

access medical assistance and their inability to buy healthy food for the child, as challenges experienced.

Naidu's (2005) qualitative study of four caregivers employed at a children's home in Durban highlighted that caregivers felt increasingly depressed and anxious when caring for children over long periods of their shifts. This study targeted caregivers who were employed in the care giving role and did not live with the HIV infected child on a permanent basis. Naidu's (2005) study established that these caregivers also described their long hours of work, caring for very sick children, and feelings of helplessness and fear of possible HIV infection, as difficulties in their jobs. However they identified training received, as a coping mechanism in dealing with their fears. They explained that the information received in training helped them to understand the disease better, and by sharing this information with others, they gained community and family support.

Studies involving caregivers who were related to and lived with HIV infected children, such as Fawzi et al. (2010) and Demmer (2011) found that caregivers experienced depression at times when caring for HIV infected children. Fawzi et al. (2010) further concluded that parental depression further influenced the extent of "anxiety, anger, depression and loss of concentration" experienced by the HIV infected child. It was recommended that family-focused interventions were required to deal with the psycho-social and physical experiences of parents and their HIV infected children (Fawzi et al. 2010, p. 153).

Furthermore, Demmer's (2011) study with mothers of HIV infected children builds on the study by Fawzi et al. (2010). Demmer found that caregivers experienced conflicting emotions at times. These emotions included feelings of relief on finding out the child's HIV infected status, to worrying and self-blame for the child's infection. The multitude of varying psychological experiences thus warrants an exploration of caregivers' psycho-social circumstances, in order to understand the care giving relationship.

The current study included caregivers that shared different relationships with the HIV infected child; some were parents, siblings, aunts, cousins and grandmothers. They all however lived with the HIV infected child and were primarily responsible

for the administering of the ART. Social workers face many challenges in their work with HIV infected children and their caregivers. It is therefore necessary to be aware of the psycho-social health of the caregivers when deciding on treatment and intervention plans for social service delivery.

Caregivers of HIV infected children have a more complex task than that of caregivers of non HIV infected children. McKerrow et al. (2010) took cognizance of this when they formulated a handbook to assist health care workers to gain a better understanding of caregiver's challenges in taking care of the HIV infected child. McKerrow et al. (2010) emphasized the caregiver's willingness to the commitment and support of the child in the treatment plan, as a factor that determined the child's successful adherence to treatment.

The authors believed that supplementing caregiver knowledge and the provision of social support, by also managing caregivers' challenges, would encourage caregivers in their care-giving role. Six areas of possible caregiver concerns that needed to be addressed in the health care setting were identified by the authors as the following:

- Physiological challenges of the caregivers

It was suggested that the caregiver's own HIV status, physical and mental health needed attention and health care workers needed to ensure that caregivers were knowledgeable about their own health issues and the management thereof.

- Economic circumstances

Caregivers access to social security, if the need arose, and their financial stability in the home were also factors to be considered, as this impacted on them bringing the child for treatment to the clinic. Health care workers were urged to check if caregivers experienced financial constraints that prevented them from affording transport to vital services like clinic appointments.

- Social circumstances

Social factors for consideration would be other adult caregivers in the home that play a role in child care, other children and adults in the family home, and whether

the caregiver and the HIV infected child's most basic needs of "water, electricity and sanitation" were being met.

- Psychological circumstances

Ideally the caregiver's support networks and coping mechanisms needed to be examined. This would include family support, social support from friends and the community, support from religious institutions and access to and support from health and welfare departments.

- Knowledge and understanding of caregivers

Of vital importance is assessing caregiver's knowledge and understanding of HIV and the child's antiretroviral treatment. Caregiver knowledge about the nutritional needs of the child and possible side effects of the ART are also an important area for concern.

- HIV disclosure

According to McKerrow et al. (2010), health care providers need to evaluate the caregiver's perceptions of HIV disclosure in order to effectively understand and clinically manage the HIV infected child's adherence to ART. This follows that it was found that caregiver's fear of disclosing the HIV infected child's status, prevented them from accessing ART for the child (Demmer 2011).

McKerrow et al. (2010) suggests that focusing on the caregiver's experiences and challenges results in good paediatric adherence to ART. It is suggested that the child's ART should be planned in accordance with the child and the caregiver's lifestyle. This should be done in conjunction with a good educational grounding of the caregiver on the treatment plan. McKerrow et al. (2010) reiterates that these measures should be employed before the commencement of the child's ART in order to maximize treatment adherence. This study thus aimed to describe the experiences of caregivers of HIV infected children in detail, in order to provide an understanding of how they provided for the care of the child, often against resource limited backgrounds.

The researcher agrees with McKerrow et al. (2010) that in order to ensure that the HIV infected child adheres to treatment, potential challenges that caregivers may

experience needs attention. The potential challenges identified by the authors serve to guide health care workers to consider the HIV infected child and the caregiver and all the psycho-social factors that ultimately impacts on their quality of life.

2.10 SUMMARY

Chapter two provided a critical review of relevant literature that applied to the current study. The chapter commenced with a global, African and South African overview of HIV and AIDS together with the government's response to HIV in South Africa. This was followed by a biomedical perspective of HIV infection in children, HIV treatment legislation, and the public health sector's response to the HIV infected child. Subsequently, the caregiver's response to paediatric ART adherence and the psycho-social health of caregivers was discussed.

Chapter three, will continue with the critique of further studies, focusing mainly on relevant legislations and the theoretical framework of this study.

CHAPTER THREE

UNDERSTANDING THE CHALLENGES OF HIV IN CHILD CARE

3.1 INTRODUCTION

Chapter two provided a literature review on the research study which included a global and South African overview of HIV and AIDS. Chapter three will continue with a literature review of the study, firstly focusing on relevant legislations and policies guiding the health and welfare of the HIV infected child and their caregiver. Secondly, a deliberation of HIV from an ecosystems conceptual framework follows. Finally the chapter concludes with discussions on the socio-economic barriers to services, and the social workers' role in the care giving relationship.

3.2 RELEVANT LEGISLATION AND POLICIES

South Africa embraced the United Nations Convention's (hereafter referred to as the UN convention) principles on the rights of the child, when the Children's Act (Act 74 of 1983) was introduced in South Africa to formally regulate the care of all children (Proudlock and Jamieson 2007). The Children's Act (Act 74 of 1983) however needed to be reviewed following the issues of poverty and HIV, which were increasing the numbers of vulnerable children and families rapidly. The Children's Act (74 of 1983) served in protecting children after abuse and thus needed to consider "prevention and early intervention services" as well (Proudlock and Jamieson 2007, p. 35). Subsequently, the Children's Act (Act 38 of 2005) came into effect to ensure that children were dealt with more comprehensively, with the inclusion of prevention, protection and care interventions (Children's Act 38 of 2005). It is clear that the South African government is aware of the importance in updating policies and legislations regarding children in order to meet their often changing needs.

This follows that the Children's Amendment Act (41 of 2007) came into effect in 2010. This Act (chapter two, sections 6 to 13) concurs with The UN Convention's principles, by referring to the importance of providing shelter for all children, ensuring financial support of children and ensuring that the child's living circumstances are appropriate. In section 1 (i and ii) of the Children's Amendment Act (41 of 2007) protection of the child is defined as: protection from "physiological and psychological harm" such as abuse, mistreatment and discrimination (Children's Amendment Act 41 of 2007, p. 24). The act is specific in stating that all children should have access to health care and education (Children's Amendment Act 41 of 2007, section 13). Children that are chronically ill and have special needs should be given special attention to meet their health and social needs and to ensure that they have optimal care (Children's Act of 2005, chapter 2 section 11). Section 11(d) of the act further emphasizes the importance of providing support and care to caregivers and chronically ill children (Children's Act 38 of 2005).

Legislations and policies serve to guide social workers and health care providers to identify children at risk of abuse and neglect and render the necessary interventions, to protect them (Children's Amendment Act 2007, section 7). This follows that two of the most common types of neglect of children are physical neglect and inadequate supervision (Zastro and Kirst-Ashman 2010).

It is widely acknowledged that children who are subjected to living in unhygienic circumstances, who have no access to health care, who are deprived of education and who are subject to food insecurity, are perceived by health care professionals and social workers as being neglected by their caregivers (Zasrow and Kirst-Ashman 2010). It is thus assumed that child neglect is a caregiver's inability to provide adequate care for the child, by failing to provide for the physical and emotional wellbeing of the child and purposefully not accessing medical and other health services for the child (Children's Amendment Act 2007).

In contrast, some authors argue that child neglect can occur as a result of families experiencing poor economic circumstances that are sometimes beyond their control (Zastrow and Kirst-Ashman 2010). This follows the assumption that sometimes parents and caregivers that are not meeting the basic needs of

children, actually lack the resources to sustain themselves or their children, this is most especially if they are infected and or affected by HIV and AIDS (Demmer, 2011).

The Children's Act 38 of 2005 (section 35) concurs with the above assumption as mentioned in its risk assessment framework, that guides social workers in their assessments of children. This framework emphasizes the need to consider children within the entire contexts of their lives, as caregivers may not be neglecting the child on purpose but their behaviour may be influenced as a result of poverty and other extraneous circumstances. Social workers are thus advised to conduct detailed psycho-social assessments and investigations of the child's circumstances when providing interventions.

However, child neglect and abuse is a serious concern and more especially in the context of the HIV infected child who has medical needs that if left unattended could be life threatening. This follows that the UN Convention described children's rights as follows:

- Children have the right to be protected from abuse and neglect and to enjoy their childhood;
- Children should be entitled to education to develop their emotional and psychological wellbeing. Special attention should be given to children with disabilities, with the intention of providing specialised services to them, so that they are able to lead productive lives;
- Children should have access to food, shelter and health care;
- Children should be treated "fairly" and any legislations or practices that infringe on the fair treatment of children should be changed; and
- Children have the right to participate in decision making regarding issues that concern them.

This however is dependent on the age of the child (UNICEF 1990). As mentioned both the UN convention's document on the rights of children and the Children's Amendment Act of 2007 serve to remind caregivers and social workers of their responsibilities towards ensuring that children are protected and cared for.

This follows that children living within the HIV and AIDS contexts are generally exposed to poverty and sickness, their families and caregivers need encouragement to be versatile in their coping mechanisms, so as to ensure they create a livable environment for the child. Families and care givers are urged to reach out for support to other family members and the community (Mathambo and Gibbs 2009).

This study is unique as it explored caregiver's difficulties in providing for the care of the HIV infected child as well as their coping mechanisms. Much too often the researcher in the role of a hospital social worker, encountered similar situations where caregivers were unable to provide for the needs of the HIV infected children. This was often as a result of them not being knowledgeable about the necessary resources. This follows in Cluver and Gardner (2007) where it was found that often children are susceptible to abuse and neglect in families and communities where there is a high incidence of HIV and AIDS.

The Children's Amendment Act of 2007, stated in its preamble of the act, that by ensuring the rights of children are upheld, this inadvertently results positively on the lives of family members and other individuals in the community. It is considered impossible to protect children without the involvement of their families and communities. This follows the assumption that the preservation of children's rights, as legislated in the UN convention on the rights of children and the Children's Act of 2005, has favorable health and welfare implications for the caregiver and the child. Furthermore it should not be considered without the involvement of the family and the community (the mezzosystem), as there is a close relationship between the three sectors. The researcher used the ecosystems theory to understand how the various systems in the caregiver's life impacted on the caregiver's choices, in the care giving relationship with the HIV infected child. Issues of poverty and stigma were framed within the ecosystems framework to show how these impacted on the caregiver's decision making choices regarding the care of the child.

3.3 UNDERSTANDING THE ECOSYSTEMS THEORY IN RELATION TO THIS STUDY

The ecological perspective of the ecosystems theory focuses predominantly on “individuals and individual family systems”, whilst the systems perspective attempts “to describe the dynamics in a social service agency or the functioning of a human family”. Both perspectives provide a conceptual understanding of human behaviour and interaction in the social environment (Zastrow and Kirst-Ashman 2007, p. 18). Thus, the ecosystems theory was chosen in this study to facilitate a comprehensive understanding of the caregivers’ experiences.

This study therefore aims to explore the caregiver’s challenges within the entire contexts of their lives, by looking at the caregiver’s interactions with the health sector, the community, the child and other systems in their environment.

Guavain and Cole (1993) describe the ecosystem’s theory as consisting of five concepts that contribute to an individual’s development and growth, as the micro system, the mezzo system, the exosystem, the chronosystem and the macro system. It is suggested that these systems should be “visualised” as the smaller systems existing within the “progressively larger ones”. This illustrates a connectedness between the various systems. Thus social workers are advised to consider each of the systems as interrelated and influencing each other, when attempting to understand social issues (Berger et al. 1996, p. 42).

3.3.1 The Microsystem

Zastrow and Kirst-Ashman (2007, p. 19) describe a microsystem as being made up of an individual and their “biological, psychological and social” systems. For social workers to understand the individual in the microsystem, they need to examine the interactions between the biological aspects of the individual, their psychological functioning and their social experiences. Each of these aspects are inter related and impact on each other, resulting in the person’s life experiences. This study thus explores the physiological, psycho-social and economic

experiences of caregivers caring for the HIV infected child, in order to understand the overall life experiences of the caregiver. For the purposes of this study the micro system in this study will include the HIV infected child and their caregiver.

3.3.2 The Mezzosystem

According to Zastrow and Kirst-Ashman (2007), the mezzosystem consists of small groups that an individual might interact with. These groups could be family groups, friends, community groups or the work environment. This follows that community interaction (mezzosystem) with the caregivers of HIV infected children are described with the aim of identifying how they affect other aspects of the caregiver's life. This study thus also examined the issues of HIV stigma and the caregivers' experiences on a community level.

3.3.3 The Exosystem

The exosystem is "the linkages and processes taking place between two or more settings, at least one of which does not contain the developing person", but the nature of the interactions in that system indirectly impacts the microsystem of the individual (Guavain and Cole 1993, p. 40). For the purposes of this study the exosystem would be the health care facility which is the hospital and its antiretroviral clinic. This follows that the interactions between the caregiver on the child's behalf and the health care workers impact on the treatment and care received by the child. Subsequently, the nature of the treatment received and access to services at the public hospital was explored from the caregivers' perspectives.

3.3.4 The Macrosystem

Zastrow and Kirst-Ashman (2010), describe the macrosystem, as the system that is larger than the mezzosystem. The macro system can be made up of various

organisations and government departments. The macro system encompasses the micro, mezzo and exosystems (Guavain and Cole 1993). Swick and Williams (2006) contend that the macro system surrounding individuals in the environment actually influences how they interact in the various aspects of their lives.

This study thus focuses on policies and legislation governing the health and care of the HIV infected child and caregivers, as part of the macro system's influence on caregivers' experiences. It also highlighted what resources were available to the caregiver and the barriers and facilitators that they experienced when accessing these services.

3.3.5 The Chronosystem

Gauvain and Cole (1993) describe the chronosystem as the changes that the individual and their environment undergo over a period of time. Examples that were presented were of people that had experienced changes in their financial circumstances over time, their change of employment and possible changes in their family compliment. This may be the case in the sample for this study, as they experience the effects of HIV and the loss of loved ones as a result, which then impacts on the very structure of their families. For the purposes of this study, the researcher will refer to the microsystem, the mezzosystem, the exosystem and the macrosystem to facilitate an understanding of the impact of HIV on the lives of the caregivers of HIV infected children at a public hospital.

3.4 CRITIQUE OF THE ECOSYSTEMS THEORY

The ecosystems theory has been used by social workers for the purposes of understanding human behavior and guiding social work practice. It has proved to have many benefits in facilitating social work practice. The ecosystems theory, despite its many benefits, also has limitations. As social workers one needs to take cognizance of these limitations and adapt their interventions when providing social services.

Homeostasis is the ability of systems to reorganize its components to maintain equilibrium. This can be interpreted as systems of individuals or groups, resisting change for the benefit of ensuring the system's balance. "Structural functionalists suggest that systems maintain a natural harmony in their relationships". It is believed that this harmony in the relationships are "mutually agreed upon", for the purposes of maintaining the entire system (Berger et al. 1996, p. 47).

These "harmonious relationships" are however not "equal nor mutually agreed upon" at times. It is suggested that issues of power between and within systems, can result in inequality between systems as power is distributed in terms of "gender, ethnicity and socioeconomic status" (Berger et al. 1996, p. 48). This follows that systems may use this power to influence the behavior of other less powerful systems. This study takes the issues of power and control into consideration when discussing HIV in relation to poverty, unemployment and gender inequality later in the chapter.

Another limitation of the ecosystems theory is its attempts to suggest that behavior can be predicted according to "cause-and-effect relationships" (Berger et al. 1996, p. 49). It is argued that these relationships "cannot be predicted with certainty". The authors base their argument on the "chaos theory", where it is explained that "within ordered systems pockets of disorder exists and that within disordered systems, pockets of order exist" (Berger et al. 1996, p. 49) This suggests that in social science one cannot predict actual responses within and between systems, as chaos can determine and change how a system responds. It is therefore vital in social service interventions to take into account issues of power and chaos when using the ecosystems theory as a framework for practice.

3.5 HIV AND THE ECOSYSTEMS THEORY

The ecosystems theory is appropriate to understand how the perceptions of HIV and AIDS have evolved over the years. It has evolved from viewing the disease as an individual problem that needed to be addressed on a personal level (micro system), to now acknowledging its effect on the various other systems of an

individual's life, namely the community and the health sector. Common assumptions were that if society was educated about the disease, it would facilitate human behaviour change and this would impact on reducing incidents of HIV and AIDS. However, over time it was realized that individuals continued with risky behaviour despite knowing about the disease and this increased the prevalence of HIV (Ross and Deverell 2004).

Following the perception that the disease could be targeted on an individual level, it was soon realized that for optimum results, the disease needed to be dealt with on a community or cultural level (UNAIDS 2002). Ross and Deverell (2004) referred to the South African context to explain the issues of cultural influence on HIV infection. It was suggested that women in South Africa often did not have the power to insist on condom use with their partners, as they often were economically and socially disadvantaged and relied on their partners for their own and their children's survival. It was thus assumed that in order to reduce HIV infection rates, community leaders, religious leaders, political leaders and other role players needed to be actively involved in HIV programmes. It is suggested that the proactive involvement of these stakeholders would be beneficial when challenging attitudes on sexuality and gender inequality in communities (Ross and Deverell 2004).

A further paradigm shift was called for, this time the problems of HIV were seen to be perpetuated at a macro level. It was suggested that gender inequality, poverty, unemployment and race relations formed the basis of the HIV problem. This paradigm shift reasoned that "although scientifically HIV is undoubtedly the cause of AIDS, it is true that poverty and other forms of structural violence create an ideal environment for HIV to proliferate" (Ross and Deverell, 2004, p. 201). This paradigm shift was not received favorably by many, as they perceived the meaning of this macro shift in dealing with the virus, to imply that the problem could not be solved. Their reasoning was that gender oppression and poverty are ongoing challenges globally, and to assume that in order to attack HIV, society needed to first tackle those challenges, was irrational (Ross and Deverell 2004).

Finally in 2002, at the International AIDS conference in Barcelona, it was resolved to implement the following strategy to effectively deal with the HIV and AIDS pandemic globally (UNAIDS 2002):

It was suggested that mass preventative measures needed to be focused on the youth of the human population, as it was found that preventative measures were most successful with this particular group.

Secondly, community mobilization was emphasized as crucial, with the improvement of economic, social and cultural circumstances of individuals and communities that are susceptible to HIV infection.

Finally, it was reiterated that access to adequate care and treatment should not be seen as a luxury reserved for the privileged. But rather, it should become a basic necessity that should be afforded to all sectors of the population irrespective of their socio-economic background.

This strategy took cognizance of the importance of addressing HIV on the micro level with the youth, and to make changes in their interactions. In order to target the youth, it is necessary to mobilize communities first, as youth generally interact with the community. The assumption was that by making changes to the community (mezzosystem) in the form of better access to services, would impact favorably on the youth (micro system). Further assumptions were that government (macro system) needed to make economic changes for the benefit of HIV infected and affected communities (mezzosystem), the results of which would influence all the systems. This follows that by improving the health and living conditions of HIV infected individuals (micro system), facilitating their access to care (exosystem), community support and education, thus creates a positive impact on their psychological wellbeing which then impacts their behavior.

Social workers however have to bear in mind that there are inequalities in terms of the power that each system has over the other. This means that despite the need to have a balance within and amongst the various systems, there are issues of power imbalances that need to be considered when rendering services (Berger et al. 1996). This follows that the current study included issues of a socio-economic

nature that influenced the caregiver's (microsystem) behavior when caring for the HIV infected child.

Figure 1 illustrates an ecosystems perspective to understanding the HIV infected child and their caregivers (Adapted from Urie Bronfenbrenner's (1979) Ecosystems theory cited in Global Health– An environmental and Cultural Perspective, 2012).

Figure 1 - Understanding the Ecosystems Paradigm within the Context of HIV and AIDS

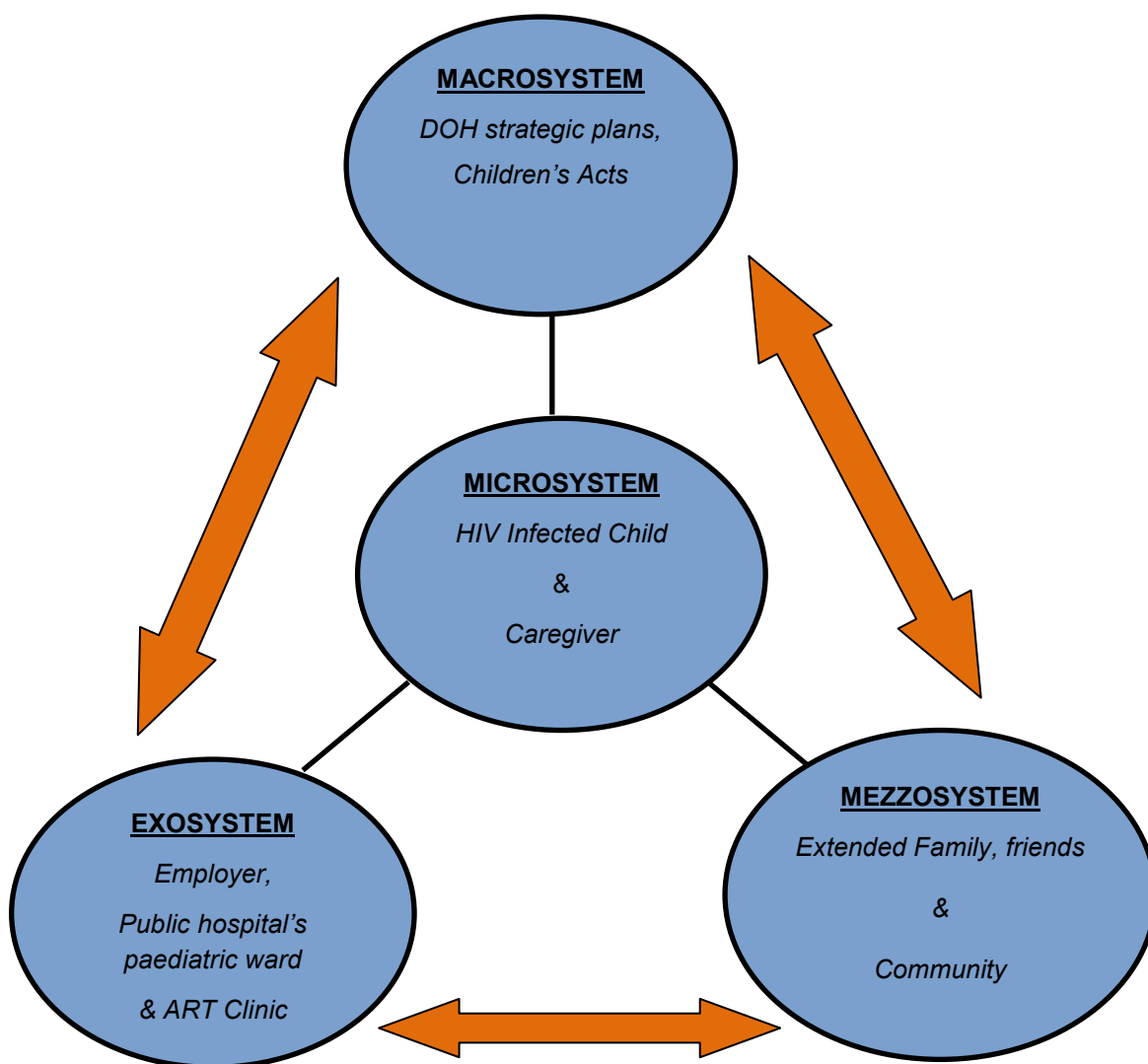


Figure one reflects how HIV and AIDS has permeated all the systems of the caregiver and the HIV infected child, on the micro level (child and caregiver), the mezzo level (the extended family and community), the exo level (the hospital and

clinic) and the macro level (government and legislation). The figure illustrates the interactions between the systems and that each system is influenced by the other.

It is imperative for social workers to bear in mind that there are inequalities in terms of the power that each system has over the other. This means that despite the need to have a balance within and amongst the various systems, there are issues of power imbalances that need to be considered when rendering services (Berger et al. 1996).

In order to facilitate the HIV infected child's right to health and welfare, Social workers have to also ensure that government and legislation (macrosystem) are adequately addressing the issues of these children and their caregivers. Thus social workers may have to advocate on behalf of the HIV infected child and their caregivers, for policy changes that would benefit them. This is often a challenge for social workers as they have to deal with complex and challenging social issues that at times can only be resolved through macro system changes (Zastrow and Kirst-Ashman 2007). This follows that the current study included issues of a socio-economic nature (macrosystem) that influenced the caregiver's (microsystem) behavior when caring for the HIV infected child.

3.6. SOCIO-ECONOMIC BARRIERS TO SERVICES

Fredlund and Nash (2007) conducted a study on ART access in a rural community in KwaZulu-Natal. Their study site was a public health facility that provided ART to the community. It was found that 40 % to 60 % of children that needed ART, could not access it as they were required to have birth certificates. Through the collaborative efforts of politicians within the community and local government departments, birth registrations of HIV infected children and identification documents for HIV infected adults were completed, so that HIV infected children and adults could access ART. The study concluded that despite the improvement of the ART programme at health care facilities and the facilitation of community networks, there were still many HIV infected people that had difficulty accessing services. This is due to the structural barriers in the health care system and or the

social barriers (fear of stigma) of the HIV infected individuals to utilize the services (Fredlund and Nash 2007).

3.6.1 HIV and AIDS Stigma: The Caregiver's Challenge

Stigma is defined as a “deeply discrediting” attribute possessed by a person with an “undesired difference”. Stigma is a powerful means of social control applied by marginalizing, excluding and exercising power over individuals who display certain traits. “It is a common response to perceived threat when escape from, or the destruction of, this threat is impossible” (Goffman 1963 cited in UNAIDS 2000, p. 11).

HIV and AIDS globally, perpetuate stigma and discrimination of infected individuals, and their families. Stigma is still considered one of the major challenges for HIV infected individuals, the community, service organizations and on a larger scale the world.

The Children's Amendment Act (Act 41 of 2007) in South Africa takes cognizance of HIV and AIDS stigma by stating that the HIV statuses of infected children should only be disclosed under certain circumstances. These circumstances are; if the child who is of sufficient maturity and understands the implications of disclosure then provides consent for the disclosure, or if it is a statutory or legal requirement for the placement of the child in care, and or if the parent or guardian of the child consents to disclosure for health or welfare reasons. In the absence of a caregiver, and if the child is under the age of 12 and not sufficiently mature, the superintendent of a hospital may consent to the disclosure of the child's status, for the purposes of planning for the child's care (Children's Amendment Act of 2007-section 133(1)). These provisions in the act protect the HIV infected child from being subjected to potential discrimination and abuse because of their HIV status.

The disclosure of HIV infection in children has implications for the child and their caregivers. This follows Bonuck's (1993) argument as cited in Ross and Deverell (2004, p. 206), that “the psychosocial impact of HIV and AIDS on families usually

begins with the disclosure of HIV infection”. The author contends that families of HIV infected people experience “social stigma and isolation”, they may sometimes fear contracting the virus themselves which results in them withdrawing from intimacy. Families may also experience guilt for not supporting the HIV infected person. Alternatively they may be overwhelmed by having to take care of the HIV infected individual, resulting in “psychological and physical fatigue”.

From this it can be surmised, that families of HIV infected individuals also experience their own burden of suffering from the disease. This is evident when their relationship with the HIV infected person is marred by their personal fears of disease contagion and their own psycho-social challenges (Powell-Cope and Brown 1992). The dynamics of the initial relationship between the HIV infected individual and the family member then transforms into a more complex relationship, resulting in new challenges for the family as a whole.

HIV and AIDS stigma is a more serious matter for HIV infected children as they rely on their caregivers for treatment and support. Caregivers perceptions of HIV stigma, therefore becomes more of a concern, as it influences their actions in accessing treatment and support for the HIV infected child.

According to Powell-Cope and Brown (1992) in their qualitative study with family caregivers of people living with AIDS, it was found that the caregivers experienced stigmatization and discrimination because of their association with the person who had AIDS. They experienced community rejection, harassment and loss of friends as a result of their care giving roles. Despite these challenges caregivers engaged in community awareness programmes and AIDS awareness campaigns, to educate communities about the HIV and AIDS pandemic. The authors in this study therefore recommended that the “social manifestations of AIDs” needed to be considered when planning health care programmes for the future (Powell-Cope and Brown 1992, p. 571).

Demmer, 2011 and Vreeman et al. 2010 contend that the nature of the caregiver’s experiences, of HIV and AIDS stigmatization in South Africa thus influences their decisions to disclose the HIV infected child’s status. Caregivers anticipated that

disclosure of the HIV infected child's status to family would result in a negative response from loved ones. Female caregivers feared the issue of blame and eventually being isolated by loved ones, this resulted in HIV infected children being diagnosed and treated much too late. These studies further indicated that caregivers feared taking the HIV infected child to the local clinic for treatment, as they feared discrimination (Demmer 2011 and Vreeman et al. 2010).

Further empirical evidence illustrates how HIV and AIDS stigma, impacts the various systems of the HIV infected person's life. Not only is it an individual and a family crisis, but it influences the HIV infected person's ability or lack thereof, to access resources. It was more clearly discussed in UNAIDS (2000) when it was stated that "HIV infected individuals are victimized and blamed". This then perpetuates marginalization of the HIV infected groups or an individual, as society continues to misunderstand the "nature of the epidemic and its causes" (UNAIDS, 2000, p. 13). This finding is conceptualized in the eco-systems theory by indicating how the HIV status of individuals (the micro system) impact on the community or society (mezzosystem). This is caused by community's stigmatization of the HIV infected individual which then results in them not accessing much needed resources (exosystem), for fear of encountering the stigmatization from society. This then has implications for the macro system where the HIV infected individual's behaviour then perpetuates the pandemic by them not accessing services and succumbing to the disease, which eventually negatively impacts the economy of the country.

Another perspective on stigma and disclosure was a study by Kimani-Murage et al. (2010) which was conducted in rural South Africa. This study focused on the impact of disclosure of the HIV infected child's status to their caregivers. This study indicated that most of the caregivers responded well to the disclosure and perceived the knowledge of the child's status as an advantage in the care giving process. It was found that counseling interventions by health care workers and the caregivers own spirituality facilitated the process of their acceptance of the HIV infected child's diagnosis and their ability to manage their new circumstances (Kimani-Murage et al. 2010).

In contrast the study by Vreeman et al. in 2010 found that caregivers were often concerned about the HIV infected child disclosing their status to others, and this contributed to the reason for them not disclosing to the child. There was immense fear and trepidation that should people find out about the child's HIV status they will be discriminated against by other family members and the community alike. The author suggested that caregivers were concerned that the child's self-disclosure to others would also inadvertently highlight the mother's HIV status and this would create discord in familial relationships. The caregiver's concern was that the child, the caregiver and the family would be ostracized and stigmatized by the community.

3.6.2 Poverty, Unemployment and Gender Inequality

A qualitative study by Raniga and Simpson in 2010, with elderly caregivers of HIV infected individuals, residing in KwaZulu-Natal, indicated that the caregivers experienced difficulty in accessing the old age pension, despite Government's commitment to provide social security for the elderly in South Africa. The lack of financial support for these caregivers and their added responsibility of providing for HIV infected dependents were found to be the major social problems in the community. Raniga and Simpson suggested increased involvement of social workers in the public and private sectors, with these elderly caregivers. Some of the social services that were recommended were assistance in accessing state grants, social work intervention in the provision of individual and familial social services, and assistance with facilitating the access to health care (Raniga and Simpson 2010).

The researcher in this study recommended further research to be conducted on the psycho-social experiences of elderly caregivers. The current study has included elderly caregivers in the sample, with the aim of contributing to the knowledge in social science research, within the context of HIV and AIDS.

According to Sherr (1996) and Doyal (1995) cited in Ross and Deverell (2004, p. 201), gender inequality is closely linked to the HIV pandemic. The authors perceive awareness campaigns that focus on "condoms and partner reduction" as

being too limited by not considering the actual socioeconomic “realities” that women in South Africa experience. It is stated that in most heterogeneous relationships, males dominate and the female is often disempowered to negotiate condom use.

The suppression of women’s rights in gender equality often puts women at risk of ensuring their own health and safety and that of their children. Gender inequality in South Africa is precipitated by poor economic factors, where women are financially dependent on men. Doyal (1995) cited in Ross and Deverell (2004), further states that certain societal beliefs imply that women have a duty to engage in sex with their husbands because he supports her financially. This further disempowers women and puts them at greater risk of HIV infection.

This correlates with findings in Raniga and Mathe’s (2011) qualitative study with HIV positive adolescent mothers, where it was found that these adolescents were often subjected to high risk sexual behaviour that made them vulnerable to HIV infection. They concluded that adolescent girls from poor communities were forced to engage in transactional sexual relations with older men in the community because of their experiences of extreme poverty.

Interestingly, it was found that the material gains of the transactional sexual relationships, was considered as an advantage despite the potential high HIV infection risk (Raniga and Mathe 2011). This follows that the adolescent girls in this study were HIV positive, experiencing dire poverty, caring for AIDS infected family members and also caring for their own children. The authors thus suggested that the economic needs of these HIV infected adolescent mothers who were also caregivers, needed to be addressed in order to alleviate their suffering, by helping them to provide for their basic needs. It was further suggested that the social security system needed to be re-visited, so that adolescent mothers were more economically empowered and were no longer reliant on the child support grants (Raniga and Mathe 2011).

A further perspective on gender inequality would be the qualitative study by Newman et al. (2011) with HIV positive men and women, community members

and health care workers in Lesotho. This study suggested that gender inequalities are most prevalent within the context of HIV and AIDS. Women and girls are predominantly the informal caregivers of HIV infected individuals in the home. It was further added that gender inequality in terms of care giving results in the overburdening of female caregivers and results in them being economically and psycho-socially disadvantaged.

According to Newman et al. (2011) the impact of HIV and AIDS on care giving is further exacerbated by the ideology that this type of care giving is considered unfavorable and mundane, involving activities that are considered women's work. The authors also found that men faced a dilemma where they were ridiculed in the community if they were to undertake HIV and AIDS care giving tasks. These challenges of care giving within the context of HIV and AIDS, thus negatively impacts females in their roles as caregivers, as they are forced to bear the burden alone.

The author's therefore suggested that policy makers and activists redress the disadvantages experienced by female caregivers by addressing issues of gender inequality within the context of care giving and HIV and AIDS (Newman et al. 2011). It is acknowledged that changing gender stereotypical behaviour in communities is complex but can be accomplished through comprehensive and sustainable health programmes and policies that focus on encouraging more male involvement in the care giving of HIV infected people (Newman et al. 2011).

This follows that the report on the global strategic plan on HIV and AIDS for 2011 to 2015 dictates that in order to achieve success in dealing with the HIV pandemic, world organisations need to prioritize HIV prevention and care of women and children. This can be done by ensuring that strong community and health systems are formed with the removal of structural barriers to the access of services. This is especially applicable to pregnant women living with HIV Infection, on a PMTCT programme. These women are often not followed up in the health care system and as a result their babies are not diagnosed at an early stage and provided with the required therapy (WHO 2011, pp. 8-22). It has thus become a priority in South Africa to ensure access to ART for all pregnant HIV infected women, so as to

eliminate the number of babies that are born with HIV in the years to come (DOH 2010).

In addition to the DOH's (2010) focus on improving the access to health services for HIV infected children, the Children's Act states that outreach services, should focus specifically on meeting the needs of "vulnerable children and their families", whilst developing the existing community services (Children's Act 2005, p. 128). Government has acknowledged the importance of not only providing medical and health services, but also that communities need to be encouraged and assisted to utilize these services, as structural and social barriers do impact on people's access to them.

Furthermore, organisations should also facilitate people's access to documents, social services and social security, thus ensuring people's access to welfare services. The Children's Act (38 of 2005) states that children and their caregivers should be able to receive services whilst at home, at school and in the community.

Outreach services should be based on a "multi-disciplinary and inter-sectoral approach" supportive services to HIV infected and HIV affected individuals, is also emphasized in the Children's Act, with special emphasis on HIV infected children (Children's Act 2005, p. 129). Community education and empowerment is also suggested as an important objective that should be included for outreach services. This follows that social workers have an important role to play in ensuring individual and community empowerment is achieved. The following section discusses the role of social workers in the care giving relationship in more detail.

3.7 THE SOCIAL WORKER'S ROLE IN THE CARE GIVING RELATIONSHIP

Social work practice is guided by the ecological theory where, it is considered that individuals need to be understood within the contexts of their backgrounds, their society and their cultural beliefs (Turner 1996). This theory thus guides social workers in their identification of social problems and their subsequent interventions with people who are experiencing challenging life events.

This follows that the role of the social worker within the context of the HIV infected child and their caregiver is multifaceted and crucial towards ensuring their psycho-social wellbeing. Social workers play a major role in the area of support of the HIV infected child and their caregiver. This is especially important in the early stages of the child being diagnosed with HIV infection.

Turner (1996, p. 1) suggests that social workers need to work within the ecological principle of “person-environment fit”. This would require social workers to intervene on a macro systems level regarding issues of social oppression. Further, social workers are advised to interact on community (mezzosystem) and organizational (exosystem) levels for the benefit of the individuals they seek to help. They should be engaging with the different sectors, with regard to legislature and policy changes (macrosystem), for the benefit of the individuals (microsystem) they are providing a service to. A further role for social workers, according to Turner (1996) would be that they need to take cognizance of the individual’s needs and to intervene at whatever level the problem arises from and to follow it through the process of resolution, if possible. The author reminds social workers to be attentive to people’s individual circumstances and to be wary of casting blame on individuals for their own problems, as they may already be experiencing oppression in other areas

Zastrow and Kirst-Ashman (2010) contend that the social worker’s role includes that of providing interventions that focus on improving people’s physiological and psychological wellbeing. Additionally, social workers should facilitate the empowerment of individuals for the purposes of encouraging an improvement of their life circumstances.

The social worker’s role within the hospital or medical setting, involves all of the above, as it often requires intervening with HIV infected individuals, children and caregivers on a daily basis, with regard to numerous social problems. The social worker often advocates on behalf of HIV infected children with various government departments. It involves obtaining documentation for the child, or for the formalizing of placement for the child, in the event of abandonment and neglect. The hospital social worker also provides psycho-social and therapeutic services to

the caregivers of HIV infected children, before, during and after the child commences treatment on ART. Social workers in the health setting are responsible for formulating a discharge plan for the HIV infected child together with the involvement of the caregiver and the hospital's multidisciplinary team (doctors, nurses, physiotherapists, occupational therapists, social workers and dieticians).

HIV and AIDS results in caregivers and children experiencing feelings of fear, distress and being overwhelmed at times (Van Dyk 2008). The social worker's role is crucial in providing social intervention by supporting caregivers of the HIV infected child to take control over the situation and to plan for the future.

It is further suggested that social workers (exosystem) can contribute valuably to the reduction of risky behaviour in high risk groups (mezzosystem) by conducting educational workshops on the implications of risky behaviour in the context of HIV, within the community. This in turn would impact on the individual's behaviour (microsystem) in the community (Zastrow and Kirst-Ashman 2010).

According to Turner (1996) the overall goal of social workers, should be to "improve the person-environment fit" by helping people on a micro and macro level to reduce stress on the individual and the community systems. In addition, social work intervention on a community level can include educating and mobilizing communities within the context of HIV and AIDS.

The diverse and multitude of roles that the social worker plays is vitally important for the assurance of psycho-social and economic wellbeing, of the caregivers of HIV infected children and the children themselves.

3.8 CONCLUSION

Chapter two and chapter three provided the background to the study. Chapter Three discussed the theoretical framework used in the study and then examined the caregivers' perceptions of HIV disclosure and discrimination, socio-economic

implications of HIV and AIDS and the social worker's role in the care giving relationship.

Chapter Four will discuss the research methodology used in this study. It includes a description of the research site, the research design, the study sample, the sampling method, the data collection method, instruments used, the data analysis method and the ethical considerations that were acknowledged. The chapter concludes with a discussion on the limitations of the study.

CHAPTER FOUR

RESEARCH METHODOLOGY

4.1 INTRODUCTION

The methodology section of a research report, serves to enlighten the reader on the data collection process, whilst also reiterating the purpose of the study (DeVos et al. 2005).

This chapter discusses the research methodology utilized, by describing the research site, the research design, the study sample, the sampling method, the data collection method, the instruments used, the data analysis method and the ethical considerations that were acknowledged. The chapter concludes with a discussion on the limitations of the study.

4.2 THE QUALITATIVE RESEARCH DESIGN

A combination of the exploratory and the descriptive designs were chosen, in order to more effectively examine, understand and describe the experiences of caregivers in this study (Babbie and Mouton 2001). The qualitative research method was appropriate for this study, as it allowed the researcher to explore in-depth, the caregivers experiences and provided a basis to understanding what the challenges were and the implications for care of the HIV infected child (Babbie and Mouton 2001).

Qualitative research adds value to studies by ensuring that data collection, results in comprehensive detailed information being brought to the fore (Royse 2004). The researcher was able to clearly describe the experiences of caregivers, the nature of the challenges faced and their responses in dealing with challenges using the descriptive research design.

4.3 RESEARCH RESPONDENTS AND THE SAMPLING METHOD

For the purposes of this study non probability, criterion sampling was used to select 30 caregivers of HIV infected children between the ages of birth to 14 years. There was a shift in the scope of the study to include children over the age of five, as it was difficult to get a sufficient number of caregivers of the under five year old HIV infected child. All the respondents in the study accessed services from a specific public hospital in Durban. The criteria for selection of respondents was that they all needed to be the primary caregiver of the HIV infected child, who was admitted to hospital or was accessing services from the ARV clinic at the hospital. The caregiver had to be living in the same home as the HIV infected child and be primarily responsible for the child's overall care and administering of ART. The caregivers were selected on the basis of their willingness to participate in the study, as well as their ability to understand and converse in English.

Researchers choose purposive sampling in order to access individuals who are not easily accessible due to them being part of a specific group (Neumen 1997). In this case it was most practical to identify individuals for the sample, from the hospital wards and the ARV clinic, as this is where caregivers of HIV infected children were more likely to access services.

In order to access the respondents and obtain the necessary ethical clearances and permissions from gate keepers, the researcher implemented the following process:

- A letter requesting permission to conduct the study at the public hospital was sent to the Hospital's CEO, the Medical Manager and the Hospital's Social Work Supervisor. The study was received favorably by all concerned and written permission was granted.
- The researcher consulted with and explained the purpose of the study to the hospital's multidisciplinary team, which comprised of doctors, nurses, physiotherapists, speech therapists, occupational therapists, social workers and dieticians. The purpose of consulting with the multidisciplinary team was to encourage team members to refer suitable respondents to the researcher.

- The researcher submitted a research proposal to the Humanities and Social Sciences Research Ethics Committee of the University of KwaZulu-Natal (UKZN), for the purposes of acquiring consent and ethical clearance for the study. This was followed by a presentation of the research proposal to the Higher Degrees Committee. Thereafter, full approval was granted by the Humanities and Social Sciences Research Ethics Committee of UKZN (see appendix C).
- The researcher sought and received Ethical clearance and permission from the Health Research and Knowledge Management Sub-Component of the Provincial Department of Health, KwaZulu-Natal (see appendix D).

Once all permissions and clearances were authorised, the researcher selected the respondents for the study. The samples of caregivers were at times the parents, the grandmothers, the siblings or aunts of the HIV infected child, depending on the individual child's circumstances. Respondents originated from various communities and were not all South African. Of the 30 respondents, two were Nigerian natives residing in South Africa. The sample also included male and female caregivers of different ages, educational and socio-economic backgrounds.

Once the respondents agreed to be interviewed, the researcher conducted the interview on site, so as to prevent any inconvenience to the respondent.

Chapter Five provides a demographic, showing the male and female profiles of the respondents of the study.

4.4 DATA COLLECTION

The use of semi-structured interviews allowed the researcher and the caregivers, the flexibility to explore certain aspects of the phenomenon under study, in more detail (De Vos et al. 2005 and Royse 2004). This follows that in semi-structured interviewing the researcher uses "pre-determined" questions, in the form of an interview schedule. The interview schedule's purpose is to guide the interview process and therefore should not necessarily be followed in a rigid manner (De

Vos et al. 2005, p. 296). The interview schedule in this study used mainly open ended questions that were aligned to the core objectives of the study.

Some of the key areas included in the interview schedule were:

- The physiological, psycho-social and economic experiences of caregivers.
- The caregivers understanding of HIV, ART and child care.
- The caregiver's support systems and coping mechanisms;
- The caregiver's access to health and social services.
- The caregiver's suggestions for the improvement of services.

The flexibility of the semi-structured interview schedule allowed the researcher to probe areas for more in depth discussion with the caregivers in order to gain clarity on some aspects of their experiences. It also allowed discussions around deep issues pertaining to caregiver's emotional challenges in the care giving process. This sharing of intimate information added richness to the study's data and allowed the researcher to view the world, from the eyes of the respondent.

Smith et al. (1995) cited in DeVos et.al. (2005, p. 296) asserts that the respondent in the interview process should be considered as the "expert" on the research subject, and be encouraged to express themselves as fully as possible. The researcher guided respondents through the interview process, by first providing them with information on the nature and the purpose of the study. It was then specifically highlighted that their participation would result as a valuable contribution to the health care of all HIV infected children and their caregivers.

Informed consent (see appendix A) was then sought from the respondents for the interview to be audio recorded so that the researcher could concentrate fully on the interview process. This is consistent with Rubin and Babbie (2011) where it was suggested that recording of interviews, afforded the researcher the opportunity to focus their attention entirely on the respondent, whilst still capturing all the information communicated verbatim. In addition, De Vos et al. (2005) contend that recording of the interviews also positively contributed to the trustworthiness of the data collected, as it allows the researcher to go back and clarify details of the interviews conducted.

A contentious issue, however, is raised by De Vos et al. (2005) where it is argued that sometimes the recording of interviews can create discomfort to the respondents and could cause them to withdraw from the interview process.

The researcher took cognizance of the above by encouraging the respondents to talk freely and emphasized the issue of confidentiality and voluntary participation. This resulted in their willingness to participate in the study and at times their relaxed attitude towards the interview process (refer to Appendix B for the interview schedule).

4.5 DATA ANALYSIS

The data analysis and interpretation plan should be related to the objectives of the study. Data analysis involves the organizing and interpreting of raw data in research, with the purpose of creating understanding and “drawing conclusions that reflect on the interests, ideas and theories that initiated the inquiry”(De Vos et al. 2005 and Babbie & Mouton 2001, p. 101).

This study used Creswell’s (1998) and Marshall and Rossman’s (1999) guidelines for data analysis, as cited in De Vos et al. (2005). The author’s stress that these guidelines or steps for data analysis, should not be followed in a “linear” or straight forward fashion but rather in a flexible manner, where the researcher uses the guidelines as they see fit. This could entail some steps preceding others, and some steps overlapping (De Vos et al. 2005).

The researcher collected data for the study by means of audio recording interviews with the caregivers of HIV infected children. The audio recordings were labelled and numbered for the purpose of tracking the interview. The audio recordings were then transcribed verbatim, and one interview was translated from IsiZulu into English. The transcripts were also numbered for the purpose of creating order in the analysis process. The transcripts were then read by the researcher and checked for any gaps, the researcher ensured that all questions

were answered in the transcripts. The researcher proceeded to ensure that all audio recordings and transcriptions were electronically backed up and saved, as per Patton's (2002) suggestion, (cited in De Vos et al. 2005), that data needs to be stored in a safe manner.

The researcher read the transcripts several times, in order to get a comprehensive sense of the interview sessions, as per the advice of Marshall and Rossman (1999) cited in De Vos, et al. (2005). After reading the transcripts, thematic analysis was used to identify, sort, categorize and report patterns. Notations were made in the margins of the transcripts in the form of codes and words. The data was then categorized and common patterns and themes were identified. Finally the coded data was defined and allocated themes and sub themes which then culminated in the analysis report. Chapter five and chapter six presents the results and provides insight into the major themes that emerged from the analysis.

4.6 RELIABILITY AND VALIDITY

Reliability and validity are considered to be important concepts in research. However, it is argued that total reliability and validity are not always possible, but rather are goals to be strived towards. Researchers always aim to attain some measure of reliability and validity in their studies (DeVos et al. 2005).

“Reliability deals with an indicator’s dependability” this means that if the researcher uses the same indicator (e.g. a questionnaire) in another study of the same subject, it should yield similar or the same result (De Vos et al. 2005). This study used a predetermined semi-structured interview guide that was formulated based specifically on the objectives of the study. This contributes to the reliability of the study.

The following suggestions to ensure trustworthiness, reliability and validity of the data collected were presented by Belcher (1994) as cited in Royse (2004) as:

- “Prolonged engagement” refers to the researcher having spent “sufficient time” with the research subject, resulting in a sound knowledge of the subject and the

ability to assimilate that knowledge into clear understanding. The researcher in this study engaged with the respondent over a reasonable period of time in the interview session. The interview sessions lasted from forty-five minutes and up to one and a half hours, at times. The researcher also provided social work services to some caregivers and children in the paediatric ward.

- “Persistent observation” – requires that the researcher monitors the subject regularly and document the observations in detail. The researcher observed the respondents verbal and non-verbal reactions to the interview questions, and documented responses in the interview transcripts. This process also impacted favorably on the reliability and validity of the study.

The researcher further improved the validity of the study by conducting the interviews personally (Royce 2004). This facilitated the researcher’s position in order to obtain detailed yet relevant data for the study.

4.7 ETHICAL CONSIDERATIONS

In order to conduct the study the researcher’s first ethical consideration required obtaining approval from various ethical committees. This is in keeping with the description of the role of ethical committees or boards by De Vos et al. (2011) in ensuring that respondents in research are not subjected to harm and that any possible risk is minimized. Once ethical approval for the study was received, the researcher commenced with data collection (see appendices A and C).

De Vos et al. (2005) state that areas of concern in research are the selection of a research site, gaining entry to the site, entering the site and developing a relationship with the respondents. Social work research requires that respondents often have to share personal information with the researcher, who in most cases is a stranger (Rubin and Babbie, 2011). The researcher established a rapport with the respondents before engaging in the data collection process. Respondents were informed about the nature of the study and what it would entail before they

completed informed consent forms which allowed the researcher to record the interviews.

According to De Vos et al. (2011, p. 119) “every individual has the right to privacy and it is his or her right to decide when, where, to whom and to what extent his or her attitudes, beliefs and behavior will be revealed”. The researcher had to be mindful of confidentiality and the respondents’ right to anonymity in the study and did not in any way detract from her responsibility to protect the respondents concerned. The researcher ensured the anonymity of the children and the caregivers by not directly identifying them at anytime during the research process. Codes and pseudonyms were used instead. The researcher assured the respondents of their confidentiality throughout the research process.

In keeping with Rubin and Babbie (2011), that respondents in research should be protected from harm at all times, the interviews were conducted in a sensitive manner and every endeavor was made to keep the respondents at ease. The researcher made every attempt to ensure that no respondent was exposed to any physical or mental harm during the course of the research process.

The researcher, who is also a social worker, was constantly mindful of the social work code of ethics and was guided by these ethics throughout the study. The researcher was also aware of the sensitive nature of the phenomenon studied and when there were instances where some respondents presented with emotional outbursts the interview session was paused. In these instances, the researcher provided the necessary intervention to help the respondent alleviate the discomfort or distress. Respondents were then given the option of ending the interview session or continuing. In all instances the respondents wanted to finish the session. Respondents were further offered social work and other services at the end of the interview if the need arose, in order to bring closure to and address sensitive issues pertaining to their experiences. This follows that De Vos et al. (2011, p. 124) emphasizes the importance of the researcher being competent and well equipped to “evaluate all possible risks” and undertaking the study in an ethical manner.

Finally De Vos et al. (2011) recommend that studies be presented to society in the form of written works, so as to enhance its value and thus be considered a research study. The researcher in this study therefore is committed to publishing the findings of this study and ensuring that the information is shared amongst health and welfare service providers.

4.8 LIMITATIONS OF THE STUDY

The interviews were conducted at three sites within the public hospital, namely: the researcher's office, a room in the ARV clinic, and an office in the paediatric ward in the hospital. The researcher had to use different venues in order to meet the needs of the respondents. The researcher perceived a better response for involvement of the study from respondents, if the researcher went to them. The other reason for going to the respondents was that caregivers that were attending the ARV clinics with the children were often following queues and had time constraints. Some were waiting at the clinic for long periods of time and often from very early in the morning. The researcher thus decided to interview them at the clinic, to save them time and to ensure that they were not at a disadvantage, by having to miss their places in the queue. However, this proved challenging at times for the researcher as time was wasted in travelling to different venues to interview respondents.

It is possible that the respondents responded to the researcher, by stating only what was favorable and did not disclose their true feelings about the services received at the hospital as they may have perceived her as being part of the hospital staff, and not only as the researcher.

Noise at the venues: This presented a challenge to the researcher, as the external environment of the clinic, where noise and the sound of people moving around outside, interfered with the clarity of the audio recordings. A limitation here could be that some information may have been lost in the process of transcribing the audio recordings of the interviews.

Language: The interviews were conducted in English however; some respondents who were first language IsiZulu speakers often lapsed into their mother tongue during the interview process. Even though a translator assisted with the translation of the IsiZulu recordings, it is important to acknowledge that some information and meaning could have been lost during this process. The researcher did however make efforts to seek clarity from respondents at a later stage with respect to those audio recordings that appeared incongruent.

4.9 THE RESEARCH CONTEXT

The study was conducted at a public hospital in Durban, KwaZulu-Natal. The public hospital is predominantly responsible for the palliative care and rehabilitation of people originating from in and around the Durban area. The hospital functions on a referral basis and only accepts individuals for in-hospital treatment from other public hospitals in Durban. The hospital was chosen as a research site as it provides ART to HIV infected individuals on an in-patient and an out-patient basis.

4.10 SUMMARY

Chapter four explained the methodology used in this study. The qualitative nature of the research, together with the chosen exploratory and descriptive designs was discussed. The researcher described the study sample, the sampling method and the process of analysis of data. Processes involving the obtaining of ethical clearance and consent were described. The chapter concluded with a discussion on the limitations of the study.

Chapter five and chapter six discuss the analysis and findings of the study.

CHAPTER FIVE

ANALYSIS AND DISCUSSION: FACTORS INFLUENCING THE CARE GIVING RELATIONSHIP

5.1 INTRODUCTION

It is historically taken for granted that family and non-kin care provide a crucial care giving role in the form of emotional and psycho-social support to HIV infected children (Mathambo and Gibbs 2009). The World Health Organisation (2005) suggests that the provision of such support by caregivers helps to reduce stress for the HIV infected child and promotes the adherence to ART and subsequently improves the child's overall quality of life.

Social workers and other health care providers are frequently faced with various challenges in providing services to HIV infected children and their caregivers. One of the major challenges faced is that of HIV infected children who default their ART or fail to access ART and social services. In order to adequately understand social problems faced by HIV infected children and their caregivers, social workers need to consider them within the entire context of their environment.

Chapter five illustrates the analysis of data that distilled from 30 in-depth semi-structured interviews with caregivers caring for HIV infected children at a public hospital in Durban. There were four major themes and sub-themes that culminated from the analysis of the data in the study, which corresponded with the objectives of the study. Even though the themes are presented as exclusive from each other, the ecosystems theory forces one to acknowledge that they are closely interconnected.

Data pertaining to the following themes are presented in two main sections in Chapters five and six. Two key themes are discussed in this chapter namely: the intrapersonal experiences of caregivers within the context of HIV and AIDS and the role of ART in relation to the fight against HIV and AIDS. This Chapter highlights the connectedness between the physiological and psycho-social

experiences of the caregiver and the influence of these experiences on the care giving relationship.

Chapter six discusses the third theme on access to health and social services and the sub themes of poverty and its implications for care and structural and social barriers to services. Chapter six also discusses the final theme of the caregivers' coping strategies.

5.2 THE DEMOGRAPHIC PROFILES

Table 1 serves to provide the reader with a description of the caregivers (hereafter referred to as the respondents) that made up the sample for this study. The table illustrates the variables of gender and age of the respondent, age of the HIV infected child, relationship of respondent to infected child and the educational level of the respondent. The sample consisted of twenty seven females and 3 male caregivers. In-depth interviews were conducted with the 30 respondents and the resulting data was analyzed and interpreted.

Table 1 - The Demographic Profile of Caregivers and Children

Respondent	Gender	Respondents Age	Child's age	Relationship to the HIV infected child	Level of education
1.	Female	28	4	Mother	Grade 12
2.	Female	42	4	Aunt	Grade 11
3.	Female	30	4	Mother	Grade 11
4.	Female	28	18 months	Mother	Grade 11
5.	Male	21	18 months	Father	Grade 11
6.	Female	24	1	Mother	Grade 11
7.	Female	18	5	Mother	Grade 9
8.	Female	34	8	Mother	Diploma
9.	Female	43	12	Mother	Grade 10
10.	Female	28	11	Mother	Don't Remember
11.	Female	34	1	Mother	Grade 12

Table 1 continued - The Demographic Profile of Caregivers and Children

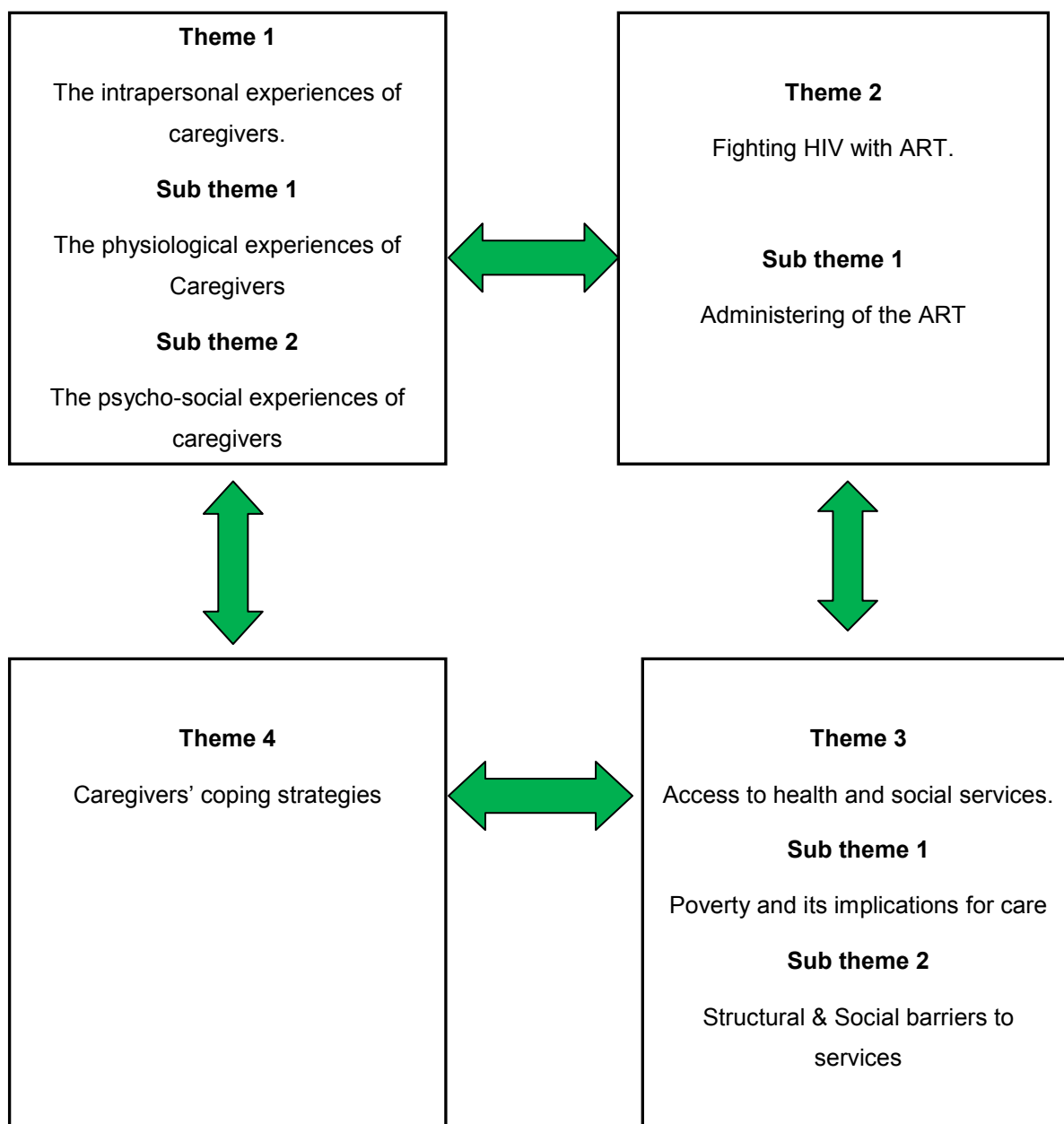
Respondent	Gender	Respondents Age	Child's age	Relationship to the HIV infected child	Level of education
12.	Female	21	2	Aunt	Grade 8
13.	Male	23	15 months	Father	Grade 11
14.	Female	33	14	Mother	Grade 12
15.	Female	23	4	Mother	Grade 11
16.	Female	26	3	Mother	Grade 11
17.	Female	53	5	Grandmother	Grade 11
18.	Female	32	9	Mother	Grade 11
19.	Female	24	12	Cousin	Grade 12
20.	Female	30	6	Mother	Grade 11
21.	Female	38	10	Mother	Grade 12
22.	Female	29	7	Mother	Grade 10
23.	Male	44	14	Father	Grade 10
24.	Female	48	10	Grandmother	Grade 9
25.	Female	19	3	Mother	No Schooling
26.	Female	34	4	Mother	Grade 12
27.	Female	33	1	Mother	Grade 12
28.	Female	17	5	Sister	Grade 10
29.	Female	27	5	Mother	Grade 10
30.	Female	28	6	Sister	Grade 11

In addition to the above table, other important themes and sub themes emerged from this study which were crucial to understanding the experiences of the caregivers of HIV infected children. These are illustrated in figure 2.

5.3 MAJOR THEMES AND SUBTHEMES

Figure 2 illustrates the major themes and sub–themes that emerged from the data. Four major themes and five sub-themes distilled from the analysis of the data for this study. The themes and sub-themes will be discussed under the objectives of the study, for the purposes of creating an understanding of the caregivers' experiences in caring for the HIV infected child.

Figure 2: Major Themes and Sub-themes Illustrating the Experiences and Challenges of Caregivers of HIV Infected Children at a Public Hospital.



5.3.1 Theme 1 - The Intrapersonal Experiences of Caregivers

HIV infected children rely on their caregivers for their antiretroviral treatment, their general care and psycho-social support. Thus the care giving role is often demanding and requires that the caregivers are physically, psychologically and socially equipped to render the most efficient care to the HIV infected child. This is especially important when HIV infected children are subjected to poor health and

socioeconomic circumstances. At times their caregivers cannot, or will not access vital health and social services for them, claiming poor socio-economic circumstances prevented them from doing so (Phili 2009).

In order to identify potential health and social risks to the HIV infected child, social workers and health care providers need to first examine the health and social experiences of their caregivers. Subsequently, the following sub themes emerged.

5.3.1.1 Sub Theme 1: The Physiological Experiences of the Caregiver

Ogden, Esim and Grown (2006) highlighted the importance of caregivers receiving support and care from all systems in their environment, in order to ensure that there is a continuum of care for HIV and AIDS infected individuals. It is argued that caregivers together with their care giving tasks often fulfill a multitude of other roles, which includes but not exclusive to “sustaining family members, communities and subsequently the nation” (Ogden, Esim and Grown 2006, p. 339). The authors therefore contend that caregivers that are not linked to formal health services and support are more vulnerable to sickness and depression.

It is therefore assumed that as HIV and AIDS progresses, the poor physiological and psychological experiences of caregivers would impact negatively on the sustainability of infected individuals, the family, the community and thus the nation (Ogden, Esim and Grown 2006). Thus it was crucial in this study to explore and interpret the physiological and psycho-social experiences faced by caregivers on a daily basis in order to plan for their health and social support.

Parents and other caregivers of HIV infected children sometimes find that it is easier to concentrate on the needs of the child than their own health and welfare. Of concern is that only 17 (57 %) of the respondents in this study disclosed that they were also HIV infected. This is interesting as there were 20 (67 %) respondents who were the biological mothers of the HIV infected children. As mentioned earlier the children in this study were all prenatally infected with HIV.

This implies that three of the respondents who were also the biological mothers of these children, did not want to disclose their own statuses.

It was a further concern that of the 17 respondents who disclosed their HIV statuses, only five were on ARVs. This indicates that despite accessing ART for the child in their care, the majority of the HIV infected respondents were not accessing health services for themselves. This correlates with findings of the study by Wanyenze et al. (2010) where provider initiated HIV testing for children and care givers in Uganda was explored. In this study, 6 877 caregivers were approached to test for HIV and 403 (5.9 %) of them refused testing for themselves, but agreed for the child in their care to be tested.

When questioned about their general health and wellbeing, aside from some respondent's disclosure about their HIV statuses, some shared that they suffered from "sinus, T.B (Tuberculosis), flu, B.P. (high blood pressure), Arthritis, stress, rash, (vaginal) discharge and asthma". Although the majority of the respondents readily presented their physiological ailments, it was done in a manner of nonchalance. This indicated that they did not want to dwell on their own medical issues. Of the thirty respondents, seven (23 %) stated that they were physically well with no health concerns.

Twenty three respondents (77 %) described their physiological wellbeing as:

"Yes I'm HIV positive, and I've just been cured on July 4th for T.B. treatment. It's very difficult but because I was just telling myself I have to face it and carry on with my life".

"No it's just HIV status, nothing else".

"There's nothing wrong with me". (Mother of HIV perinatally infected child).

This finding correlates with the quasi-experimental designed study by Kasese-Hara et al. (2008) on the life experiences of 40 mothers at a public hospital in

Johannesburg. The study sample comprised of one group of 20 HIV infected mothers and their children and a second group of a further 20 HIV negative (or statuses unknown) mothers and children. The study found that HIV infected mothers did present with signs of depression and concerns regarding their illness, however they were able to deal with their depression and illnesses, with the purpose of protecting their children from the knowledge of their HIV statuses (Kasese-Hara et al. 2008).

5.3.1.2 Sub theme 2: The Psycho-social Experiences of the Caregiver

Effective HIV “prevention, treatment care and support” programs have been identified as the key factors that positively influence the impact of HIV and AIDS in the world (WHO 2011, p. 13). Subsequently, caregivers play an important role in ensuring the health and welfare of the HIV infected child, and it is therefore imperative that they receive psycho-social support as suggested by WHO (2011).

This follows that respondents in this study described their psychological health as experiencing feelings of stress, sadness, guilt, anger, fear, shame and remorse when they thought about the child being sick. This finding corroborates Ogden et al’s. (2006) sentiment that caregivers of HIV infected individuals can experience stress and exhaustion as a result of their care giving duties. It was interesting to note that those respondents who were the parents of the HIV infected child and were also HIV infected, described having feelings of guilt and blamed themselves for the child’s status. They voiced their feelings as:

“I feel very bad. What do I think about? If I didn’t do unprotected sex, my baby would have been protected.”

“Actually it’s not a good feeling. I have to blame myself for that every day, because she got the disease I can say. It’s probably my fault, my carelessness. So I always feel guilty about that, every day, ya.”

“Oh! I feel so angry. I feel afraid, ‘cause I know HIV....”

Respondents, who were either the aunt or grandmother of the HIV infected child, indicated that they felt very hurt about not knowing the status of the child before the parent died. These findings corroborate with the ANECCA's 2006 assertion that the family responded with feelings of "shock, fear, guilt, disbelief, anger and sadness" when discovering the HIV status of their children (ANECCA 2006, p. 202).

Similarly, respondents in this study broke down and discussed openly their emotional challenges in the care giving relationship. They displayed emotional responses of sadness and despair during the interview and some appeared to be still dealing with the shock of discovering the child's HIV status. At times some respondents burst into tears, when speaking about their concerns for the life of the HIV infected child.

In these instances, the researcher, who is also a social worker, stopped the interview, and calmed the respondent by supporting and reassuring them. Once they were calmer, the researcher asked them if they were comfortable to continue or if they wanted to end the interview. Respondents most often wanted to continue, as they felt they needed to talk about their experiences. Some of the responses were:

"I just feel numb and confused sometimes, ya. That she's not gonna be able to make it maybe. But I always have the positive side."

"Very difficult for me. I feel very very painful painful, because my sister is a passed away in 2008 and we wasn't know that the child is affected with this disease..."

A further finding was that twenty seven (90 %) of the respondents were African females. Of this 18 (60 %) were unemployed and 17 (57 %) confirmed their HIV statuses. This corroborates findings by Shacham et al. (2009) where it was found that unemployed HIV infected females, specifically those that were from disadvantaged or from minority groups, who had to take care of small children, were more likely to experience depression and at times suicidal tendencies.

The researcher in the current study agrees with Shacham et al. (2009), as it was found that the majority of the female respondents, who were from a previously disadvantaged group, were HIV infected and unemployed. Further the respondents in this study were faced with the issues of HIV in all aspects of their lives, from their own health issues to that of the HIV infected child in their care. Respondents also indicated that they were often stressed and depressed about the HIV infected child's ill health.

Van Dyk (2008) contends that people experience stress on a daily basis, either as a result of job stress, financial problems or relationship issues. Whilst normal stress is not devastating to people's health, being overwhelmed by stressful circumstances can cause harm to the body. This follows that ten (33 %) of the respondents described experiencing feelings of stress, worry and fear of the child or themselves dying.

Eighteen (60 %) of the 30 children in this study were five years old or younger, this has implications in terms of their health care. This implies that caregivers of the HIV infected children in this study have valid concerns regarding the child's health and wellbeing. This follows that the DOH (2010) indicates, South Africa is still struggling to reduce the mortality rates of the under five year old HIV infected child. KwaZulu-Natal, the Eastern Cape and the Free State provinces in South Africa, had the highest under five year old mortality rates in 2010 (DOH 2010).

Some of the concerns expressed by respondents about the health and wellbeing of the child were:

"When the child is sick it stresses me...."

"I was so upsetted. I was thinking my child is gonna be die"

"Very bad. If I die what about her, who will take care of her."

“.....he’s my responsibility in the home. His mother passed away last year. I think maybe I can get sick, I can die, maybe I took something from him, and die before him and maybe he’s left in the back, with no one else to look after him.”

This correlates with ANECCA (2006, p. 3) where it was stated that caregivers experience a sense of “helplessness, sadness and anger” when the children in their care are struggling with illness. Respondents in this study therefore expressed deep seated emotional distress, when they found out the HIV infected child’s status and subsequently were faced with their episodes of illness. Respondents referred to the issue of their own mortality, and it raises the question as to whether they were experiencing more serious health issues that they were not addressing, because of their preoccupation with ensuring the health of the HIV infected child in their care. Similar findings were by Kasese-Hara et al. (2008) who found that mothers, who were also caregivers of young children, were more concerned about not being able to take care of their children rather than their own deteriorating ill health.

This follows that Cole et al. (1997) cited in Van Dyk (2008) have shown that psychosocial and physical experiences can impact on disease progression and severity. It was further added that chronic stress compounded an individual’s vulnerability to illness and disease. It is perceived that psychological issues of stress and anxiety, poor self-esteem and poor support systems have a direct correlation to disease progression in HIV infected individuals, from HIV to the AIDS phase. This bears serious consequences for the HIV infected caregivers in this study, who were not taking care of their own physical and psychological health as they were prone to serious illness and possible death themselves.

The current study is thus consistent with that of Kasese-Hara et al. (2008) as caregivers tended to focus solely on the health and welfare of the children in their care and were distracted from their own health issues.

One can also argue though that the caregivers found strength in their roles as caregivers to the infected child and thus their illnesses did not overwhelm them, but rather improved their knowledge in managing the disease. The care giving role

in respect to HIV infected children thus can also be a positive experience, as research suggests, however it does also present with a multitude of economic and psycho-social challenges.

5.3.1.2.1 The Joys of Caring

Respondents described the bond that they shared with the child as motivation to provide for the child's care and wellbeing. This finding corroborates with Kasese-Hara et al. (2008) where it was found that the caregivers in their study were, at times, positively affected by the reliance of their minor children on them. Thus the nurturing and caring role that caregivers played, served to help them to downplay their own vulnerabilities.

Some of the respondents reported:

"I can say I am good at taking care of my child because I love him, even my sister and my cousin they love taking care of her when I'm not around."

"It's the things that are making me Because she got that special thing on her that, she's special to me, she's the first baby that called me mum."

"The nice thing of taking care of the child, you have to be friendly to the child. You have to take the child like she's your friend. You have to be calm with the child. You have to feel close to the child."

"My sister's child is like I'm the one that she's close to in the family. When I get my own house, I will take her; she can come and live with me, because I understand her."

Respondents discussed the self-satisfaction that they felt when the child was healthy and they emphasized that their role was to 'grow the child up'. This implied that many caregivers also viewed their role as a duty to the HIV infected child.

Despite the challenges of taking care of the HIV infected child, some respondents stated that the child made them laugh and they experienced feelings of happiness. This reflected that there was some reciprocal relationship between the respondent and the child, so that the caring relationship resulted in favorable outcomes for both. Some respondents described the children as relying on them for the treatment and care and this sense of reliance appeared to have been good for the respondent's self esteem. This could be perceived as a form of coping for the respondents, as it helped them to recharge and continue in the caring relationship. This aspect of caring for the HIV infected child will be discussed further under coping strategies in chapter six. Some reports regarding their joys of caring for the child were:

"I'm so blessed. He has got stories now. Because he is getting better, he tells me stories, "Gogo when I grow up you know" he writes letters for me, I will keep them and read them when you grow up. Gogo I will buy a car and take you to the doctor and treat you as the doctor, and look after you Gogo."

The findings from the study indicate that despite the various challenges experienced in the caring relationship, many respondents enjoyed fruitful relations with the HIV infected child. They found joy in the mere survival of the child, and their ability to have a role in the child's wellbeing. This joy that they experience could be as a result of them accepting the child's HIV status and feeling a sense of hope as they were accessing services for the child. This finding is further supported by Haney (1988) as cited in Zastrow and Kirst-Ashman (2010), where it is suggested that positive situations can result from negative situations. This is based on the perception that as individuals work through their difficulties, they become stronger and wiser. When an individual learns to accept their limitations, they develop a sense of clarity of purpose and they then are able to get in tune with their strengths and thus are able to live more fulfilling lives.

5.3.2 Theme 2: Fighting HIV with ART

Antiretroviral therapy is vital for the improvement of the HIV infected child's quality of life and for their ultimate survival, as the treatment helps to prevent opportunistic infections from developing (Van Dyk 2008 and ANECCA, 2006). It is imperative for the caregivers to have a good knowledge of ART and a strong commitment to ensuring the HIV infected child's adherence to the treatment (McKerrow et al. 2010; Van Dyk 2008 and McKerrow, Stephen and Reddy 2006).

It was also interesting to note in this study that 28 (93 %) of the respondents had secondary school education and this related to their fairly good understanding of HIV and ART administration to the child.

Some respondents likened the antiretroviral treatment that the child was taking, to their own chronic treatment, and this made it easier for them to understand. This corroborates with Demmer's (2011) study, which also found that mothers of HIV infected children understood ART when it was compared to chronic treatment of other illnesses.

Respondents stated:

"I think it's like B.P. Because when you started your medication with B.P they said something, same thing like when you take the tablets. If you stop you going to suffer."

"I think the other thing if you can take the tablets the same time with the child, it's better if you take your treatment with the child, so that it makes it easier she can see, it's okay."

An anomaly of the study, however was a response from respondent number four of table 1, who stated that even though she knew she had to give the child the treatment, people died anyway. This respondent had experienced both her parents dying of HIV and AIDS and as a result she was secretive about her own status and that of her child's, as she was the primary caregiver of younger siblings. She had

not commenced ART herself and her child was commenced on ART only on admission to hospital for serious illness. The respondent stated the following:

“It’s a disease. That’s it’s a bad disease that kills people all the time. When you have it you’ll die anyway, whether you take the pills or you don’t you will die...”

This was a unique response, especially since she initially mentioned that she understood and acknowledged the benefits of ART. It is of concern that caregivers, who share similar beliefs as respondent four, could be demotivated to follow the ART programme for the HIV infected child. This could also mean that individuals who felt that ART was a waste of time would not access it and/or health services timeously for the sick HIV infected child (Kimani-Murage et al. 2011).

Subsequently studies have found that issues of HIV stigma and discrimination do impact on caregivers accessing ART for the HIV infected child (Demmer 2011 and Vreeman et al. 2010).

Overall the majority of the respondents in this study were very knowledgeable on the correct dosing of medication for the HIV infected child and the importance of giving the right treatment at the right time. Respondents in this study endeavored to provide optimally to meet the medical needs of the HIV infected child. Respondents also appeared to have a good knowledge of the child’s basic needs however they still faced challenges in ensuring those needs were met. This implies that having a good knowledge about ART and child care is insufficient if not supported by the resources to meet the needs of the HIV infected child.

5.3.2.1 Sub theme 1: Administering of the ART

Respondents described various challenges in ensuring that the child tolerated ART. The problems that were cited at times were that children complained about the form and taste of the medication. Children sometimes vomited the medication and that was a challenge, as respondents then had to ensure that the child be given another dose of ARVs, to avoid the development of resistance to treatment. Some of the concerns were as follows:

“Sometimes he vomits. I just wait and give him the medication after 20 minutes.”

“How come can swallow that. Tablets is very difficult (child is 4 years old). It's better if it's the syrup.”

“The problems I had in the first time was, because she didn't want to take the medication because the pills were not nice, so I had to put the sugar or something.”

“I feel sorry for her. Because at other times, she wants to cry, I try to make her understand that me I got, she thought she must die and I say see me. In our family three of us got HIV. “

This study found that the ARVs were unpleasant for the children, as the tablets were too big and generally the syrups and tablets were not palatable. This is of concern as 18 (60 %) of the children were under the age of six. The children were sometimes traumatized about taking the treatment and this in turn impacted negatively on the respondents. The younger children proved challenging for respondents, as they often couldn't reason with them to take the medication as they were too young to understand the disease and its treatment. The 12 (40 %) older children may have experienced similar problems but respondents were able to reason with them and at times bargain with them to take their treatment. This study is unique because despite the numerous challenges faced by respondents in the actual administration of the ART, they were creative and patient in their methods of dealing with the sick child. They often employed positive reinforcement to encourage the child to take the treatment. One respondent stated:

“I speak, I becoming calm to the child, speaking to the child, trying to tell her that “I will buy you so and so....you know... So that she can do it.”

This empathic attitude of the respondents served to encourage the sick child to persevere in the treatment plan. Respondents also tried to make the child feel comfortable by taking their treatment at the same time with the child, so as to

create a sense of normalcy. This indicated to the child that it was okay to take the treatment as they were not alone.

Respondents thus shared mixed feelings at times about the ART programme, when they were faced with the resistance of the sick child. Respondents described feelings of sadness when the child had problems with taking the treatment but also renewed hope and joy at knowing that the treatment was available and would help the child get well. This follows that the care giving role also enhanced the self-esteem of respondents and they felt good about what they were doing.

“..... It hurts me because it's the child that has to take the medication, but happy cause they get the help.”

In difficult times some respondents employed the following skills to ensure that the child took their ART:

“...so you have to concentrate of what we are doing to the child, and talk to the child, he has to understand what's going on....”

“A mother, caring, care, support, just to be loved you can say.”

Some respondents even spoke about engaging in healthy communication with the child, to facilitate the relationship of trust, so that the child's emotional needs would be met. Most females in the sample emphasized the issue of love and the need for a mother in the care of HIV infected children.

This reflected that the respondents in this study related the child's emotional wellbeing to their co-operation in adherence to ART. This implied that they were more knowledgeable about the comprehensive care that children need, specifically the HIV infected child that presents with so many more medical and social challenges than non HIV infected children.

Respondents also worried about who would take care of the HIV infected child if they died. This finding is similar to Demmer's (2011) study where it was found that caregivers feared their own death because it meant there would be no one to take

care of the HIV infected child. Another concern from those that had not disclosed the child's status to family members was the lack of an additional caregiver in the home, to administer the ART in the absence of the primary caregiver.

This follows that the 11 (37 %) respondents that were engaged in full time or part time employment, or those that were taking care of other family members, found it challenging to depend on anyone else to administer the ART or take care of the sick child at times. They stated examples of going away for work or returning home late from work or other commitments as instances that created stress. Hejoaka (2009) also had similar findings with regard to disclosure where respondents were concerned about not having a responsible second person available to ensure paediatric treatment adherence, should they be incapacitated for any reason.

Here again one can see how stigma and fear of disclosing the child's HIV status can prevent the caregiver (microsystem) from enlisting the help of family members and the community (mezzosystem), to help take the child for clinic and doctor's appointments (exosystem), which then impacts on the child's lack of adherence to ART.

Interestingly, the DOH NSP (2010) and UNAIDS (2000) as the macrosystem speak to issues of HCT and care and support for HIV infected individuals. However, it is evident that HIV stigma and discrimination still presents many challenges in communities and is preventing caregivers of HIV infected children from reaching out for support (Vreeman et al. 2010). This follows that Kimani-Murage et al. (2011) also found that caregivers in their study were reluctant to disclose the HIV statuses of children and would only do so to second line caregivers for the purpose of adhering to ART.

5.4 CONCLUSION

This chapter provided an insight into the factors influencing care giving. Two key themes were discussed namely: the intrapersonal experiences of caregivers within the context of HIV and AIDS and the role of ART in relation to the fight against HIV and AIDS. Chapter five highlights the connectedness between the physiological and psycho-social experiences of the caregiver and the influence of these experiences on the care giving relationship. Respondents were stressed mainly about the health and wellbeing of the HIV infected child and their own health concerns were not a priority. Respondents in this study appeared to be selfless and deeply committed to the care of the child, despite their own psycho-social challenges.

Chapter six will include a discussion of two further themes that distilled from the analysis, namely: the caregivers' experiences in accessing health and welfare services and caregivers' coping strategies.

CHAPTER SIX

ANALYSIS AND DISCUSSION: STRUCTURAL AND SOCIAL CHALLENGES INFLUENCING CARE GIVING

6.1 INTRODUCTION

Caregivers of HIV infected children require ongoing support and care in order for them to cope with maintaining the health and well being of the HIV infected child (Demmer 2011 and McKerrow et al. 2010). It is thus not sufficient to understand their physiological and psycho-social experiences, but also their interactions with their communities and health and welfare service providers. This Chapter will therefore include discussions on caregivers' experiences in relation to their interactions with health and social service providers. The Chapter concludes with a discussion on the caregivers' support networks and their coping mechanisms.

6.2 THEME 3: ACCESS TO HEALTH AND SOCIAL SERVICES

6.2.1 Sub Theme 1: Poverty and its' Implications for Care

According to Statistics South Africa (2012), South Africa's unemployment rates have risen to 25.5 % which translated to 4.7 million people being unemployed in 2012. Previous studies have found that unemployment and poverty added to the burden of care for caregivers of HIV infected children and often impacted on them accessing health and welfare services (Demmer 2011; Kimani-Murage et al. 2011 and Raniga and Simpson 2010). It is concerning that 19 (63 %) of the respondents in this study, were unemployed and found it challenging to acquire employment and to generate some income. Of the 30 (100 %) respondents, 27 (90 %) were reliant on state grants (child support grants) to survive. Further, eight (27 %) of the 27 (90 %) were also permanently or casually employed and also depended on the state grant.

The majority of the respondents in this study were solely responsible for the income and sustainability of the family. The majority of the respondents stated that they needed money to buy “healthy food, milk/formula, supplements and medication, clothes and toiletries, to pay for transport to hospital/clinic (to be monitored by doctors), to pay for transport to work/school, crèche fees, school fees, care giver’s studies, rent, water, electricity, school uniforms, doctors’ fees, and money to help extended family members.”

They discussed their experiences in taking care of the child as:

“.....I’m living with my mother and my sister is taking treatment... ..she can’t Support us, sometimes we sleep without eating.....I’m HIV positive”

“.....and sometimes the children don’t even get a lunch, and this is what’s stressing me.”

“Money situation is very bad. Luckily I am receiving my grant (disability grant) and the grant for the two children (child support) that one it helps me a lot, otherwise how can I survive.”

“... Before I was not working. The grant before the amount was R250 we used to buy food with that. I was suffering. He was so sick sick sick, because he was not getting.....I was working five o clock and coming with my sickness carrying him on my back (crying)”

“I think, like this one he eats a lot, he likes food, and I can feel like I’m not satisfying his need. I feel he needs more in the sense of food, protection...”

The respondents described their economic experiences as a great concern for them, especially when they considered the needs of the HIV infected child. They were often distressed about not being able to afford nutritious food for the child, as recommended by health care professionals at the hospital. Respondents also doubted their abilities in taking care of the child, as they struggled financially to meet the needs of the child. In addition they sometimes did not have stable accommodation and this was an ongoing source of concern for those respondents

that relied on family members for accommodation and support. This contributed to their feelings of helplessness. This finding correlates with that of Demmer's (2011) study, where it was found that the issues of unemployment and poor socio-economic circumstances, compounded feelings of depression and helplessness in most of the caregivers.

It is interesting that Kasese-Hara et al. (2008) argues that depression and worry was not necessarily related to HIV infection in communities, but rather depended on the socio-economic experiences of caregivers. The findings of this study further corroborate Kasese-Hara et al. (2008) as respondents spoke of not having money at times to cover transport costs to bring the HIV infected child for their appointments to the clinic. This was often a major source of stress and frustration, as respondents stated that the child support grants were mostly used to buy food for the child and at times other family members. Respondents also stated that when the child became ill, there was no money to take the child to the doctor.

In contrast it is argued that food insecurity is directly correlated to low income in the household within the context of HIV and AIDS (Raniga and Motloug 2013; Raniga and Simpson 2010 and Smith et al. 2010). Subsequently, it can also be assumed that the extensive costs of travelling to hospitals and clinics for the child's ART significantly impacted on the respondent's experiencing financial strife.

Demmer (2011) concluded in his study that caregivers of HIV infected children required support group interventions coupled with psycho-social assistance to deal with their stresses and their material needs.

Further findings of this study were respondent's commitments to and responsibilities for other family members which was at times an added economic burden that created stress for them. Respondents spoke about the following:

"...Or because of the nutrition that I am giving the child. Maybe it's not healthy nutrition because I'm not working and I cannot afford the food for me and the child and the whole family."

"...have to go to that other child, the one she has to also go to the crèche. To buy milk, the child is taking the formula, the nappies all that"

It implies that often the basic needs of the HIV infected child, like nutrition, may not be adequately met because of the need to provide for other family members, and the pressure of financial strain is exacerbated, as was also found in Raniga and Simpson (2010).

Aside from their difficulties experienced in meeting the basic needs of the child, respondents spoke about their knowledge of the child's educational and social needs, and their ability or lack thereof to ensure the child's social well being was maintained. This follows that the study sample included 12 (40 %) children who were six years and older and therefore of school going age. Respondents spoke about not affording school fees and transport costs at times for the child to attend school. Thus at times the HIV infected child (microsystem) was deprived of their basic right to education. Subsequently, this impacted on the intellectual growth of the HIV infected child.

The Children's Act (Act 41 of 2007) and UNICEF (1990) argues that all children should have access to education as a basic right. It is evident in this study that legislation in the macrosystem guiding the rights of children is sometimes not upheld in the microsystem of the HIV infected child, as the family experiences financial strife and challenges to ensuring that the child's rights to education are maintained, as most often they are struggling to meet the child's basic needs of shelter, nutrition and medical care. This contributed further to the caregivers experiencing feelings of helplessness and despair.

Respondents recommended that the old age pension, disability grants and child care grants be increased. They further suggested that the disability grant should be applicable to all HIV infected children, as their needs were so much more than that of non HIV infected children. This finding correlates with Kimani-Murage et al. (2010) and Raniga and Simpson's (2010) studies, where it was also found that respondents experienced the social support grants as being inadequate in providing for the respondents and HIV infected child's needs.

6.2.1.1 Employment Versus Care Giving

According to Ogden, Esim and Grown (2006), the impact of HIV and AIDS within the family and community contexts often target women to carry the burden of care. It is further claimed that these female caregivers have to take on the dual roles of the breadwinners and of the caregivers in the family. This multitude of responsibilities sometimes means that caregivers have to divert their efforts of generating an income for the family, to rather caring and tending to the family in the home (Raniga and Motloung 2013).

Similarly, the 19 (63 %) unemployed respondents discussed their dilemmas that despite their need for jobs, so that they could provide better for their families, they were concerned that if they were employed they would have to leave work when the child was ill, as there was no one else to take care of the child.

Respondents related that they had to often struggle between deciding whether to go to work or keep the child's clinic appointments. When questioned about their experiences in taking care of the child's medical needs respondents shared the following:

“Difficult. Cause I have to be absent at work.”

This follows that a male respondent in this study mentioned that he had to stay at home and take care of his sick HIV infected wife, the HIV infected child and other children in the home, as there was no one else who could assist. Another father had to re-locate to Durban, leaving his job in the process, so that he could help his HIV infected girlfriend with the care of their three children, which also included the HIV infected child. This finding correlates with Raniga and Motloung's (2013) study where it was also found that despite huge economic demands of individuals, caregivers had to leave employment in order to provide care and support to HIV infected individuals.

There is a paucity of studies with respect to the role of male caregivers in the context of HIV and AIDS, however it is more widely recognized and understood

when females are the main caregivers in the home, as often they are responsible for the overall care of the family. It is further suggested that extended family members who are caregivers are most often forced into their care giving roles out of a sense of duty and obligation (Ogden et al. 2006). The researcher is in agreement with Ogden et al. (2006) as the majority of the respondents in this study were women, however it is evident in the current study, that male members of families will in time engage more intensively in the care giving role of HIV infected children, as female caregivers become overburdened with their own health demands, and that of the children in their care.

6.2.2 Sub Theme 2: Structural and Social Barriers to Services

According to the qualitative study by Kimani-Murage et al. (2011) with 31 caregivers of HIV infected children in Mpumalanga province in South Africa, it was found that access to paediatric ART was limited. It was suggested in this study that this was as a result of structural and social barriers that hindered the acquiring of health services. This follows that often issues of poverty and HIV stigma and discrimination prevent caregivers from accessing health and welfare services for the HIV infected child within communities (Kimani-Murage et al. 2011 and Vreeman et al. 2010).

Kimani-Murage et al. (2011) further suggested that government increase the number of clinics within communities for the purposes of facilitating access to paediatric ART and to reducing travelling costs for caregivers in the Mpumalanga province.

However, it can be argued that addressing these structural barriers of poverty and infrastructure is insufficient in ensuring the caregivers' access to ART and other services for children. Social workers and other health care providers need to also address issues of HIV stigma and disclosure for services to be truly effective. It is further suggested that caregivers should be encouraged and supported in their disclosure of the child's HIV status to second line care givers (Vreeman et al. 2010).

This study found that 24 (80 %) of the respondents were aware of health and welfare services that were available to them and the HIV infected child. The most commonly identified and used services were hospitals, clinics, medical services, dietetic and social services at the hospital.

Whilst 20 (67 %) of the respondents stated that services were accessible, eight (27 %) claimed to have difficulties accessing services. An explanation for this finding could be that the HIV infected children were referred to the hospital ward for admission and continuation of treatment, from their local hospital, which at times was in outlying areas. Respondents thus had to, at times, travel to this hospital from the outlying areas, when the child was admitted to the paediatric ward for treatment. Other possible reasons that prevented access to services were lack of transport fees to get to the hospital and having to take time off work to keep clinic appointments. It is also possible that issues concerning fear of stigma prevented respondents from accessing services within their own communities and thus resulted in them traveling out to the hospital clinic.

Respondents also related their experiences of feeling overwhelmed by their lack of employment, financial difficulties, lack of stable accommodation and the responsibility of taking care of other sick family members, which prevented them at times from accessing services for the HIV infected child.

Some of the respondents stated the following:

“It’s difficult, because sometimes I don’t have the transport money.”

“...the problem is that I’m not staying in one place, I’m always looking for a job...”

The 20 (67 %) of the respondents that easily accessed services lived within a five to ten kilometer distance from the public hospital and the close proximity of the hospital could explain why so many were receiving services here.

With the introduction of the scaling-up of the ART roll out in South Africa in 2010, where ART is being made more accessible to HIV infected individuals, the number

of people accessing services have increased substantially thus impacting on health care systems nationally (DOH 2010). The scaling-up of ART can be perceived in a positive light, as the convenient access to health services for HIV infected adults and children, impacts well on their physical health and quality of life. However the increased number of HIV infected people requiring health services means that there is often a longer period of waiting for services at health facilities.

Furthermore, Sharkey et al. (2011) was found that the quality of health services received by people at public health facilities determined their decisions to returning for services. Subsequently, It was found that caregivers also tended to choose health care facilities, even if it was far from their homes, where they were more likely to receive a favorable response and hence a good service from health care workers. This correlates with the findings in the current study, as respondents implied that they received a cordial response from health care staff at this public hospital's ART clinic, and therefore chose to travel long distances to the public hospital.

They seemed to express that they worked together with the health care workers as a team; they saw themselves as equals, and for them that was important. The acknowledgement by health care workers of the respondent's individuality and their interest in the HIV infected child as a person was important for respondents in their assessment of services received. Some of the responses were:

"Everyone is kind here. The doctors are so friendly, the nurses are so nice. They make him feel like he's someone."

"The clinics are very important in my life, if you are sick you need small money to go, in the clinic it's free."

"Feel good, because you know you are not alone. We support each other"

Some respondents shared that accessing services for themselves and the HIV infected child made them feel a sense of hope and they felt that there was support.

These respondents therefore interpreted the services received from the hospital as a safety net for them; it motivated them to do all that they could for the health and care of the HIV infected child.

“I feel the pain, maybe sometimes I say hey! How God do this to me? Now I see if I go to the clinic the baby will recover very quickly.”

“I feel better. When I go to the clinic I know I speak to the nurses, I know that I feel better again, even the social worker.”

“Hey I’m so glad. They ask me “Gogo how is he doing?” then I have to tell them. It feels like have someone else for support”

It is therefore also perceived that with the access to services, respondents realized their inherent abilities to be creative in resolving their problems for the benefit of the HIV infected child. Some respondents shared that they learned valuable information on how to deal with difficult situations in their lives from interacting with health care workers.

One respondent spoke about bringing the child to the hospital for treatment when the child was extremely ill and expressed feelings of relief when the child’s condition improved. She also stated her confusion with the community clinic for failing to detect the severity of the child’s illness timeously. This caused her to lose faith in the community clinic and she therefore accessed the child’s treatment at the hospital.

The DOH’s Strategic Plan for 2010/2011-2012/2013 (macrosystem) has set guidelines for the “prevention, treatment, care and support” of all South Africans within the context of HIV and AIDS (DOH 2010). These guidelines are reinforced by health care workers on the hospital and clinic level (exosystem) to treat caregivers of HIV infected children in particular, with courtesy and dignity and to never discriminate against the caregiver or the child (McKerrow et al. 2006).

It is evident that many of the caregivers are experiencing services from the hospital and clinic as consistent with these guidelines. This then favourably

impacts on the relationship between health care workers (exosystem) and the caregivers, which then results in caregivers feeling a sense of self-worth and empowerment. This then allows them to readily access services for the child, which inevitably contributes to the health and the wellbeing of both caregivers and the HIV infected child (microsystem).

It is evident that there were social barriers like HIV stigma that impacted on the respondents accessing services within their immediate communities. Some respondents spoke about their fears of being discriminated against by community members, as a result of HIV stigma which is consistent with Demmer (2011), where it was found that caregivers of HIV infected children experienced apprehension about accessing services from health care facilities due to their fear of stigma.

This supports the current study's finding where although some respondents had knowledge of health and welfare services in their own community, they didn't utilize it for fear of being identified as having HIV. This again raises the challenges of stigmatization and its resulting barrier to accessing services.

The relationship between the respondent and the community (mezzosystem), at times, may be somewhat strained as the respondent struggles with maintaining the secret of the child's HIV infection. This socially excludes the child and the respondent from society. This then impacts on the lack of support that the respondent could have accessed from community members and resources. The vicious cycle continues, as the respondent feels alone and cannot access support in caring for the HIV infected child, which then leads to the respondent experiencing exhaustion and stress. This could also impact on their own health and subsequently hinder their ability to provide for the child's care (Vreeman et al. 2010 and Ogden 2006).

Respondents spoke about their experiences as:

“No...., but I know there is a social worker at my community, but I didn’t plan to attend them, because I’m scared, because some of them they are my neighbors.”
(Respondents fear of stigma).

Although some respondents had fears of accessing the service in the community due to HIV stigma and their perceptions that it could be harmful to the HIV infected child if people found out the child’s status, respondents felt comforted by the fact that the service was available. The other perception was that knowing that the services were available in the community gave respondents a sense of knowing that they were not alone and a sense of power in choice, even though they chose not to use the services.

“... Feel better, knowing it’s there.”

“Feel good, cause you know you are not alone...”

Social barriers that prevent caregivers of HIV infected children from accessing health and welfare services can have a devastating effect on the health and quality of life for the HIV infected child. Demmer (2011) found in his study that mothers of HIV infected children waited too long because of their fear of stigma to access health services for their HIV infected children, which resulted in these children becoming severely ill. It is therefore imperative to consider both social and structural barriers to access of services for HIV infected children and their caregivers when providing health and welfare services to them.

6.2.2.1. Stigma as a Social Barrier to Accessing Services

Table 2 provides the reader with a description of the number of respondents and their perceptions of HIV stigma within their communities. The table further illustrates the respondent’s varying attitudes to disclosing the child’s HIV status.

Table 2 - Caregivers Perceptions of Community Stigma and HIV Disclosure

Respondent	Stigma in Community (Yes/No)	Disclosure of Child's Status (Yes/No)
1	Yes	Yes
2	Yes	No
3	Yes	No
4	Yes	Yes
5	Yes	Yes
6	Yes	No
7	Yes	No
8	Yes	No
9	Yes	No
10	Yes	No
11	Yes	Yes
12	No	Yes
13	No	Yes
14	Yes	No
15	Yes	Yes and No
16	Yes	Yes
17	Yes	No
18	Yes and No	No
19	Yes and No	No
20	No	No
21	Yes	Yes
22	Yes and No	Yes
23	No	No
24	Yes and No	No
25	Yes	No
26	Yes	No
27	Yes	Yes
28	Yes	Yes and No
29	Yes and No	Yes and No
30	Yes	No

Table 2 illustrates that 21(70 %) of the total 30 respondents perceived that their communities stigmatized against HIV infected individuals. Four (13 %) of the respondents felt that communities did not stigmatize against HIV infected people. Whilst five (17 %) of the respondents felt that communities were divided and that some did stigmatize whilst others didn't. Ten (33 %) of the respondents stated that they would disclose the child's HIV status, whilst 17 (57 %) of the respondents were adamant that they would not disclose the child's HIV status. Three (10 %) of the respondents were undecided and related that they could disclose the child's status but only to certain members of the community based on their level of trust of those individuals, however they also stated that they would not disclose if it was not going to benefit the child in any way.

It is interesting to note that respondents were from middle to low income communities. However, for the purposes of maintaining the respondent's confidentiality, the communities have not been illustrated in the table 2.

Both the middle and low income communities had health care facilities which were easy to access, but respondents chose to travel out to the hospital and its clinic for services. This could mean that respondents were reluctant to use the services within their communities for fear of being discriminated against, as 21 (70 %) of the total number of respondents felt that HIV stigma and discrimination was prevalent in their communities. This corroborates with the study by Vreeman et al. (2010) where caregivers of HIV infected children were reluctant to use health care facilities, within their communities due to their fear of HIV stigma.

This follows that respondents were often concerned about how communities, their families and health care workers perceived them in their roles as caregivers to the HIV infected child. One of the respondents described how her family and the community chastised her about her child being sick in hospital. She said that that was one of the reasons why she would not disclose her child's status, as they already discriminated against her because her parents had also died of AIDS. She stated the following:

“No I’m feeling so bad because I love my child. I do love my child. And I think that she’s in hospital for so many months, and I’m feeling so bad, the others they thinking that I don’t love my child. No (not family) the neighbors, all the people (the community), ya. They think that I’m not interested.”

Seventy percent of the respondents described their feelings about community related stigma as ranging from feeling immense fear, sadness, disappointment, hopelessness and helplessness. They claimed that those communities that discriminated against HIV infected people often joked about HIV and laughed at people that they knew were HIV infected. They also gossiped about individuals and families that were HIV infected. The perception was that communities didn’t discriminate against children normally, because the HIV infection in children was not easily noticeable and that they treated all the children the same, as long as they didn’t know the child’s status. Once a child’s HIV positive status was known some communities isolated the child and the caregiver, and would not allow their children to play with the HIV infected child. This follows that Raniga and Motloun, (2013) found that caregivers of HIV infected individuals, kept the status of the HIV infected person secret by travelling out of their communities to access health services. This impacts negatively on the caregivers economic circumstances and adds to the burden of care.

Many respondents felt that if their families were aware of the child’s HIV infection, it was sufficient and there was no need to inform neighbors or the community, as the community was not going to contribute in any way to making the respondent’s life or the child’s life easier. This finding is similar to the findings of the qualitative study by Kimani-Murage et al. (2011) on the barriers to paediatric HIV treatment with caregivers of HIV infected children. It was found that respondents did not feel comfortable disclosing the child’s HIV positive status to non-family members, such as the community. Respondents’ perceptions of their communities were indicated as follows:

“When they in group, they chatting about you, and they know about me. They are okay. They don’t treat children differently because they don’t know whether the children are positive. I feel good for myself, not for my children, I’m afraid for my children.”

“..... they (community members) bad they say anything they want to say to him. I’m talking from experience, he would come crying and telling me some other days, “Gogo (Granny), someone tells me I’mCame with rash”

“No, it’s fine. I just scared for neighbors for everyone, It’s just people who know me, even for nurses, I can’t just pick and say this and this about the child’s status.”

“No.aye!, how! It’s not right. People are talking; they will talk about you everywhere.”

“They treat them like they animals, if they know you are HIV.”

Respondents generally did not worry so much about people finding out about their own HIV positive statuses, in those instances where the respondent was HIV infected, however they maintained that some communities were not knowledgeable about the disease and would discriminate against the child.

“I can tell about my status, but not about his status. I don’t feel comfortable.”

“Because of un education they still think that HIV is for people, it’s for dirty people. So they are not educated enough.”

“No, I don’t think there’s a point for that. I thinks they sometimes around the community all they do is criticize about HIV, and we don’t want that for the baby.”

Ten (33 %) of the respondents felt that telling others about the child’s HIV status would help gain support, if they were for some reason not available and the child got injured or needed medical assistance, people would know how to help the child. This corroborates the study by Vreeman et al. (2010) where it was found that mothers only disclosed the HIV status of their children in order to gain support.

The respondents that felt that they would disclose the child’s status cited the following reasons, namely: it was important for neighbors and community

members to know about the child's condition so that they would not expect them to do things that could cause them potential harm, like playing in cold water on cold days, or doing things generally that may make them susceptible to illness. It was felt that other children and adults needed to know the child's HIV status, so that they could protect themselves from infection, if the child got hurt and was bleeding. Respondents also felt that disclosing the child's status would help in educating and creating awareness around issues of HIV and AIDS, thus helping to reduce community stigma.

Common responses were:

"It's important.... cause they have to know exactly what is the problem of the child so when you not there they can help."

"It's killing me. I'm scared, I am scared. But I will tell because they don't know what is HIV ..."

This study found that 17 (57 %) of the total respondents were concerned about HIV stigma in their communities and it follows that 21(70 %) of the respondents related that they would not disclose the child's HIV status. Thirty-three percent of the respondents that had concerns about HIV stigma, felt that they would disclose for the benefit of the community and if the HIV infected child would benefit from the disclosure.

This follows that HIV stigma and discrimination impacted negatively on respondent's accessing services for the HIV infected child within their own communities. This then prevented them from reaching out for support and assistance from their community members. This is similar to the findings of Vreeman et al. (2010) where the caregivers were concerned that HIV disclosure would result in the infected child and the family being subjected to discrimination by the community. As a result caregivers withdrew from their community and subsequently any possible community support.

The reasons cited by the respondents for wanting to disclose the child's status in this study were for the health benefits of the child and, interestingly enough, to ensure that the community was protected from HIV infection. This finding is in contrast to those of Vreeman et al. (2010), where respondents cited reasons to disclosing the child's status as wanting to encourage treatment adherence for older children and for community support.

This follows that support for the caregiver is important as it helps relieve the burden of care to some extent. According to Ogden et al. (2006) caregivers that have support in their care giving roles are able to enjoy a better quality of life, with reduced stress levels and general wellbeing.

Some respondents recommended the increase of human resources at health facilities, to help shorten the waiting times for services, because of the large volume of people that utilize those facilities. This finding could be directly linked to the impact the scaling up of the ARV rollout has on health care facilities (WHO 2010). In addition it was suggested that the addition of staff at hospitals and clinics and the hours of operation at health care facilities should be extended, so that they could access services after work or after attending to other commitments. Respondents further felt that the training and support of staff at health care facilities within their own communities to improve the quality of service delivery would be beneficial for them. This recommendation correlates with that of Phili (2009) where caregivers felt that staff at clinics needed to be trained to provide more efficient services.

6.3 THEME 4: COPING STRATEGIES

According to Van Dyk (2008), HIV infected children require extensive care and support and this can result in their caregivers experiencing exhaustion and fatigue. The current study thus focused on the caregivers coping strategies, in order to understand the experiences in the care giving relationship with the HIV infected child.

This diversity in terms of the age groups of the respondents provided rich information in terms of how respondents experienced the care giving role. It was found that five (17 %) of the respondents aged 42 to 53 were more accepting of the HIV infected child's status and were able to deal with their challenges by being confident in their care giving capabilities. This could mean that they were also better focused on ensuring that the HIV infected child was reasonably well care for, despite other challenges.

This finding is similar to findings in the cross-sectional study by Kuntawee et al. (2010) focusing on social factors and the quality of life of 114 HIV infected children in Thailand. It was found that HIV infected children enjoyed a better quality of life with older care givers as opposed to younger respondents. The authors suggested that this could have been due to younger care givers experiencing ill health due to HIV infection themselves, being unemployed and also commonly younger people had to go to other provinces for work, resulting in the lack of care received by the HIV infected child.

This follows that the ages of the respondents in the current study varied, 18 (60 %) of the respondents were aged 17 to 30 years, while seven (23 %) were between 31 and 41 years and five (17 %) were between 42 and 53 years of age.

Common responses were:

“Because I am matured now and I experience a lot in life and I'm like a nurse in my house, if the child gets sick I try my whole best to get the child better now....”

Of concern is that 18 (60 %) of the respondents aged 17 to 30 still seemed to be dealing with issues of their own health and concern over their ability to provide adequate care for the child. This suggested that they were barely coping with the demands of their care giving roles.

Some of the responses were:

“.....I know they sick and they might die. That I'm a bad mother sometimes that I

don't take good care of them."

"No the problem is that I've got so many children and I'm worried about the one who is in hospital?"

These 18 (60 %) of the younger respondents were still also caring for other children in the home and responded that it was challenging at times, especially when the HIV infected child was sick and had to be hospitalized. It can thus be interpreted that the maturity and experiences of the older respondents proved to be beneficial in equipping them to deal with the care giving challenges that arose.

This finding is in contrast with Raniga and Simpson (2010) study where it was found that older caregivers experienced overwhelming socio economic challenges in their care giving roles, which then impacted on their own health.

The younger respondents in the current study found their life experiences overwhelming and at times unmanageable, in the care giving relationship with the child. They also doubted their care giving abilities which then impacted negatively on their self esteem.

6.3.1 Social Support, Coping Mechanisms and the Caregiver

Further findings were that 22 (73) of the respondents had close friends, that they relied on for support. Four respondents (13 %) stated that they could count on family members for their support. And the remaining four (13 %) of the respondents stated that they had no one that they could confide in.

Those that did not have support discussed issues of mistrust, discrimination, fear and shame as barriers to enjoying social relationships with friends, colleagues and family members. Subsequently, these respondents were very protective over the HIV infected child and felt that no one else could take care of the child like they did and felt there was no need to tell anyone about the child's medical condition, as they could cope on their own. Thus these respondents' experiences in providing

for the care of the HIV infected child, was at times extremely difficult, as they tended to rely on themselves for the health and welfare of the HIV infected child. Finally, from the demographic profile of the respondents in table one, it can be suggested that the care giving role is evolving in the context of HIV and AIDS, with more involvement from all members of families and sometimes communities. This is further supported by Raniga and Simpson's (2010) qualitative study with grandmothers in Bhambayi, where it was found that family and friends offer vital support to the caregivers of HIV infected individuals and are considered an informal support system.

Aside from the support received from family and friends, the majority of the respondents did utilize various other forms of coping techniques. Many engaged in discussions with confidantes about the child's illness, this served as a form of catharsis for them and helped them to clearly see problems and possible solutions.

Generally, the respondents described activities like, doing house work, listening to music, singing, dancing, watching T.V (television), sleeping, exercising, writing poetry or taking the HIV infected child on outings as methods of relaxation and recharging.

"I just want to work. I speak to my friend and I feel better."

"Just clean the house. Listen to music."

The majority of the respondents did engage in some form of relaxation, however many hesitated when asked this question. This could mean that many did not actually take timeout to relax, or have time for themselves, as they were occupied with the tasks of taking care of the child. This is indicative by them stating that they relax when they sleep, or they relax when they are busy with house work. This is a cause for concern as respondents need some form of relaxation to prevent burnout and total exhaustion in the caring role.

6.3.2 Spiritual Upliftment and Psychological Wellbeing

Respondents often dealt with their challenges by praying. This implied that some respondents used their faith as a method of coping. This reflects the depth of desperateness and the power of faith that respondents experience in their adverse circumstances. The belief in God also helped many of the respondents accept their situations and the child's HIV status, as they believed in the will of God. These respondents constantly referred to accepting and moving on to make sure that everything was done so that the child could be healthy and happy.

“Sometimes he gets sick, every time if he gets sick, I have to take care of him. Maybe if he's playing I have to take care of him (nonverbal about rash-uncomfortable). I pray to God to give me the strength to take care of the child.”

“When I don't have money, when I'm jobless, cause I can't do anything without money right? Nothing, I pray, and I ask for help from my family. If they can they will, if they can't, they don't.”

These findings are thus consistent with findings in Raniga and Simpson, 2010 study where the grandmothers who were caregivers shared their coping strategies as receiving visits from members of their families, the church and engaging in prayer. Despite the temporary relief these strategies offered, the concern arose that it was an informal and unsustainable source of support, as family and church member's visits were ad hoc in nature (Shebi 2006). It was further recommended that social workers and government structures needed to take cognizance of the caregivers' coping mechanisms and provide intensive social interventions to address their psychological and emotional challenges (Shebi 2006).

Interestingly, respondents also described how they focused on positive thoughts and actions, in dealing with difficult circumstances, this meant that often they had to boost their self esteem and remain psychologically strong to deal with the difficulties on a daily basis.

“It’s very difficult but because I was just telling myself that I’ve got this thing here so I have to face it and carry on with my life.”

“I just telling myself I’m ignoring the stress. I’m telling myself this is my life I’m carrying on with it, I want to live longer, this is my responsibility, I have to live with it.”

“....I told myself that my child is important, (made yourself strong?) yes (emotional crying.)”

This finding supports Haney’s (1988) assertion as cited in Zastrow and Kirst-Ashman (2010) that individuals can have positive life experiences despite encountering a negative life event. In the current study some of the care givers adopted a positive attitude towards the HIV infected child and their own circumstances and this resulted in them experiencing a sense of hope for their future.

6.4 CONCLUSION

Chapter six was a continuation of the data analysis, which included a discussion on the third and fourth themes of the study. Here, respondent’s experiences of poverty and its implications for care and their experiences of structural and social barriers to services were described in detail. Generally, all respondents were negatively affected by poor socio-economic circumstances that prevented them from providing optimal quality of care. The challenges that they faced on the micro level (economic and psycho-social experiences), the mezzo (stigma, community and family support) and exo levels (health and welfare services) together with the macro level (DOH strategic plans and childcare legislations) determined how they provided for the care of the HIV infected child. Despite these challenges respondents’ acknowledged the support received from spiritual networks, family and friends which contributed to their coping with the care of the HIV infected child.

CHAPTER SEVEN

CONCLUSIONS AND RECOMMENDATIONS

7.1 INTRODUCTION

The United Nations Joint Programme on HIV/AIDS (2010) reported that 800 000 HIV infected people in South Africa were on ART, but only ten percent of HIV infected children who needed the ART were receiving it (UNAIDS 2010). This is catastrophic for HIV infection in children as the disease progresses much faster to the AIDS phase for them, than in the HIV infected adult (ANECCA 2006). Subsequently, paediatric health care facilities are becoming overburdened as the AIDS epidemic peaks and children progress rapidly through the disease, resulting in an increasing number of HIV infected children being admitted to hospital for serious illness (Evian 2003). Sadly, it is reported that children who have AIDS often die before their second birthdays (WHO 2011).

It is positive to note however, that since 2010 there has been much progress in terms of the treatment and management of the disease (WHO 2011). An example of progress made would be the Department of Health's National Strategic Plan (2010) which focused on scaling up the availability of ART for HIV infected children. Through the implementation of the DOH NSP (2010) the disease is now perceived as a manageable chronic illness, thus resulting in an improvement of the HIV infected child's quality of life (DOH NSP 2010 and Van Dyk 2008).

The caregivers have a vital role in ensuring that the health and social needs of children are met. Subsequently, health care providers are encouraged to focus on providing caregivers of HIV infected children with more support in their care giving roles (Mckerrow et al. 2010 and McKerrow et al. 2006).

The challenge however still exists for caregivers, who are unable to access health and welfare services for themselves and the child, due to the various social and structural barriers experienced (Vreeman et al. 2010)

As a social worker in a health care setting, the concern therefore arose that many HIV infected children were being admitted to hospital for serious and often life threatening illnesses. It was found that in many instances the poor socio-economic experiences of the caregivers of these children, impacted on the child's access to medical care. Respondents cited various socio-economic challenges that prevented them from accessing medical attention for the sick child timeously. This had serious implications for the discharge plan of these children as the social workers at the hospital and within the community, could not ensure that the child was receiving the optimal care when they returned home.

Hence the overall purpose of this study was to understand the experiences of caregivers in the relationship of caring for the HIV infected child. It is envisaged that by understanding the experiences and challenges of caregivers of these children, social workers in the health setting will be better equipped to identify vulnerable children who may be subjected to poor socio-economic circumstances. Subsequently, social workers and health care providers would be in a better position to also plan and provide relevant services to the caregivers for the benefit of ensuring the child's well being.

The summary of the study's findings and conclusions will be presented in this Chapter, under the initial objectives of the study. The researcher also discusses recommendations made based on the findings of the study to the various stakeholders who provide services to HIV infected children.

7.2 OVERVIEW OF THE STUDY

In order to understand the experiences of the caregivers of HIV infected children, a qualitative descriptive research design was chosen to guide the process of the current study. The study sample consisted of 30 caregivers of HIV infected children that were accessing services at a public hospital in Durban, KwaZulu-Natal. The data for the study was collected using semi structured interviews. The researcher used the ecosystems theory to describe and understand the

experiences of caregivers and the challenges that they faced in their care giving roles.

The emerging themes from this study facilitated a discussion on the physiological and psychosocial experiences of caregivers. The caregivers understanding of HIV and ART and their experiences in administering the treatment to the child followed. Chapter six included an analysis and discussion of the caregivers' structural and social barriers to health and welfare services. Finally, the coping strategies and support systems available to caregivers were described. The caregivers' recommendations for improved services were included under analysis and discussions of the various themes and sub-themes.

Chapter seven summarizes the main findings based on the objectives of the study and using the ecosystems paradigm. It is also important to bear in mind that there is a close connectedness between the key themes that distilled from the data analysis, as discussed in detail in chapters five and six.

Secondly, this chapter discusses the caregivers' recommendations for improvement of services; the researcher's recommendations to Social Workers, the public hospital multidisciplinary team (doctors, nurses, physiotherapists, occupational therapists, social workers and dieticians) to government and finally recommendations are made for further research.

7.3 SUMMARY OF FINDINGS AND CONCLUSIONS

This chapter summarizes the findings of the study based on the key objectives.

7.3.1 Objective one was to ascertain caregivers' experiences and their implications for the care of the HIV infected child.

The psychosocial health of caregivers is influenced by their support systems and their ability to provide for the HIV infected child's medical, material and psychosocial needs (Demmer 2011). It is evident from the caregivers' responses

in this study, that there were gaps in the various systems in their lives, which impacted on the actual care of the child. Further findings revealed that caregivers also concentrated more on the health and well being of the child in their care and did not dwell on their own physiological health concerns. Subsequently, respondents minimized their physiological ailments and chose to discuss the health of the child instead. Shebi (2006) asserts that caregivers' avoidance of their own health concerns could be interpreted as a coping strategy that they used in order to direct their energies towards the care giving responsibilities.

Nevertheless, Ogden et al. (2006) argues that caregivers can be consumed in their roles and are vulnerable to illness and burnout as a result, which will eventually impact on the quality of care that they are able to provide. This follows that the majority of the HIV infected respondents in this study were also not accessing ART for themselves, as they focused all their attention on the health of the HIV infected child. This is a serious concern and it is recommended that health care workers and social workers focus interventions on creating awareness of self care for care givers.

On the whole the respondents in this study were open and expressive about their psycho-social experiences, despite them minimizing their own physiological health issues. Furthermore, this study found that often the poor socio-economic experiences of the respondents resulted in their inability to ensure that the health and welfare needs of the child were adequately met. This then impacted negatively not only on the caregivers' psychological wellbeing, but also sadly on the poor health and well being of the child, resulting in a ripple effect of caregivers experiencing feelings of further sadness and fear when the child became ill.

Converse to the majority of the respondents' many negative psychological experiences, it was found that at times they also experienced happiness and a sense of fulfillment in their relationship with the HIV infected child. As consistent with Haney (1988) as cited in Zastro and Kirst-Ashman (2010) most of the respondents may have accepted the HIV status of the child and were therefore able to have a positive outlook for the child's future, which also resulted in favorable psychological outcomes for themselves. The major factors that

influenced the meaningful and rewarding experiences of the respondents in this study were their observations at times of the improved physiological health and growth of the HIV infected child. Consistent with the findings of Kasese-Hara et al. (2008) and Eneh (2010) where it was found that the over reliance of HIV infected children on their caregivers for all their needs, also contributed positively to the caregivers' psychological wellbeing, which also resulted in strengthening the unique bond that was shared between them.

Furthermore, the nature of this shared relationship added quality and fulfillment to the lives of the caregivers and subsequently impacted favorably on the care and wellbeing of the child. Over all it can be concluded that the caregivers and the HIV infected child shared a reciprocal relationship where both individuals benefitted at times, the child by receiving improved health and wellbeing and the caregiver by having a sense of improved self worth and psychological well being.

It was also found that at times the access to health services and the improved health and wellbeing of the child, together with the bond shared contributed to caregivers experiencing a modicum of hope, happiness and fulfillment. This then also resulted in positive outcomes for the care of the HIV infected child.

Overall, one can therefore see the interrelatedness of the various systems and how it impacts on the physiological, psycho-social, and economic experiences of the caregivers' lives, which in turn determines their actions in meeting or not meeting the needs of the HIV infected child.

7.3.2 Objective two was to explore caregivers' understanding of HIV infection and adherence to treatment.

This study found that the majority of the caregivers generally had good knowledge and understanding of HIV and AIDS. Despite not understanding the actual various medication regimens and other medical complexities, they were able to understand the value of ART for the HIV infected child and they were committed to following the treatment process. As consistent with Demmer (2011) the

respondents likened ART to chronic medication that they themselves were taking; this helped them to also encourage the children at times to adhere to treatment by normalizing the disease.

Interestingly, despite at times the caregivers having limited knowledge on the actual medical and pharmacological characteristics of ART, they were able to display good knowledge on the administering of the treatment for the HIV infected child.

All the respondents experienced challenges of some kind, but they were determined to ensure the health and wellbeing of the HIV infected child in their care. This follows that they used innovative methods to ensure that the child adhered to treatment, which included negotiating, bargaining, counseling and providing support in a loving manner. These strategies were helpful when dealing with the older children; however, it became more challenging for respondents when they had to coerce traumatized younger children to take unpalatable medication that they sometimes vomited. This was a serious concern as the majority of the children in this study were 6 years old and younger, which made it difficult for their respondents to reason with them.

Similar to findings in Vreeman et al. (2010) respondents also experienced challenges in disclosing the child's HIV status to others for the purposes of having a second line caregiver. This created stress and worry for them when they considered that they were therefore solely responsible for the treatment adherence and ultimately the life of the child. Vreeman et al. (2010) thus contends that the issues around stigma and discrimination do impact on the respondents' ability or lack thereof to reach out for support.

This is especially of concern when administering the paediatric ART, as the mere survival of the child depends on it and should the caregiver be indisposed for some reason, there would be no one else to ensure the child's treatment adherence.

7.3.3 The fourth objective was to explore and describe existing services, programmes and resources available for caregivers and HIV infected children.

Due to unemployment and poverty respondents were sometimes unable to ensure that the HIV infected children accessed the education system, as they were unable to pay school fees and cover the transport costs of the child to school. This is direct contravention of the Children's Act (41 of 2007) and UNICEF (1990) which asserts that children's rights to education is a basic right (macrosystem). It can be argued however, that education is important, but so are the health and basic needs of the HIV infected child. Respondents in this study thus were stressed by their inability to meet all of the child's needs. They were often in a dilemma as to what required priority as they experienced financial strife.

Additionally, the majority of the respondents depended on child care grants (macro system) but indicated their dissatisfaction with the financial support received from government, as these grants failed to meet all of the HIV infected child's needs. These findings are consistent with Ogden et al. (2006) who also discussed issues of caregivers' economic strife, as impacting on their care giving abilities. Caregivers experienced conflicting emotions about whether to seek employment, or remain in employment as the HIV infected child in their care required extensive medical attention and care at times, which required their full involvement.

The findings revealed that due to respondents' fears of HIV stigma and discrimination; they were reluctant to use more accessible health and welfare services situated within their own communities. Of concern was that, at times respondents struggled to provide the basic necessities of nutrition and shelter for the child, due to unemployment and poverty but they still chose to access services from the hospital and clinic which was further away from their homes. It was found that they subjected themselves to the added cost of travelling out to the public hospital and clinic, because of the satisfactory nature of the services received there, as well as to maintain the confidentiality of the child's HIV status from their community. This correlates with findings of the qualitative study by Vreeman et al. (2010).

These barriers and challenges to service access resulted in exacerbating the health of the HIV infected child, as the child would sometimes be sick for extended periods of time and not have access to health care as the respondents would wait for available funds to travel to the public hospital's clinic.

It was also found that some respondents were able to deal with their challenges based on the level of support they received from their families and communities, whilst others were attempting to provide the best they could for the HIV infected child in the absence of all support. Despite the different circumstances of the respondents they all shared the common purpose of attempting to provide the best possible care for the HIV infected child.

The majority of the respondents perceived the health and social services at the hospital and clinic (exosystem) and their relationship with the health care workers as a positive factor in their lives, which contributed favorably to the life of the HIV infected child as well. Respondents were not keen on accessing health and welfare services within their communities, as they feared disclosure of the HIV status of the child would have negative consequences for the child.

7.3.4 The third objective was to explore the coping strategies of caregivers caring for children with HIV infection.

The majority 18 (60 %) of the respondents described feeling overwhelmed at times with the care giving responsibilities, due to experiences of stress over the health of the child, difficult financial circumstances, pressure of taking care of other family members and demands of the medical treatment required by the HIV infected child.

It was positive to note that the majority 22 (73 %) of the respondents had some form of support, which they commonly identified as friends and family. The respondents in this study used interesting strategies to cope with their challenges. The majority of the respondents described discussions with friends (mezzo system) as helping them to cope with the challenges they faced in the caring process. It therefore can be concluded that the process of confiding in friends

acted as a kind of catharsis for respondents to work through psycho-social challenges (microsystem challenges).

It can also be concluded that the family and friends situated in the mezzo system often served as a means of financial and material support to the unemployed respondent (challenges of the exosystem). In contrast however, despite some respondents receiving support from family members, there were those that had the added burden of having to support their family members financially and materially, which was sometimes done at the expense of the health and welfare of the HIV infected child.

Respondents also mentioned that the exosystem which comprised of the multidisciplinary team (doctors, nurses, dieticians, social workers) at the hospital's paediatric ward and ARV clinic offered them support and gave them a sense of hope for the HIV infected child's future.

As consistent with findings by Vreeman et al. (2010) it was found that the few respondents that reported not having any support, suggested reasons of mistrust, fear, shame, stigma and discrimination as issues that prevented them from reaching out to family and friends.

Never the less, generally it was found that caregivers did have some forms of coping mechanisms that they relied on. The conventional coping strategies were identified as, listening to music, singing, dancing, watching T.V (television), sleeping, exercising, writing poetry or taking the HIV infected child on outings as methods of relaxation and recharging. Some respondents also listed tasks such as cooking and doing house work as well as relaxing only when they sleep as their coping mechanisms. This is concerning as it is clear that these caregivers lack the necessary coping mechanisms that will help them to cope with stress and burn out. Some caregivers also spoke about their issues of spirituality and how they received support from their respective church members. These caregivers believed that their faith and prayer would be a constant support to them. However, it is argued that this form of coping is ad hoc and not sustainable (Shebi 2006).

Respondents expressed a need for the introduction of support groups, at the hospital and within their communities, for the purposes of educating caregivers and as a means of a platform for them to discuss their issues. Respondents also felt that more social workers needed to be employed at ART clinics, not only for the purposes of the psycho-social assessments at the initial phase of the ART but also as an ongoing supportive measure.

7.4 RECOMMENDATIONS

Taking into account the voices of the caregivers, the literature as well as the findings of the study, the following recommendations are made:

7.4.1 Recommendations for Social Work Practice in Health and Welfare

This study recommends that social workers intervene at the micro level (HIV infected child and their caregiver), to provide ongoing supportive services both within their communities and at public hospitals and clinics. Social workers in the health sector are urged to ensure that HIV infected children and their caregivers are provided with information regarding the ongoing care that is needed for the child on discharge from hospital. Finally, it is suggested that these individuals are followed up by the public hospital and or ART clinic social worker, to ensure that they are linked to the appropriate support networks in the community.

Caregivers and HIV infected children experience stress, anxiety and depression on frequent occasions during the course of their interactions with their communities, their families and the health and welfare settings. In keeping with the first and the fourth objective of the study it is therefore recommended that a psychologist be included as part of the multidisciplinary team (doctors, nurses, physiotherapists, occupational therapists, social workers and dieticians), for the purposes of rendering psychological interventions and monitoring to caregivers and HIV infected children.

It is suggested that social workers be creative in planning and implementing support group programmes at the public hospital that would deal with issues of difficulties experienced in ART administration and HIV stigma and discrimination, for caregivers of HIV infected children.

It is recommended that social workers initiate community interaction to deal with issues of HIV and AIDS stigma and discrimination, by encouraging the active involvement of ward councilors and other community leaders together with members of the community.

Social workers in health and welfare departments should further advocate for policy changes so that this population groups' social security issues are addressed and their financial needs are met.

7.4.2 Recommendations for Legislation and Policy Changes

From the study respondents recommended that additional staff should be employed at ART clinics for the purposes of shortening waiting times for treatment. It was suggested that with the increase of clinic staff and social workers, HIV infected children and their caregivers would have ongoing social support, which would lead to more positive outcomes for their psycho-social wellbeing.

It is also recommended that the operational hours of health care facilities like the ART clinic be extended to after normal working hours, to accommodate those caregivers that are in employment or have other commitments during normal working hours.

A further recommendation is for an interdepartmental approach to addressing the needs of vulnerable children with involvement from the health, welfare and education departments (Giese 2003). It is envisaged that with the inter collaboration of services and the pooling of resources, the socio-economic and health needs of HIV infected children and their caregivers would be more efficiently addressed.

7.5 RECOMMENDATIONS FOR FURTHER RESEARCH

In this study the sample consisted of individuals that belonged to the African sector of the population, hence there was no representation of the other race groups within the Durban, KwaZulu-Natal geographic area. It is recommended that a qualitative study, be conducted with a more racially representative sample provincially, within a public health setting, in order to compare the experiences of caregivers on a broader spectrum.

There is a paucity of studies of male caregivers of HIV infected children, it is recommended that a qualitative study, be conducted with male caregivers, so as to add to the growing body of information on caregiver's experiences.

A further recommendation would be for this study to be repeated using a longitudinal triangulated design across provinces in South Africa.

Further qualitative research to investigate the correlates between poverty and care giving of HIV infected children should be conducted.

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APPENDICES

APPENDIX A: INFORMED CONSENT LETTER

The Participant

Dear Sir/Madam

I am Dhashini Ramsamy, a Social Worker, who is currently registered to complete my Masters in Social Work at the University of KwaZulu-Natal (UKZN). The Masters degree in Social Work requires that I submit a Research Dissertation.

The purpose of this study is to understand the experiences of caregivers of HIV infected children who are accessing services from a public hospital. One of the objectives of the study is to explore and describe some of the challenges faced by the caregiver in providing for the HIV infected child. This information will serve to assist Health Care Workers to have a better understanding of the type of services that need to be provided to the caregiver, so that they are better able to manage the care of the HIV infected child.

The sample of the study will comprise of caregivers of the under 5 year old HIV infected child who is accessing services from a public hospital in Durban.

Your participation in this study is voluntary and you may withdraw at any time. You would be required to participate in an interview session with the Researcher, for the purposes of gathering data. We would require your permission to audio tape the interview. The Researcher will make every effort to maintain confidentiality and will ensure that the results of the study's findings are fed back to you.

Kindly complete the consent form below.

Yours faithfully

Dhashini Ramsamy (Mrs.)

Tanusha Raniga (Dr.)

Research Title: Understanding the experiences of caregivers of HIV infected children at a public hospital in Durban.

The research study has been explained to me and I understand what will be required of me, and what will happen to me if I take part in the study.

The Researcher has answered any questions that I may have had about the study and I understand that:

- I may visit the Social Work Department at this hospital or contact Dhashini Ramsamy on 0734320735, I have more questions.
- If I choose to participate in this Research I will be providing information that could improve people's understanding of the experiences of caregivers of HIV infected children in the Durban area.
- My participation in this research is voluntary, and I will not be penalized or lose benefits if I refuse to participate or decide to stop.
- My contribution if I participate in this research will be kept confidential.
- I may withdraw from the study at any time without giving a reason.

1. I agree to take part in the study: YES / NO (circle answer)

2. I agree that I can be tape recorded: YES / NO (circle answer)

Name of Participant: _____

Signature: _____

Date: _____

APPENDIX B: SEMI-STRUCTURED INTERVIEW SCHEDULES

SEMI-STRUCTURED INTERVIEW SCHEDULE IN ENGLISH

INTERVIEW SCHEDULE - CAREGIVERS

1. PERSONAL DETAILS OF CAREGIVERS:

- How old are you?
- Gender?
- Are you married?
- Where do you live?
- Do you have other children in your care? if yes how many? what is their relationship to you?
- Did you go to school? What was the highest grade passed?
- Do you work? If yes what do you do?

2. PHYSIOLOGICAL, PSYCHO- SOCIAL AND ECONOMIC CIRCUMSTANCES:

- 2.1. What are some of your own health problems that you are experiencing?
- 2.2. Tell me about how you feel when you think about taking the child to Hospital or Clinic for treatment?
- 2.3. How do you feel when the child is sick? What are some of the things that you think about at those times?
- 2.4. How would you describe your financial situation? What is your primary source of income?
- 2.5. What are some of the expenses that you need money for on a daily basis?

3. CAREGIVERS' UNDERSTANDING OF HIV INFECTION, HAART AND CHILD CARE:

- 3.1. What do you think HIV infection is? Explain
- 3.2. What do you understand by HAART?
- 3.3. What do you know about the anti retroviral treatment that the child is taking

or going to take in the future?

3.4. Do you think knowing about the child's treatment is important? Why?

3.5. What do you think a child needs in order to grow up as a healthy person?

3.6. What do you think an HIV infected child needs to grow up as a healthy person?

4. SUPPORT SYSTEMS AND COPING STRATEGIES:

4.1. Who else knows about the child's HIV status? Give reasons for your decision to tell or not to tell.

4.2. What is the relationship between you and other people in your family? Explain

4.3. Do you have friends or someone close that you can talk to?

4.4. Do you think that it is important or not, for you to tell people in the Community about the child's HIV status? Why?

4.5. How do people in your community react to HIV infected people? How does this make you feel?

4.6. What are some of the difficulties you experience when you need to medicate or take care of the child? How do you deal with this?

4.7. What are some of the positive experiences of taking care of the child?

4.8. What are some of the activities you engage in to relax?

4.9. Where do you get help from?

5. ACCESS TO SERVICES

5.1. Do you know of any medical and social services that are available to you and the child? explain

5.2. Did you use these services? Explain

5.3. How does having these services in your life make you feel?

5.4. Was it easy / difficult to access these services? Discuss

6. RECOMMENDATIONS:

6.1. What improvements can hospitals, other organizations and Government

make to their existing services that would be beneficial to you and the child?

6.2. What new services would you like, that you don't have now to help make taking care of the child easier?

SEMI-STRUCTURED INTERVIEW SCHEDULE IN ISIZULU

UHLELO LWEMIBUZO LWABABHEKI BEZINGANE

1. IMININGWANE YABABHEKI BEZINGANE:

- 1.1. Uneminyaka emingaki?
- 1.2. Buyini ubulili bakho?
- 1.3. Ingabe ushadile?
- 1.4. Uhlala kuphi?
- 1.5. Zikhona ezinye izingane ozibhekile? Uma zikhona, zingaki? Buyini ubudlelwane bakho nazo?
- 1.6. Ingabe waya esikoleni? Iliphi ibanga noma izinga lokufunda owaliphumelela?
- 1.7. Ingabe uyasebenza? Uma kungu yebo, usebenza kuphi?

2. ISIMO SAKHO ESIMAYELANA NEZEMPILO, EZENHLALAKAHLE KANYE NEZOMNOTHO:

- 2.1. Iziphi izinkinga zempilo ezimayelana nawe uqobo obhekene nazo?
- 2.2. Chaza mayelana nokuthi uzizwa kanjani uma kufanele uhambise ingane esibhedlela noma emtholampilo ukuze iyothola ukwelashwa noma imithi yayo?
- 2.3. Uzizwa kanjani umangabe ingane igula? Iziphi izinto ozicabangayo ngalesosikhathi?
- 2.4. Ungasichaza kanjani isimo sakho somnotho? Ingabe iyiphi indlela ongenisa ngayo imali?
- 2.5. Iziphi ezinye zezizidingo ozidingela imali ngazo zonke izinsuku?

3. UKUQONDA KOMBHEKI WENGANE MAYELANA NOKUTHELELEKA NGESANDULELA NGCULAZI, UHLELO LWE HAART KANYE NOKUNAKEKELWA KWENGANE:

- 3.1. Ingabe ucabanga ukuthi kusho ukuthini ukutheleleka ngesandulela ngculazi?
- 3.2. Yikuphi okuqondayo mayelana nohlelo lweHAART?
- 3.3. Ikuphi okwaziyo ngemishanguzo ethithibalisa igciwane lengculazi ingane eyisebenzisayo noma eyoyisebenzisa ngomuso?

3.4. Ingabe ucabanga ukuthi kubalulekile ukwazi ngemithi esetshenziswa ingane futhi kungani?

3.5. Ucabanga ukuthi ingane yini eyidingayo ukuze ibe umuntu okhula ephile kahle?

3.6. Ucabanga ukuthi ingane etheleleke ngegcwane lengculazi idingani ukuze ikhule ingumuntu ophile kahle?

4. IZINDLELA ZOKUNQOBA INGCINDEZI KANYE NOKUSELELEKA.

4.1. Ubani omunye owazi mayelana nesimo sengane sesandulela ngculazi? Chaza kabanzi mayelana nesinqumo sakho sokwazisa nokungazisi abanye?

4.2. Bunjani ubudlelwane bakho nabanye emndenini wakho? Chaza.

4.3. Ingabe unabo abangani noma umuntu osondelene naye okwazi ukuxoxa naye?

4.4. Ucabanga ukuthi kubalulekile noma akubalulekile ukwazisa abanye abantu emphakathini mayelana nesimo sengane sesandulela ngculazi? Kungani?

4.5. Ingabe abantu emphakathini wakho bababheka kanjani abantu abatheleleke ngesifo sengculazi? Kukuphatha kanjani lokhu?

4.6. Iziphi ezinye zezizinselo obhekana nazo uma kufanele unikeze ingane imithi yayo noma uyinakekele? Ubhekana kanjani nalokhu?

4.7. Yiziphi izinto ezikukhuthazayo ekunakekelani kwakho ingane?

4.8. Iziphi izindlela ozisebenzisayo ukuze uphumule?

4.9. Ingabe ulutholaphi usizo oludingayo?

5. UKUFINYELELEKA KWEZINSIZA:

5.1. Ingabe zikhona izikhungo zezempilo nezezenhlalakahle eziseduzane kwakho nengane? Chaza.

5.2. Ingabe ubuzisebenzisa lezikhungo? Chaza.

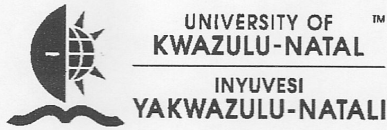
5.3. Ukubakhona kwalezikhungo noma izinsiza kwenza uzizwe kanjani empilweni yakho?

5.4. Ingabe kwakunzima noma kwakulula ukufinyelela kulezikhungo noma izinsiza? Chaza kabanzi.

6. IMIBONO YAKHO NGOKUFANELE KWENZEKE:

- 6.1. Ikuphi obona kufanele kwenziwe izibhedlela, nezinye izinhlango zahulumeni nezizimele kulezinsiza ezikhona ukuze wena nengane nizuze?
- 6.2. Iziphi izinsiza ezintsha ongazithanda ezingekho njengamanje ezingadala ukuthi ukunakekela ingane kubelula?

APPENDIX C: UKZN ETHICAL CLEARANCE FOR RESEARCH



20 August 2012

Mrs Dhashini Ramsamy 9037050
School of Applied Human Sciences – Social Work

Dear Mrs Ramsamy

Protocol reference number: HSS/0556/012M
Project title: Understanding the experiences of caregivers of HIV infected children at a Public Hospital in Durban.

Full approval notification

This letter serves to notify you that your application in connection with the above has now been granted full approval following your response to queries raised by the Humanities and Social Sciences Research Ethics Committee.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number. Please note: Research data should be securely stored in the school/department for a period of 5 years

Best wishes for the successful completion of your research protocol

Yours faithfully

.....
Professor Steven Collings (Chair)
Humanities & Social Sciences Research Ethics Committee

cc Supervisor Dr T Raniga
cc Academic leader Professor JH Buitendach
cc Ms D Hattingh

Professor S Collings (Chair)
Humanities & Social Sc Research Ethics Committee
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban, 4000, South Africa
Telephone: +27 (0)31 260 3587/8350 Facsimile: +27 (0)31 260 4609 Email: ximbap@ukzn.ac.za / snymanm@ukzn.ac.za
Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville



APPENDIX D: DEPARTMENT OF HEALTH ETHICAL CLEARANCE FOR RESEARCH



health

Department:
Health
PROVINCE OF KWAZULU-NATAL

Health Research & Knowledge Management sub-component
10 – 103 Natalia Building, 330 Langalibalele Street
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3200
Tel.: 033 – 3953189
Fax.: 033 – 394 3782
Email.: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

Reference : HRKM85/12
Enquiries: Mrs G Khumalo
Telephone: 033 – 395 3189

04 September 2012

Dear Mrs D Ramsamy

Subject: Approval of a Research Proposal

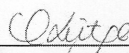
1. The research proposal titled 'Understanding the experiences of caregivers of HIV infected children at a public hospital in Durban' was reviewed by the KwaZulu-Natal Department of Health.

The proposal is hereby **approved** for research to be undertaken at Clairwood Hospital.

2. You are requested to take note of the following:
 - a. Make the necessary arrangement with the identified facility before commencing with your research project.
 - b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

For any additional information please contact Mrs G Khumalo on 033-395 3189.

Yours Sincerely



Dr E Lutge
Chairperson, Health Research Committee
KwaZulu-Natal Department of Health
Date: 04/09/2012

uMnyango Wezempilo . Departement van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope