

**Disclosure of HIV infection by caregivers to children with
HIV/AIDS in Thamaga Primary Hospital- Botswana: Reasons
and Experiences**

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Declaration

I declare that the work presented in this dissertation (“Disclosure of HIV infection by caregivers to children living with HIV/AIDS in Thamaga Primary Hospital – Botswana: Reasons and Experiences”) and hereby submitted to the University of Limpopo, MEDUNSA campus for partial fulfilment of the degree of Masters in Public Health has not been previously submitted for any other degree or qualification at this or any other University; that it is my work in design and execution, and that all resources contained herein has been duly acknowledged by means of complete referencing.

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Abstract

Introduction

With the increased availability of the life-saving ARVs in most Sub-Saharan Africa more HIV-infected children are surviving into their adolescent years and beyond hence giving rise to the question of whether the caregiver should disclose or not disclose the child's HIV diagnosis to child. Little is known of the reasons and experiences that motivate or hinder caregivers from disclosing the HIV diagnosis to the child.

Study Aim and objectives

This was aimed at identifying caregivers' reasons for HIV diagnosis disclosure and non-disclosure to HIV-infected children under their care. The study also explores their experience with process of HIV diagnosis disclosure and non-disclosure to the child.

Study methodology

Using qualitative descriptive research approach, twenty (20) caregivers of HIV-infected children aged between 6 – 16 years receiving ART at Thamaga Primary Hospital IDCC with unknown HIV diagnosis disclosure status were subjected to audio-taped in-depth interviews for data capturing. Thematic content analysis was used for data analysis using Nvivo8 software and 16 themes with their sub categories were identified.

Findings

Both caregivers of disclosed and non-disclosed HIV-infected children perceived disclosure as a good thing to do with majority of the caregivers (60%) having disclosed. Reasons for telling the children their HIV diagnosis were that the child had the right to know his/her status; caregiver tired of keeping child HIV diagnosis a secret; the caregiver's believe that disclosure will improve the child's ART adherence and finally some caregivers felt the child had reached the right age or maturity for disclosure. Non-disclosing caregivers felt that health care workers should assist them in doing disclosure and identified the reasons for non-disclosure as the child being too young and not asking questions about their illness; fear that disclosure might hurt the child psychologically; fear that the child might not keep their HIV diagnosis a secret leading to discrimination in the community while some caregivers lack of knowledge on how to disclose. Non-disclosing caregivers managed disclosure by not telling the child the truth about their diagnosis and using threats to coerce them to take their ARV drugs.

Conclusions and recommendations

The decision to disclosure or not to disclose the HIV diagnosis to a child by a caregiver is influenced by a number of reasons and their experiences. Caregivers of HIV-infected children need to be assisted by a health care provider when disclosing to the child and further assessment should be made in making disclosure part of the holistic management of an HIV-infected child.

List of abbreviation and acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ARV	Antiretroviral
BAIS	Botswana AIDS Impact Survey
DHT	District Health Team
DMSAC	District Multi-Sectoral AIDS Committee
HIV	Human Immunodeficiency Virus
IDCC	Infectious Disease Care Clinic
MCREC	Medunsa Campus Research and Ethics Committee
MTCT	Mother to Child Transmission
NACA	National AIDS Coordinating Agency
PLWH	People living with HIV
QoL	Quality of Life score

List of Operational Definitions

Disclosure: Where the caregiver said that the child knows his/her HIV diagnosis. As such caregivers who have disclosed the child's HIV positive status to the child will be those who have perceived that the child already knew their HIV diagnosis.

Non-disclosure: Where the caregiver said that the child does not know his/her infection or where the caregiver was unsure if the child knew his/her status.

Caregiver: A person, who lives with the child, participates in the child's daily care and is the most knowledgeable about the child's health. They were either biological parents or guardians like aunt, adoptive parent acting as surrogate parents to the child.

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Chapter 1: Introduction and Background

1.1 Introduction

With more than three decades since Human Immune Deficiency Virus (HIV) was first discovered the AIDS pandemic still proves to be a major challenge to the world's health care delivery system as HIV/AIDS prevalence continues to rise thus stretching the limited health resources in most countries. According to UNAIDS Report, (2010) there were 33.3 million people living with HIV by the end of 2009 compared with 26.2 million in 1999, 27% increase in ten years. The care of children living with HIV infection worldwide has become an area of concern for most health care providers and caregivers, as the number of HIV-infected children also continues to grow. According to the UNAIDS Report, (2010) by the end of year 2009 the cumulative number of children with HIV worldwide stood at 2.5 million with Africa being the hardest hit continent accounting for 70% of all the HIV pediatric population. An estimated 430 000 children worldwide were newly infected with HIV in 2008 and over 90% of HIV-infected children live in sub-Saharan Africa(UNAIDS, 2009). Globally the majority of children who are HIV positive are infected through mother-to-child transmission (MTCT). From the estimated 430 000 new HIV infections which occurred in infants and children in 2008, 90% were acquired through MTCT (WHO et al., 2009; WHO, 2010).

The absence of HIV prevention interventions in the care of the HIV positive mothers during: pregnancy, labour, delivery and post delivery as is the case in most African countries or developing countries is blamed for this high rate of HIV infection in children. Data shows that without any intervention, the risk of MTCT of HIV is common and it is estimated that 15 to 30% of HIV positive mothers will transmit the infection to their infants during pregnancy and delivery, with an additional 10 to 20% transmission occurring through breastfeeding (Ferrand, et al., 2010; Rosenberg,

2007). It is important to note that this high population of HIV-infected children will not decrease anytime soon as more children born HIV positive are now being able to survive up to adolescence and beyond (WHO, 2010). This is largely due to the advent of antiretroviral therapy (ART) which was introduced in the late 1990's in most Africa states source. Data shows that the clinical benefits of effective use of ART is that children with HIV experience fewer opportunistic infections and lower risk of disease progression (Biadgilign, et al., 2009; Ferris, et al., 2007). Furthermore access to ART resulted in many HIV infected children who were not expected to survive childhood entering adolescence and young adulthood, increasing the population of children living with HIV as a chronic illness (Butler, et al., 2009; Wiener et al., 2007b). The availability of ART has remarkably improved the life expectancy of HIV-infected children from low rates of below 8 years to encouraging ages of 13 years and above thus giving rise to a demand in their management as they grow and mature (Lesch, et al., 2007).

1.2 HIV Prevalence in Botswana

Botswana is located in the Sub-Saharan African region. According to the Botswana Government Census Report, (2005) Botswana has a population of approximately 1.8 million people and it is one of the countries which are still grappling with the AIDS epidemic as it has one of the highest national HIV prevalence rates in the world at 17.6% and a total of 89 000 children infected with HIV (Botswana AIDS Impact Survey III Report, 2010). This accounts for 9% of the HIV positive population in Botswana. Studies have shown that MTCT of HIV is responsible for the majority of HIV infections in the pediatric population when inference is drawn from the Ante natal sentinel surveys (Nehring, et al., 2000). According to National AIDS Coordinating Agency (NACA) Annual Report, (2001) a HIV Sentinel Survey on pregnant women and men with sexually transmitted infections in the year 1992 estimated the HIV prevalence rate to be 18% among pregnant women, the report

went on to record a sharp rise to 36% HIV prevalence rate in the year 2001 among pregnant women in the 22 health districts in Botswana. Because of limited interventions in prevention of mother to child transmission (PMTCT) of HIV at the time, a significant proportion of children were infected through MTCT giving a corresponding rise in the HIV pediatric population in the country. By the end of the 2008 there were over 3 600 HIV-infected children in the Kweneng East District (Kweneng East DMSAC Quarter 4 report, 2008).

Indications are that the number of children with HIV will for sometime increase as the country still continues to experience new infections in babies born to HIV positive mothers. This has been highlighted by the BAIS III Report, (2009), where there were 890 new HIV infections in children aged 14 years and below in the year 2007 alone. With this increase in the pediatric population in Botswana as well as the life expectancy of babies born with HIV infection, this gives rise to challenges such as HIV diagnosis disclosure by caregivers and health care professionals to children as they mature.

1.3 HIV Disclosure in children

Because of the remarkable developments about the availability of life saving ART highlighted in the above paragraph that children with HIV can now live longer, certain issues that were not present when the life expectancy of children with HIV was very low have now come up and need serious attention (Lesch, et al., 2007). One of these issues is the disclosure of the child's HIV diagnosis by their caregivers or health care providers. There is a general consensus among researchers in paediatric disclosure that as the population of HIV infected children on ART matures the issue of disclosure of diagnosis becomes more significant (Myer, et al., 2006, Oberdorfer, et al., 2006, Rujumba, et al., 2010). In this context, HIV diagnosis disclosure in children refers to the caregiver's perception of having told the children about their HIV

diagnosis regardless of whether they told the child specific information that the child is HIV-infected or has AIDS.

With increased survival, pediatric disclosure has come up as one of the greatest psychosocial challenges that parents and caregivers of peri-natally HIV-infected children face as HIV diagnosis disclosure entails communication about a potentially life threatening, stigmatized and transmissible illness hence many caregivers fear that such communication may create distress for the child or even potentially damage caregiver-child relationship (Ostrom, et al., 2006). Certainly as HIV-infected children grow their caregivers are faced with this challenging task of making the child aware of their HIV diagnosis and this has now come up as an important issue in the care of HIV-infected children which has for a long time been ignored by both caregivers and health care providers (Nehring, et al., 2000).

Despite the importance of pediatric HIV diagnosis disclosure, there has been surprisingly little research done on it particularly in Sub-Saharan Africa which is home to most of the HIV-infected children world-wide WHO 2010 source. However, the little research carried out show that rates of disclosure seem to be low in Africa and internationally with data from United States of America suggest that less than half of HIV infected children have been disclosed to (Flanagan-Klygis, et al., 2002; Lipson, 1993). Similar findings were reported in less developed countries, a study by Boon-Yashidhi, et al. (2005) in Thailand showed that only 19.8% of the caregivers reported to have disclosed the HIV diagnosis to their child; while Bikaako-Kajura, et al. (2006) in Uganda report that only 29% of the caregivers had explained to the child about the child's HIV infection and the relationship between their HIV disease and their medication.

1.4 Reasons for disclosure

What has come out from most literature is that caregivers report that they are reluctant to disclose the HIV diagnosis because of a wide variety of reasons like the caregiver belief that the child is too young or still immature to fully comprehend what being HIV –positive means (Ledlie, 1999; Weiner, et al., 1996). What should however be taken into consideration is the fact that unlike HIV infected adults, HIV -infected children usually have little control over who, when and how they are informed of their status, as their caregivers control the flow of information about their HIV status to them and others hence this then presents a big challenge to caregivers and healthcare workers around disclosure, including deciding on what is in the child’s best interest and when and how information about his/ her HIV status will be shared with the child (Lesch, et al., 2007).

This has given rise to a situation where some caregivers fail to disclose due to some reasons while. A study by Oberdorfer, et al. (2006) shows that disclosing the diagnosis of an HIV infected child by his/her caregiver can be an emotionally charged issue as some caregivers will struggle to disclose due to various barriers such as fear that disclosure might have negative psychological consequences on the child Other reasons also thought to be responsible for preventing most caregivers from disclosing the child’s HIV diagnosis include the fear that HIV disclosure will negatively affect the child’s will to live; fear that the child might express anger at the parent for infecting them; the caregiver may also feel guilty over transmission of the infection to the child; the fear that the child will disclose his or her HIV- diagnosis to others; the caregiver’s own difficulty in coping with their disease and denial that the caregiver or parent are HIV infected (Lester, et al., 2002; Funck-Bretano, et al., 1997; Weiner, et al., 1996; Oberdorfer, et al., 2006; Weiner, et al., 1996). In some cases, caregivers do not disclose because of lack of knowledge and skills on HIV pediatric disclosure (Rwemisisi, et al., 2008).

1.5 Benefits of disclosure

Studies have shown that caregivers and health care providers believe that disclosure benefits both children and their caregivers (Domek, 2010; Oberdorfer, et al., 2006)

One of the reasons caregivers disclose HIV diagnosis to children is that HIV serostatus disclosure positively influences adherence to ART for some HIV-positive children (Biadgilign, et al., 2009). It also enables children to understand HIV infection and to make sense of disease-related experiences and the importance of adherence (Kallem, et al., 2010, Waugh, 2003). Furthermore, as children reach adolescence and begin risk-taking behaviors, knowledge about their disease becomes essential for both personal health maintenance and HIV prevention within the larger population (Butler, et al., 2009). Another important benefit of disclosure is that, has shown to have positive effects on the clinical course of the disease and has important implications for the success of HAART (Ferris, et al., 2007; Kallem, et al., 2010; Oberdorfer, et al., 2006)

1.6 Consequences of non-disclosure

There is some evidence to suggest that non-disclosure may negatively affect HIV positive children. Data shows that lack of disclosure may impair treatment understanding and participation and it may also increase psychological and behavioral problems. Moreover lack of disclosure may lead to social and emotional isolation (Instone, 2000; Lester et al., 2002). Nondisclosure is also associated with anxiety and depression, in addition to being excluded from social support. If not disclosed to, adolescents may experiment with risky sexual and drug-use behaviours, which in turn may result in further transmission of the virus (Gray, 2010).

1.7 Overview of HIV Disclosure to children in Botswana

Based on the clinical experience from Scottish Livingstone Hospital ART clinic in Botswana it has been found that most caregivers are not disclosing to their HIV-infected children. The concern of health care professional in paediatric care is that despite caregivers not disclosing the HIV diagnosis to children, they eventually know of their HIV diagnosis and in most cases by accident like their friends teasing them about their illness or through reading about their illness and medication in books or seeing it on television or other media of communication which in-turn can result in negative psychological impact on the child and as well as create strain on the caregiver-child relationship and ultimately hinder child's acceptance of his/her HIV diagnosis.

1.8 Statement of the problem

Literature and clinical experience in ART clinics show that HIV diagnosis disclosure is rarely done by caregivers to HIV-infected children in Botswana and in other resource limited settings and this is despite children in Botswana having access to ART since 2002 (Botswana AIDS Impact Survey Report 2009). This is against evidence from studies conducted mostly in well developed countries where it has been found that telling children about their HIV diagnosis can have positive psychosocial and clinical outcomes (Vaz, et al., 2008). There is a general consensus among researchers that caregivers especially in developing countries like Botswana remain reluctant to disclose the HIV diagnosis to HIV infected children furthermore, little is known about pediatric HIV disclosure in sub-Saharan Africa and about the complex issues of when and how to tell a child about the HIV diagnosis (Vaz, et al., 2010).. Where data on disclosure of HIV diagnosis to children is available, disclosure rates remains low, particularly in less developed countries. According to Moodley, et al., (2006) in the context of the scale-up of HIV treatment services in developing countries, greater attention to issues of disclosure of HIV status to infected children

may contribute to the improved quality of long-term care for this vulnerable population.

It is therefore imperative that we understand the reasons and experiences of the caregivers during HIV diagnosis disclosure and non-disclosure to children in the context of the cultural setting of Botswana.

1.9 Aim of the study

This study will identify reasons for HIV positive diagnosis disclosure and non-disclosure by caregivers to HIV-infected children and also study the experiences that caregivers went through during HIV positive diagnosis disclosure process to their children.

1.10 Research questions

1. What are the reasons for disclosure of HIV diagnosis to HIV-infected children by caregivers?
2. What are the reasons for non-disclosure of HIV diagnosis to HIV-infected children by caregivers?
3. What are the caregivers' experiences with disclosure of the HIV diagnosis to their HIV-infected children?

1.11 Research Objectives

1. To explore the reasons for HIV diagnosis disclosure by caregivers to HIV-infected children.
2. To explore the reasons for HIV diagnosis non-disclosure by caregivers to HIV-infected children.
3. To describe the experiences of caregivers with HIV diagnosis disclosure to their HIV-infected children.

1.12 Significance of the study

- The findings of this study will help develop knowledge on reasons for HIV diagnosis disclosure and non disclosure by caregivers of HIV-infected children and lay foundation for further research on this issue.
- Furthermore the study findings will also be used for intervention purposes in the management of HIV-infected children particularly in the development of culturally relevant pediatric HIV diagnosis disclosure guidelines in ART clinics in Botswana.
- The study will contribute to answering some of the questions related to disclosure of the HIV diagnosis to children in view of the growing number of children living with HIV and who are also taking antiretroviral treatment.

Chapter 2: Literature review

2.1 Introduction

The global epidemiology of pediatric HIV has changed in recent years with the prevalence of children living with HIV reaching a steady rise coupled with a significant decline in HIV related morbidity and mortality rates among HIV-infected children. In fact, this development has also been observed in most developing countries as well, as there is a growing availability of ART in many resource limited countries found in Africa and Asia hence more children infected through MTCT are surviving to middle childhood and some to adolescence (Peralta, et al., 2007). These positive achievements are however accompanied by numerous challenges which if left unattended to have a potential of reversing the gains made in the management of children with HIV (Mialky, et al., 2001). Among the pressing challenges which need attention is the issue of pediatric HIV disclosure. As more and more children live into adolescence and beyond as highlighted above, the questions of when, how and what to disclose to the child about their HIV positive diagnosis has proved to be a complex issue to be addressed by most caregivers and health care providers (Ledlie, 1999). However in this third decade of HIV/AIDS, questions related to paediatric HIV disclosure and the management of sensitive disease-related information have become salient within the paediatric population (Ledlie, 1999).

2.2 Overview of HIV diagnosis disclosure in children

As early as 1999, the American Academy of Pediatrics Committee recommended that school aged children and adolescents with HIV be informed about their diagnosis (Committee on Pediatric AIDS, 1999). According to Mialky, et al., (2001) at the time the recommendations were made, children who were perinatally infected with HIV in the early 1990s were attending public schools in the USA in larger numbers than ever before. However, caregivers in well developed and less developed settings remain reluctant to discuss a child's HIV infection with the child

(Mellins, et al., 2002). One of the major difficulties when the person being disclosed to is a child is that one is dealing with many layers of disclosure: disclosure of HIV diagnosis to the child; the concomitant disclosure of HIV diagnosis of the parent/s and other siblings or other family members; and having to anticipate the child's own disclosure to his/her friends, extended family and community (Naeem-Sheik and Gray, 2005). The other thing that makes disclosure to children complex is the social stigma and life-threatening nature of HIV infection, parental guilt over perinatal transmission, or loss of another family member to AIDS makes disclosure difficult for many parents and caregivers (Instone, 2000; Lesch, et al., 2007)

2.3 Benefits of HIV diagnosis disclosure

Over the three past decades of HIV and AIDS existence, HIV voluntary counselling and testing programmes by health care workers from resource-limited settings paid little attention to HIV disclosure to HIV-infected children, thus this resulted in limited access to pediatric HIV/AIDS testing and treatment thus resulting in most HIV-infected children dying at a very early stage of their lives (Lesch, et al., 2007). Furthermore, delayed HIV diagnosis in children resulted in most discussions about children living HIV to center around death and grief being more appropriate than HIV disclosure (Instone, 2000). Though most scholars don't dispute the importance of HIV pediatric disclosure in the lives of both the child living with HIV and their caregivers, some have found that there is little impact that pediatric disclosure will have on the improving the quality life of children living with HIV. A study by Butler, et al., (2009) observed that HIV disclosure in children does not significantly change health-related quality of life (QoL) scores but however cautions that HIV diagnosis disclosure to children with HIV should not be delayed because of fear of a negative impact on QoL in future i.e. there were no other significant changes in mean domain scores based on comparing the last undisclosed to first disclosed visit

or comparing the first undisclosed to the last disclosed visit, with all of the changes within 0.7 points.

However a strong body of knowledge recommends that HIV pediatric disclosure should be done as it is vital that the child knows about their status and management of HIV/AIDS (Butler, et al., 2009). In fact there is no evidence to suggest that disclosure negatively affects HIV-infected children. There is however some evidence to suggest that non-disclosure may negatively affect HIV-infected children, when analysing children's drawings and stories, Instone, (2000) uncovered feelings of loneliness, sadness and fear among HIV-infected children who reported that, despite not being told of their diagnosis, they were aware of it but sensed that they could not openly discuss it with their parents. This is particularly important for HIV-infected children on lifelong ART as treatment adherence will ultimately become the responsibility of the child or young adult later in life (Instone, 2000).

Another important benefit of pediatric disclosure is that it offers caregivers or health care providers an opportunity to counsel HIV positive preteens or teenagers on their sexual activity with the aim of deterring them from spreading the virus or getting re-infected unknowingly and this is further validated by findings from a study done by Lester, et al. (2002) which found that teenagers with HIV interviewed expressed anxiety about the future, particularly about whether they should make the effort to attend school or if they could have sex or become parents.

2.4 Caregivers' reasons for disclosure

Caregivers who decide to disclose the HIV positive diagnosis to their HIV-infected child cite many reasons for this decision including the following findings from a cross-sectional study by Lester, et al. (2002) which was based on parent interview, child cognitive testing and medical records identified parental communication style, parental illness, child rights, treatment adherence and health care provider pressure

as one of the main reasons which influence caregivers to disclose to children living with HIV/AIDS. Another study by Ostrom, et al. (2006) found that the most strongly endorsed reasons for HIV positive disclosure to HIV infected children included wanting the child to hear the diagnosis from the mother, that the child had a right to know, wanting the child to know what was wrong with the mother and wanting the child to prepare for what might happen in future and the study further found that overall (95%), women did not regret disclosing their children.

Other studies found that caregivers who disclose early tend to be HIV negative and have older children while some caregivers reported greater satisfaction with their social support system and have greater family expressiveness as being the reason why they chose to disclose.

2.4.1 Child's age and cognitive ability

Based on findings from several studies, age remains the strongest predictor of whether or not the child has been disclosed to. Parents generally view children below the age of five years as too young for disclosure of HIV status, and children over the age of twelve as old enough for HIV disclosure (Funck-Bretano, et al., 1997; DeMatteo, et al., 2002). In a study by Lester, et al. (2002) among caregivers of children with HIV, only 46% of the children aged 6–10 years had been disclosed to whereas only 43.1% of all study children had been told about their HIV diagnoses by both parent and medical provider report. A child's IQ has also been linked with HIV disclosure in children by their caregivers, children with lower IQ scores were less likely to have experienced HIV disclosure hence the choice of adolescence by most caregivers as an optimal time for disclosure as they feel the children may relate well with the information cognitively (Mellins, et al., 2002). Ironically some children who have been disclosed to felt their disclosure was done at the right time and even young ones had no regrets with being disclosed to at a young age but only felt the

child would only really understand what HIV is when they are 11 years of age or older (DeMatteo, et al., 2002)

2.4.2 Opposing or tiring of secrets

Research shows that most caregivers who have disclosed to their HIV-infected children feel the practice of keeping the child's HIV diagnosis a secret to be an emotionally burdensome thing thus forcing them to disclose as a way of relieving themselves off the pressure of keeping secrets from the child (Flanagan-Klygis, et al., 2002). This was also found in a study by Wiener, et al. (2007), where caregivers who disclosed experienced lower maternal depression and better quality of parent-child interactions after disclosing to the child.

Furthermore, keeping the child's HIV diagnosis a secret can be detrimental to the child's psychological being as undisclosed children who are on ARV medication may develop fantasies about their illness or treatment out of curiosity and end up learning about their HIV diagnosis inadvertently. This is further confirmed by Bhattacharya, et al. (2010) where the commonest reason for disclosure reported by the caregivers of children living with HIV 42/60 (70%) was fear that the child may come to know of his HIV positive status from other sources and that such information may not be accurate hence caregivers would decide to disclose in order to prevent that from happening.

2.4.3 Believe that the child has a right to know their health status

Though acceptance of an HIV positive diagnosis still remains a challenge for both children and adults, some caregivers of HIV-infected children believe the child has the right to know about their HIV positive diagnosis. Most mothers feel that once the child knows his/her HIV positive status they will learn to accept and live positively with their HIV diagnosis. A study by Moodley, et al. (2006) found that 98% of caregivers said they felt that the child has a right to know his/ her HIV status. While

in a study by Vaz, et al. (2008) a large majority of caregivers who had disclosed to their children responded that it is better if the children know what they are suffering from as they felt that once the child knows their HIV diagnosis they could now protect themselves and others from HIV infection.

2.4.4 Hope that disclosure will improve medication adherence.

There is believe by most caregivers that telling the HIV-infected child about his/her HIV diagnosis will influence them to better understand their illness and further influence them to comply with their treatment regimen. A study by Irvine, et al. (2003) among caregivers of HIV-infected children found that children's awareness of their illness was presented as a factor for acceptance of medications and a determinant of access to certain kinds of peer support and HIV-related resources. While a study by Vreeman, et al. (2010) using focus group discussions among caregivers and adolescents found that caregivers were motivated to disclose as they believed that disclosure might have benefits such as improved ART adherence, especially for older children and better engagement of a helping social network. The HIV-infected child's refusal to adhere to ARV medication and clinic appoints has in some cases forced caregivers to disclose to the child with the hope that this will improve the child's adherence (Kallem, et al., 2010).

2.5 Caregivers' reasons for non-disclosure

Though most pediatric HIV/AIDS management clinicians strongly advocate for caregivers of HIV-infected children to disclose to the child, majority of caregivers are still lagging behind in disclosing. The decision not to disclose by caregivers is mostly influenced by a number of reasons which can be caregiver, healthcare provider or child orientated. A number of studies found that most caregivers did not disclose due to fears of stigma, lack of knowledge and skills of disclosing, emotional unpreparedness. The authors argue that caregivers may be reluctant to disclose to

their children because of their own anxieties about having to answer questions about their own infection and how the disease entered the family. Furthermore caregivers may be reluctant to disclose because the child is too young and might be psychologically harmed (Kouyoumdjian, et al. 2005; Boon-Yashidhi, et al. 2005; Wiener, et al. 2007).

2.5.1 Child is too young

Most caregivers who haven't disclosed the HIV diagnosis to the child often state that their main reason for non-disclosure is that they believe the child is still too young to understand the nature of a terminal illness like HIV and AIDS. A study by Lester, et al. (2007) among parents of children infected with HIV who have not been disclosed, found that 75% of caregivers of children younger than 6 years of age reported concern about the child's inability to understand both HIV and AIDS and death-related information, consequently chose not to disclose the HIV diagnosis to the child. These findings were further supported by a cross-sectional study by Oberdorfer, et al. (2006) where the study discovered that all children who were 16 years old and above knew their HIV status whereas only 37% of children who were younger than 10 years knew their status. Data shows that caregivers generally view children below the age of five years as too young for disclosure of HIV diagnosis and children over the age of twelve as old enough to be informed of their diagnosis (Funck-Brentano, et al., 1997). This suggests that the child's age has a great influence in the caregiver's decision to disclose the HIV diagnosis to HIV infected children

2.5.2 Child is not asking questions

As one of the reasons for non-disclosure, caregivers often cite the excuse that children are not ready for disclosure because they have not been asking any questions about their illness hence they assume children are not interested in knowing about their illness. Data shows that caregivers often delay or conceal

disclosure and cite the excuse that children are not ready for disclosure because they have not been asking questions. The authors further argue that caregivers are often unaware of children's questions and concerns following full disclosure (Domek, 2010, Vaz, et al., 2010). It has however been observed that children may decide not to ask questions about their illness because have already seen family members die and can associate their own infection with the disease that took the lives of these relatives (Domek, 2010). However, Lester, et al. (2002) found that some non-disclosing parents say that the children had not asked any questions about their illness or that they had not yet become ill so any discussion of illness or infection was unnecessary.

2.5.3 Do not want to upset the child

Another reason that hinders caregivers from disclosing to their HIV-infected children is their desire to protect children from harmful information as they feel they don't want to upset the child by telling them that they are living with a life threatening infection like HIV in fact some caregivers often feel HIV diagnosis disclosure might lead to negative psychological consequences to the child in the event they learn that they have an incurable deadly disease (Kouyoumdjian et al., 2005; Biadgilign, et al., 2011). Lester, et al. (2002) found that some parents who admitted non-HIV status disclosure to their child viewed telling a child about the HIV infection as an automatic death sentence, others worried that the child would fall out run away, give up all hope, or simply die from grief.

Contrary to what non-disclosing caregivers think about disclosure, non-disclosure may even contribute to poor psychosocial adjustment for the child (Instone, 2000). A study among HIV-infected children with a mean age of 8.9 (range 6–11) who knew their diagnosis reported significantly lower scores on depression and anxiety measures than children who did not know their diagnosis (Butler et al., 2009; Wiener et al., 2007).

2.5.4 Child cannot keep a secret and fear of parental disclosure

Some caregivers avoid disclosing to their HIV-infected children because they fear that the child will not be able to keep their HIV diagnosis secret (Ostorn, et al., 2010). Some caregivers fear that the child might accidentally reveal his/her HIV diagnosis and that of the caregiver and other family members to their friends. Caregivers are fearful that accidental disclosure may expose the family to stigmatization and being ostracized by the community (Waugh, 2003, Wiener, et al., 2007b; Biadgilign, et al., 2011). Therefore the anticipated negative consequences related to stigma by most caregivers may cause caregivers to delay or prevent disclosure (Kallem, et al., 2010). Ostorn, et al. (2006) found a statistically significant correlation between fear that the child cannot keep their HIV diagnosis secret and fear of stigma that might come with the community knowing about the child's HIV diagnosis. HIV related stigma and discrimination remains a challenge in most communities such that going public about HIV status has often resulted in being ostracized. Domek, et al. (2010) found that HIV/AIDS is perceived as being associated with deviant sexual and drug-related behaviors, and parents may fear having to explain to their children how they became infected.

2.5.5 Caregiver does not know how to initiate the disclosure process

Most caregivers often struggle with the details of when and how to begin telling the HIV-infected child about their HIV diagnosis and this has in a way prevented most caregivers from disclosing the child's HIV diagnosis despite having the desire to do so. Rwemisisi, et al., (2008) found that Ugandan parents often delayed disclosure to children for lack of skills and guidance about how to approach such a sensitive topic. Not having enough information to explain the diagnosis or their inability to explain the illness accurately was identified as some of the reasons caregivers struggle with how to disclose the HIV diagnosis to children. South African, caregivers reported that they did not know enough about HIV to be able to explain it to their children or

answer questions that children may ask (Kouyoumdjian, et al., 2005). Consequently most caregivers want doctors to be involved in helping them to disclose the HIV diagnosis to their children (Moodley, et al., 2006).

The study further found that of the caregivers who had not discussed disclosure of the child's HIV diagnosis, 96% stated that they would like to be the ones to disclose to their HIV-infected children. Though several studies have reported that majority of caregivers see themselves as primarily responsible for disclosing the HIV diagnosis to their children, most expressed the need to be supported in the disclosure discussion by health care providers (Kouyoumdjian, et al., 2005, Moodley, et al., 2006, Myer, et al., 2006, Oberdorfer, et al., 2006, Vaz, et al., 2010). Similarly Kalleem, et al., (2010) reports that caregivers felt that formal training in counselling and disclosure was critical in order to enable them to be equipped enough to do disclosure. The study further recommends that professional support by healthcare and social service providers in preparing families and more formal guidelines for both families and providers have been suggested as important means to improving disclosure to HIV-infected children.

2.6 Child's reaction to disclosure

By its nature as a dreaded disease, HIV diagnosis disclosure to HIV-infected children results in a wide variety of negative feelings about the illness as HIV/AIDS is commonly associated with fears of getting sick and dying as well as stigma and worries of how one got infected. Caregivers who have disclosed the HIV diagnosis to children reported that the most frequently reported emotional responses to the initial HIV disclosure process were: neutral or no response, sadness, confusion, hope and worry, crying, anger, symptoms of anxiety and depression (Dematteo, et al., 2002; Mellins, et al., 2002; Vaz, et al., 2010).

In studies conducted with children, when children were asked if knowing about HIV ever made them feel sad or upset, most (87%) said that it did, with some children reporting that the sad feelings never went away. Furthermore, children reported that knowing about their HIV diagnosis made them fear that they would become sicker (DeMatteo, et al., 2002; Vaz, et al., 2008). Interestingly, some children displayed both sad feelings and feelings of relief that they now know what is wrong with them. Children described feelings of being heartbroken or sad immediately upon learning their HIV status at the same time, reported being relieved to have a name to put to their suffering (Vaz, et al., 2002). There is however evidence that feelings of anger, sadness, nervousness, inquisitiveness, worrying, and crying that normally occur after disclosure become less common over time (Blasini, et al., 2004).

2.7 Strategies to manage disclosure

As highlighted above, HIV diagnosis disclosure remains a complex issue to most caregivers such that even caregivers who have not disclosed are constantly struggling with managing the un-disclosed child. Research has shown that as a way of managing disclosure caregivers are using a number of strategies. According to (Ledlie, 1999) these strategies are practiced with the goal of either keeping the secret, limiting information, or disclosing the diagnosis. A number of studies reported on the use of deception in disclosing HIV diagnosis to children (Wiener, et al., 1996; Funck-Brentano, et al., 1997; Oberdorfer, et al., 2006). Caregivers used various methods of deception in telling the children about their illness, such as hiding the HIV diagnosis behind other conditions unrelated to HIV illness (Funck-Brentano, et al., 1997). Deception often entailed caregivers, frequently out of concern for the child's psychological well-being, telling their children only about a co-morbid condition (e.g. asthma, cancer), and attributing all medical needs (e.g., appointments, medication) to that less stigmatized condition (Wiener, et al., 2007; Vaz, et al., 2010).

Vaz, et al., (2010) found that before being told their HIV diagnosis, children knew they were sick and suffering from multiple symptoms but were only told to keep drinking their medication as they would be cured one day. Literature shows that Caregivers often used coercion to persuade children to continue drinking their medication. Hejoaka, (2008) found that some mothers in her study used the threat of death to persuade their children to take their medication. Bikaako-Kajura, et al. (2006) also reported that non disclosed caregivers often needed to apply a combination of force and persuasion to get their children to adhere to the regimen.

2.8 Who should tell the child?

Disclosing the HIV diagnosis to the HIV-infected child can be an emotionally charged experience for whoever is doing the disclosure as they are the ones to deal with the child's reactions to disclosure first hand. Because of the immense responsibility that comes with telling the child about their potentially life threatening illness caregivers feel they and the health care providers are the ones best placed to do the disclosure. In fact a study by DeMatteo, et al. (2002) found that HIV-positive adults were more likely than those who were negative to feel they were the best person to disclose as they felt they could easily relate with the child's HIV infection.

In studies by Biadgilign, et al. (2011) and Vaz, et al. (2008) caregivers revealed that they would like the doctor or nurse to hold disclosure preparation activities prior to the disclosure and they wish the preparations would include talking to responses to questions the child might ask during disclosure which the caregiver might not be having knowledge on. When interviewing clinic providers, Kallem, et al. (2010) found that Seventy-eight percent clinic providers interviewed said disclosure should be done by the caregiver and 18% of them said it should be done by both caregivers and clinic providers. However, when caregivers who had not yet disclosed were

asked the same question, nearly a third of them wanted to defer disclosure to the clinic personnel.

CHAPTER 3: MATERIALS AND METHODS

3.1 Introduction

This chapter presents the study methodology and materials used for data collection and analysis. In this chapter the methods and materials used in the study including study design, study population and study setting, sampling, data collection methods, recruitment procedure and data collection procedure, data analysis and ethical consideration are outlined. Furthermore the strategies used to ensure trustworthiness are explained. This chapter further discusses ethical consideration observed in this study.

3.2 Study Design

The study employed an exploratory qualitative approach using in-depth interviews to collect data among caregivers of HIV-infected children. The focus of the research was on everyday lived experiences of caregivers about HIV disclosure, which could only be obtained from those who lived such experience which in this case is the experience of HIV diagnosis disclosure to a child infected with HIV.

3.3 Study setting

The study was conducted at the Infectious Disease Care Clinic (IDCC) in Thamaga Primary Hospital. The clinic offers comprehensive ARV treatment to adults and children infected with HIV. Most the patients at the clinic were drawn from Thamaga village and its catchment areas. Thamaga village is located is in the southern part of Botswana about 85km from Gaborone (the capital city of Botswana), in the Kweneng South Sub-District. The village also serves as the headquarters for Kweneng South Sub-District and has a total population of 18 117 people, comprising of 7884 males and 10233 females (Botswana central statistic report, 2009). The hospital is one of the only two hospital-based ART treatment centers in Kweneng

District and also has five ART satellite clinics which fall under the management of the District Health Team. The hospital ART clinic services a total of 1 580 patients on ARV treatment of which 82 were children aged between 5 and 19 years. (Thamaga Hospital ART Quarterly Report July 2010). The hospital has a patient information data management system called MASA that enables the capturing and retrieval of relevant patient information with some degree of accuracy and reliability.

So as to ensure smooth running of the clinic and increase focus on the management of HIV/AIDS in children, Thursdays of every week are reserved for HIV-infected children taking their ARV medication at the clinic. Hence this site was selected as it is convenient to the participants as it is the place where they bring their children who are on ART for medical check up as per their Thursday bookings. Though the clinic was small and busy the researcher was given one free doctor's consulting room when the clinic was not busy. In cases where all doctor's consulting rooms are occupied the researcher had to use a Pap smears room to conduct the interviews and had to alternate using the room with the nurse doing Pap smears if she had clients.

3.4 Study population

Study participants were primary caregivers of children infected with HIV enrolled on ART program at Thamaga Primary Hospital IDCC/ART Clinic. The target population was all caregivers of children infected with HIV attending the ART pediatric clinic and falling within the aged bracket of 6- 16 years irrespective of their race, relationship with the child, disclosure status or socio-economic status.

Literature on disclosure suggests that children younger than 6 years are too young to be told about their HIV diagnosis while majority those aged above 16 years have been disclosed to.

According to the Thamaga Primary Hospital ART Quarter 1 Report (2010) there were 82 children aged 5 - 19 years enrolled for ART in Thamaga Primary Hospital IDCC, at the time of data collection

3.5 Recruitment of study participants

After obtaining ethical approval from Medunsa Research Ethics committee of the University of Limpopo, from Ministry of Health (Botswana) and the Thamaga Primary Hospital internal ethics review board initial participants recruitment was done through assistance from the nurse in charge of the IDCC and her staff. Firstly the researcher was introduced to the IDCC staff by the nurse in charge who then allocated the researcher a nurse to assist with the recruitment of prospective study participants.

To begin the recruitment exercise the nurse gave an overview of their clinic operations i.e. their operating times, the type of clients they cater for, schedule for nurses, doctors and patients. The researcher was made aware of the fact that children on ARV medication come for medical review on Thursdays only. Initially the researcher had scheduled to recruit prospective participants from the caregivers as they bring the children to the ART clinic every day but was forced to change the recruitment strategy as children on ARV were seen for consultation on Thursdays only hence recruitment was confined to Thursdays only.

The researcher was also introduced to the hospital ART patient data management system called MASA, where the nurse and the data entry clerk who is responsible for patient registration and bookings helped the researcher to compile a list of children whose caregivers met the study inclusion criteria of being a caregiver of an HIV infected child and aged between 6 – 16 years.

A list of 30 caregivers with their contact details, both physical address and telephone contacts was compiled. The researcher then looked up caregivers whose children were due for medical check up on the coming Thursday and called them to establish if they were interested in participating in the in-depth interview, the other interviews were tied with the day booked for the caregiver to bring the child for medical check-up. In some cases where the caregivers didn't provide their telephone numbers, the researcher used the caregiver's physical address and drove to their

houses to explain the purpose for their visit and also set up an appointment with them. This proved to be time consuming as the households in Thamaga village don't have house numbers or labelled streets and therefore difficult to locate. On a positive note, all the caregivers who agreed to an appointment with the researcher accepted to be interviewed and the recruitment process had an almost 100% response rate. The recruitment process took between 2 – 3 months as the researcher experienced a number of challenges such as patient consultation dates which were far apart, the researcher relocating to another place after changing jobs hence the researcher had to halt recruitment for 1 month as he was not granted study leave in the new workplace to continue recruitment and data collection.

3.5.1 Inclusion and exclusion criteria

Caregivers of children infected with HIV attending ART clinic at Thamaga Primary Hospital whose children were aged between 6 and 16 years and consented to participate in the study were included in the sample.

All caregivers of children aged five (5) years and below attending ART clinic at Thamaga Primary Hospital were excluded from the study. Caregivers of children aged above 16 years were also excluded as literature and clinical experience show that most of children in that age bracket have been disclosed to.

3.5.3 Study sample

Caregivers were selected using purposive sampling procedure as only caregivers of children living with HIV aged between 6 and 16 years were selected for this study. The sample was heterogeneous in nature i.e. caregivers of various backgrounds; socio-economic, level of education, relationship with the child etc to maximize variability and eliminate selection bias. After caregivers who met the selection criteria were identified from the computer print out of children on ART bookings,

the purpose of the study and procedure were explained to the caregivers and those who gave consent to participate were then interviewed.

3.6 Data collection

Before data collection could begin, the researcher conducted a pilot study at Scottish Livingstone Hospital IDCC. The pilot study was done firstly to ensure that the interview guide will give the researcher the information he has set out to obtain. The pilot study also helped to ensure the clarity of the data collection tool as well as to help determine the time it will take to carry out the interviews. The pilot study also provided the researcher with an opportunity to test efficiency and effectiveness of the MP3 audio recorder. The researcher was assisted by a nurse at the IDCC to recruit participants for the pilot study. After six (6) pilot study interviews were done, the interview guide was found to be accurate in collecting the data. The researcher then proceeded with data collection.

The researcher had a computer print list of prospective study participants who had agreed to participate in the study. On the interview day, the participant was welcomed into a quiet consultation room to ensure privacy. Caution was made to ensure that the caregiver didn't go into the interview room with the child so as to avoid accidental HIV diagnosis disclosure to the child during the interview. The researcher explained the study purpose and the interview procedure to the caregiver then explained their role in the study, the anticipated duration of the interview and the assurance of confidentiality and anonymity.

A total of 20 in-depth interviews were conducted. Of the twenty participants who took part in the interviews, four caregivers contacted had their medical appointments coming up in two months time hence the researcher had to arrange for home visits in order to carry out the interviews. Of these four participants, three

interviews were conducted in the participants' homes, while another one took place at the participant's workplace office. The sixteen (16) remaining in-depth interviews were conducted in one of the three doctor's consultation rooms at the hospital ART clinic but due to limited space in the clinic the last four (4) interviews were conducted in the cervical cancer screening room as the researcher had to make way for the doctor who was doing consultations. In the cervical cancer screening room, the researcher had to sometimes give way to the nurse doing who was doing Pap smear test thus causing delay to the caregivers and the data collection process. An MP3 Player was used to audio tape the interviews. All interviews were done in Setswana and each lasted an average of 1 hour -1 hour 20 minutes. Participation in the interviews was voluntary and no incentives were given to respondents. Interviews were conducted from June 2010 to October 2010 which is 5 months.

3.6.1 Data Collection tool

An in-depth interview guide was constructed based on literature and clinical experience of the researcher who was a certified ART nurse prescriber at the Scottish Livingstone Hospital. The data collection tool comprised of two sections part one looked at the caregiver and child's socio-demographic characteristics. Part two of the data collection tool consisted of the in-depth interview section which had two distinct interview guides. One guide was for caregivers who had disclosed the HIV diagnosis to the child while another guide was for caregivers who had not disclosed the HIV diagnosis to the child. The guide for caregivers who have disclosed the HIV diagnosis to the child had a total of eight (8) broad questions while the interview guide for caregivers who did not disclose had five (5) broad questions. This section also focused on caregivers' decision-making regarding disclosure i.e. whether they have disclosed or not, including a narrative recounting of any diagnostic disclosure to the child, the caregiver's perceptions of disclosure vs. non-disclosure, support and information regarding disclosure.

The key questions addressed the following areas: the child's HIV disclosure status, reasons for HIV disclosure by the caregiver, information given to child during HIV disclosure and his/her reaction and the caregiver's experience with HIV disclosure to the child. A separate set of key questions were asked to caregivers who haven't disclosed to their children and they included the following key questions which had probes: the child's HIV disclosure status, reasons for HIV non-disclosure by the caregiver, information given to child about this medication and illness/periodic medical reviews and his/her reaction and the caregiver's experience with HIV non-disclosure to the child.

The interview guide was also translated to the local language Setswana for caregivers who did not understand English. Interviews were then translated into English by the researcher and the research assistant who was conversant with both Setswana and English.

3.7 Trustworthiness

According to Patton, (2002) trustworthiness addresses validity and reliability in qualitative research, and strategies to enhance trustworthiness include credibility and dependability. Credibility refers to whether the researcher accurately represented what the participants think, feel and do. It refers to the confidence one can have in the truth of the research findings.

In qualitative research the skills of the researcher is fundamental to ensuring credibility and dependability of the research. In preparation for data analysis, the researcher attended a three days NVivo data analysis workshop to ensure that the researcher is skilled in data analysis. The data collection tool was translated into the local Setswana language as the interviews were conducted in Setswana and also the data collection tool was piloted with 6 caregivers of HIV-infected children on ART at Scottish Livingstone Hospital IDCC by the researcher to test the guide for clarity of questions and whether the guide actually collects the information required. The

questions were then modified appropriately to ensure that it addresses what the study was investigating. In addition other strategies that were used to ensure credibility and dependability included the use of a good digital recorder, verbatim transcribing of interviews, data triangulation and the use of NVivo software to aid data analysis as well as the use of an independent coder for analysis.

3.8 Ethical considerations

Ethical standards for conducting the study were maintained throughout the study by the following measures;

- Ethical clearance was obtained from the MEDUNSA Campus Research and Ethics committee (MCREC) prior to the implementation of the study.
- Permission to conduct the study in Botswana was sought from the Ministry of Health's Research Ethics Committee in Botswana and furthermore permission to conduct the study in Thamaga Primary Hospital was obtained from the Chief Medical Officer of the hospital.
- Confidentiality was maintained as the researcher used pseudo names opposed participant's name or the child's name so as to protect the participant's or child's identity.
- In order to maintain privacy interviews were conducted in private in consultation rooms and interviews were carried out in the absence of the child or any other family member so that the respondent can fully express his/her self and this also avoided the children from accidentally learning about their HIV diagnosis during the interview.
- All the participants had the study thoroughly explained to them and informed consent obtained from them before they could be interviewed.

3.9 Data analysis

Data collected from in-depth interviews was analyzed using the general inductive approach, which is used for analyzing qualitative data where the analysis is guided by specific research objectives.

For qualitative data captured from in-depth interviews the researcher translated the audio-taped interviews verbatim from Setswana into English and then transcribed it using Microsoft Office Word 2007 Version. As the first step of data analysis, the researcher attended an intensive fundamentals workshop on the use of NVivo version 8 Software used for analyzing qualitative data. The next step of the data analysis entailed that the researcher listened to the audio files over and over again before they were transcribed. The interviews were then transcribed by the researcher and the research assistant. The transcripts were then formatted to comply with NVivo and exported into NVivo as data sources. NVivo version 8 was used to aid coding. The content analysis approach which entails reading and re-reading of the transcripts until emerging themes were identified was used for data analysis. All transcription scripts were analyzed by this process until all data were integrated into the final descriptive structure. The research supervisor was the independent coder and studied the transcription scripts to ensure that data analysis was credible and bias was minimized.

Data captured in the demographic section of the data collection tool which was quantitative was coded and entered into an excel spread sheet -Microsoft Office Excel 2007 Version to derive the caregivers and children's demographic characteristics.

Chapter 4: Findings

4.1 Introduction

This chapter presents findings of data collected through in-depth interviews with caregivers of children living with HIV as well as the demographic characteristics of the participants. The first section of this chapter will present the demographic profile of the participants and it will be followed by a section on the themes that have emerged during the data analysis process.

The aim of this study was to explore caregivers' reasons for disclosure or non-disclosure of HIV diagnosis to children living with HIV and to also examine caregivers' experiences with disclosure and non-disclosure.

4.2 Section 1: Socio - demographic characteristics

Participants of this study were a sample of caregivers of children living with HIV and receiving antiretroviral treatment (ART) in a paediatric clinic at Thamaga Primary Hospital. A total of 20 caregivers of children on ART participated in the in-depth interviews. The age of the caregivers ranged from 21 – 68 years while the age-range for the children was between 6 and 15 years. Majority of the caregivers were females as they accounted for (90%, N= 18) of the participants while males accounted for only (10%, N= 2).

Most of the participants were literate even though their level of education was generally low. Of the 20 caregivers who were interviewed, (10%, N= 2) have never received formal education, (45%, N= 9) had primary education, (20%, N= 4) had junior secondary education, (20%, N= 4) had senior secondary school education and only (5 %, N= 1) had tertiary education. All the children were attending school with (90%, N= 18) being at primary school level and (10%, N= 2) being at junior secondary school level. In terms of the caregiver's relationship with the child, most of the caregivers were the biological mothers of the children (40%, N= 8), whilst (35%, N=

7) were other family member such as aunt, uncle or sibling. Caregivers who were grandparents were (20%, N= 4) while biological fathers represented (5%, N= 1). The majority of the caregivers (60%, N= 12) reported that they had told the child about his/her HIV positive status while the remaining (40%, N= 8) reported that they had never told the child about his/her HIV positive status.

Figure 1: Caregivers' Age Distribution

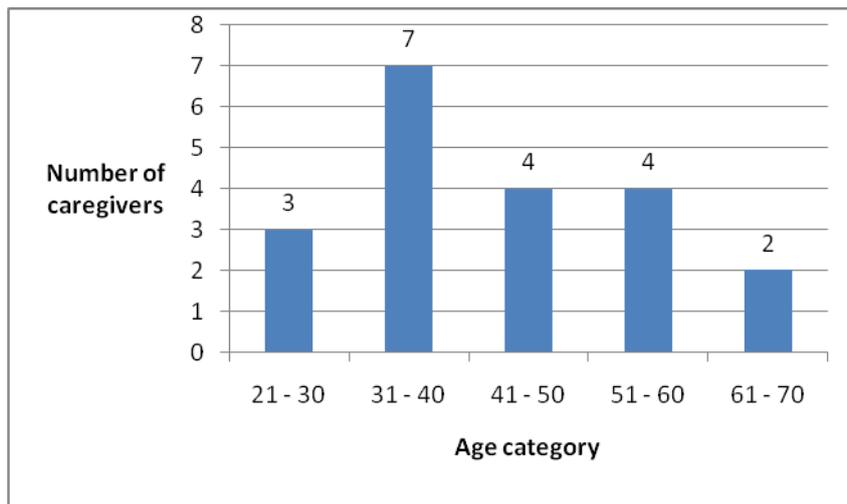


Figure 1 shows that majority of caregivers (7) fall in the age group 31 – 40 years while the age group 61 – 70 had the least number of caregivers with only 2 caregivers.

Figure 2: Caregivers' Sex Distribution

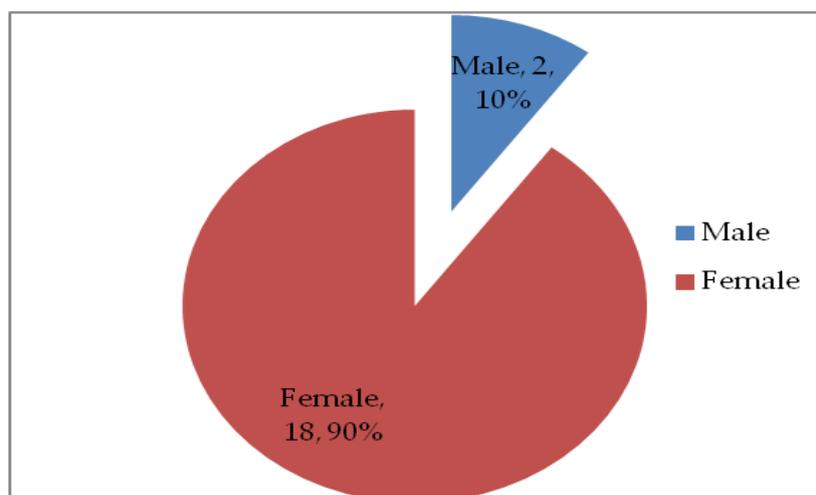


Figure 2 above, shows the gender distribution of caregivers and the majority of the caregivers were females (90%) whilst only (10%) were males.

Figure 3: Caregivers: Level of Education

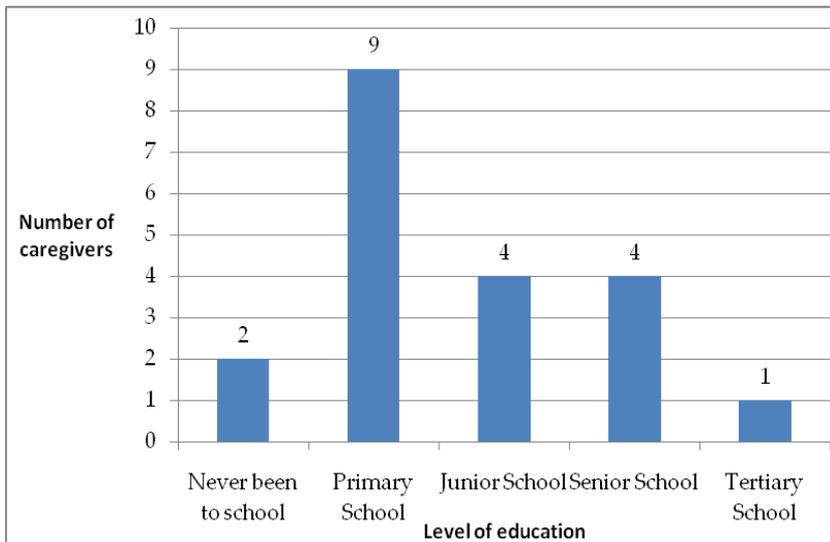


Figure 3 is a presentation of the educational attainment of the caregivers and shows that the majority of the caregivers 9 (45%) had attained only a primary level of education while only 1 caregiver had attained education up to tertiary level.

Figure 4: Children: Level of Education

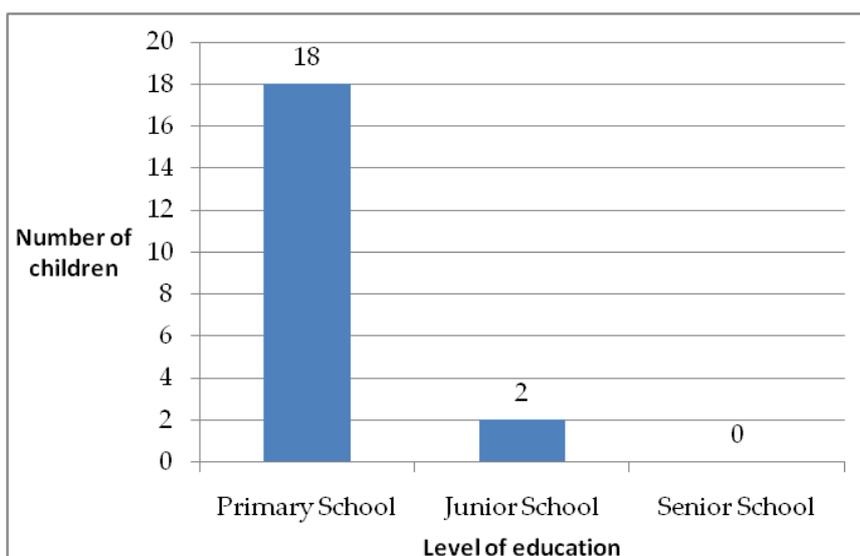


Figure 4 presents the educational levels of the children whose caregivers participated in the study, 18 (90%) of children were attending primary school while only 2 (10%) children were at junior secondary school and no child was at senior secondary level.

Figure 5: Caregiver’s Disclosure status

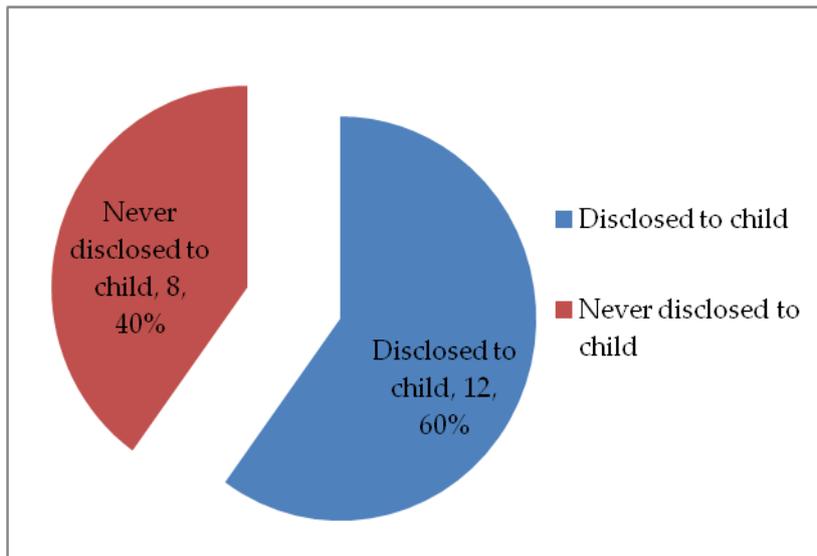


Figure 5 above shows the number of caregivers who reported that they have told or not told their HIV infected children about their HIV positive status. The data show that majority of caregivers 12 (60%) had told the child about their HIV positive status while 8 (40%) reported that the child had not been disclosed to.

Figure 6: Caregiver’s relationship with Child

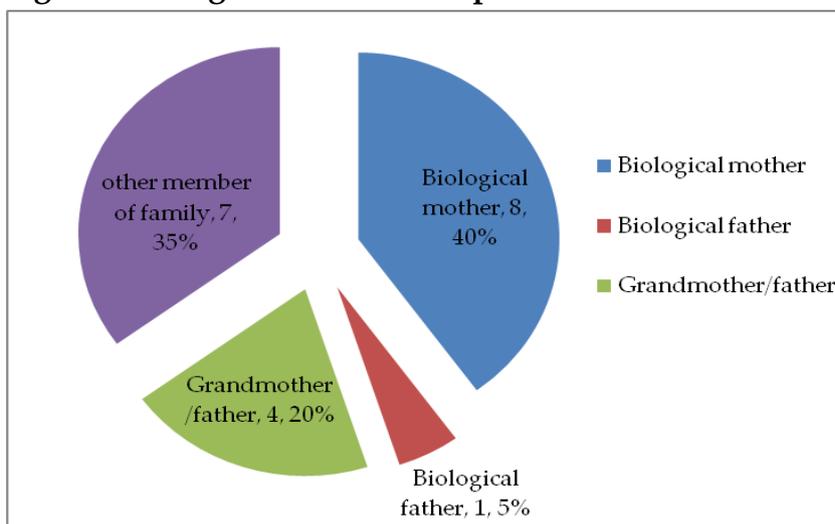


Figure 6 above shows the categories of caregivers in this sample and majority of the caregivers who participated in the study were the biological mothers 8, (40%) of the children, biological fathers were the least with only 1, (5%), 7(35%) were other relatives including aunts and uncles and 4 (20%) were grandparents.

4.3.0 Section 2: Themes identified

An analysis of the qualitative data collected from 20 in depth interviews on caregivers' reasons for disclosure or non-disclosure of the HIV diagnosis to children living with HIV and their experiences with disclosure and non-disclosure was done. Below are the themes and sub-themes that emerged from the data.

4.3.1 Caregiver's perceptions about HIV diagnosis disclosure to the child

When both caregivers who have disclosed and non-disclosed were asked to reflect on whether the issue of telling HIV infected children about their HIV diagnosis is a good or bad thing, most caregivers felt that disclosing the HIV diagnosis to the child was a good thing to do. This is illustrated by the statements below:

"In my opinion I find it to be a very good thing, which is why I have decided to disclose to my child. It is a sign of true love that a caregiver has for the child particularly when the child is yours biologically." (Disclosed biological mother of a 9year old girl)

"Though I haven't told the child that she is living with the virus I do believe it is a good thing to tell the child that they are living with it. But like I said it will only be right if you tell them at the right time otherwise you can only hurt them while you think you are doing a good thing." (Non-disclosed Aunt of an 11year old girl)

“It is a good thing to tell the child that they are living with AIDS you see some parents just like to deprive the children this valuable information which they need so much. The child needs to know what being HIV positive means because they are going to leave like that for the rest of their lives.” (Disclosed biological father of a 13year old boy)

“Even if my child is failing to accept his situation or is hurt by the positive results, I still think telling the child that they are living with AIDS is a good thing. You see when a child knows that they have the virus they will be hurt yes but at the end of the day they will accept the situation.” (Disclosed Sister of a 10year old boy)

The data also shows that most caregivers felt that disclosing the HIV diagnosis to the child is a sensitive issue hence they preferred that the child’s biological mother should be the one doing the HIV diagnosis disclosure to the child with the assistance of healthcare providers from the clinic or hospital where the child receives HIV treatment. This is illustrated by the following statements:

“...As her mother I have to shoulder the responsibility to tell her this sensitive information about this life disease she is having.” (Disclosed biological mother of 9year old girl)

“I think when the child is told by any other person it can be a bit painful unlike being told by the mother because mothers are the closest to the child and as parents I think we have to be open to our children.” (Disclosed biological mother of a 16year old girl)

“I find health workers helpful in disclosing to the child. This is because there are social workers there as they can come to you as caregivers and help you with how to inform the child that he/she is HIV positive.” (Disclosed aunt of a 12year old boy)

In contrast, some of the caregivers felt that when the child's biological mother is not there, someone who is responsible for the primary care of the child should do the disclosure. This is illustrated by the statements below:

"But it doesn't only have to be me even his aunt can do it because they are already involved in the care of the child, in fact I think what matters is that the person who does the disclosure should be having a good relationship with the child." (Non-disclosed mother of an 8year old boy)

"HIV disclosure to the child is best done by someone who is closer to the child and has a cordial relationship with the child like someone who has been taking care of the child." (Disclosed grandmother of a 13year old girl)

Both caregivers who had disclosed and those who had not disclosed the HIV diagnosis to the child felt that the healthcare workers at the ARV clinics should initiate disclosure so that they can help answer complex questions the child might ask during disclosure. The statements below demonstrate that:

"It is important that nurses help in disclosure to child as in some cases some child might need extra information so the nurses will provide extra information particularly for caregivers who are secretive to their children. Also the nurses can lay a foundation as some children value information from the nurses more than from us as we don't know much." (Disclosed aunt of a 12year old girl)

"I find health workers helpful in disclosing to the child. This is because there are social workers there as they can come to you as caregivers and help you with how to inform the child that he/she is HIV positive." (Disclosed aunt of a 12year old boy)

“I think the health care providers should help me do the disclosure as they have more information about HIV disclosure and can be able to answer difficult questions that the child might ask which I wont be having answers for. In my case as a caregiver I am not well educated in many things about AIDS so I think the nurses can do the disclosure better.” (Non-disclosed biological mother of a 6year old girl)

4.3.2 Reasons for HIV positive status disclosure to the child

Caregivers who had disclosed the HIV diagnosis to the child were asked why they decided to tell the child and also what motivated them to do so. On reflection, some caregivers who have disclosed to their children state that they decided to disclose to the children because they felt the child had the right to know of his/her HIV positive status, some felt the child had to know about ARV pills and his/her illness. This is illustrated in the statements below:

“... The child constantly wondered why he is taking these pills and why he takes them at a regular time like every 7 o'clock. Therefore it becomes pressing to us as caregivers hence we had to tell the child more about the pills and how they work in their body.” (Disclosed aunt of a 12year old boy)

“I felt I had to tell her about her HIV positive status because at the hospital they always emphasized to her that she should make sure she drinks the pills everyday and on time.” (Disclosed grandmother of a 11year old girl)

On reflection, some caregivers who have disclosed to their children stated that they decided to disclose because they felt the child had the right to know of the reason why they were taking medication and the reasons for going to the hospital for medical check up. This is illustrated in the statements below:

“She always wanted to know if she is going to stop drinking the syrup medication, stop being pricked for blood collection, stop having to see the doctor time and again. (Disclosed aunt of a 12year old girl)

“I had to tell her that the reason why she is taking her medications, going for medical check up and being pricked for blood collection is because she is sick and she has to take the treatment.” (Disclosed aunt of a 15year old girl)

“You see I didn’t want to keep her in the dark about her knowing that she has AIDS. I also wanted to her aware and have the right information.” (Disclosed grandmother a 11year old girl)

Data also shows that some caregivers decided to tell the child about their HIV positive status because they feared accidental HIV status disclosure as the child can get to learn of his/her HIV status from other sources. The statements below attest to that:

“I told her at a later stage when I realised that keeping the secret from the child doesn’t help as she will know eventually.” (Disclosed grandmother of a 11year old girl)

“I also didn’t want her to ask me about her HIV status first unexpectedly which can make things even more difficult.” (Disclosed biological mother of a 16year old girl)

“Kids can be inquisitive sometimes, in some cases there is a chance that one day they he will ask me “mama, what are these pills that you always make me to drink for?” so I had to tell him in advance why they take their pills.” (Disclosed biological mother of an 8year old boy)

“We had a fear that the more we delayed telling her about her illness the more the chances that she might end up getting some wrong information from other people she meets.” (Non-disclosed grandmother of a 13year old girl)

Some caregivers reported that they decided to disclose the child’s HIV positive status to the child because the child was curious about their condition and was asking them questions about their illness. The following statements show this:

“She is always worried about her condition and her questions showed concern. She always wanted to know if she going to stop drinking the syrup medication, stop being pricked for blood collection, stop having to see the doctor time and again.....those are difficult questions you know.” (Disclosed aunt of a 12year old girl)

“No he once asked, though it was recent around last year but I told him that there is something called HIV germ and it is not curable. He then asked me how he gets it and how he ended up having it while he is still a child. Well I told him that I don’t know and maybe his parents can better explain how he got the infection.” (Disclosed aunt of a 12year old boy)

4.3.3 Child’s reaction after being told about their HIV positive status

Caregivers who had disclosed the child HIV positive diagnosis to the child reported varying statements with regards to how the child reacted during and after being told about their HIV positive status. Some caregivers found that children showed hurt feelings when told about their HIV positive diagnosis but later accepted their status:

“Well at first he became withdrawn and asked me questions like “is this thing curable?” I then told him that it is incurable but can be suppressed by treatment and that is why he was taking ARVs.” (Disclosed aunt of a 12year old boy)

“I would say her behaviour never really changed. Well it’s just during the first day when I disclosed that she was a bit panicky and asked me if the disease that she has isn’t the one that is notorious for killing people.” (Disclosed grandmother of an 11year old girl)

“She cried and I saw that she was much stressed because it was not long after her mother’s death. But nowadays I can see that she is starting to accept her HIV positive status.” (Disclosed aunt of a 15year old girl)

In contrast, some caregivers reported that the children didn’t show any hurt feeling after being told about their HIV positive status. That is shown by the following statements:

“No he was fine, he just showed no hurt feelings, in fact I suspect he already knew that he was taking the pills because he had HIV.” (Disclosed biological mother of a 9year old boy)

“No she didn’t show any hard feelings.. I think she has given up. The only thing worrying her is that she doesn’t want to come for check up instead she wants to go to school.” (Disclosed aunt of a 12year old girl)

“To my surprise she took the disclosure very well. She didn’t show any hurt emotions, I think maybe it is because she is still young and didn’t comprehend the implications of being HIV.” (Disclosed biological mother of a 9year old girl)

4.3.4 Disclosure information by caregivers who disclosed

Caregivers who had told their children about the child’s HIV positive status were asked to share the information they told the child about their condition and it

emerged that majority of them accurately told the child about HIV and AIDS and how the child got the infection. This is demonstrated by the statements below:

“We told him that he is in a state where he has a germ called HIV therefore he has to take ARV treatment which he will need to take for the rest of his life so that the germ doesn’t ‘wake up’.” (Disclosed aunt of a 12year old boy)

“I didn’t hide anything from her, I told her the truth that she is living with AIDS.” (Disclosed mother of a 9year old girl)

“I told her not to worry because it was not her fault, the problem is with her mother in fact her mother is also not at fault because she had this disease and not noticed it as she didn’t check her HIV status hence passed it to her.” (Disclosed aunt of a 15year old girl)

4.3.5 Caregiver’s experience with HIV diagnosis Disclosure

After being asked to reflect on their experiences with disclosing the HIV diagnosis to the child some caregivers noted that they were relieved that they no longer keep secrets from the child particularly questions about the reasons for taking pills. The caregivers felt that they no longer have to face challenges of guarding against accidental disclosure when answering questions about the child’s pills. This is illustrated in the quotes below:

“After telling the child about their HIV positive diagnosis there is no longer that suspense where you keeping wondering if somebody have disclosed to the child secretly before you hence harming the child.” (Disclosed grandmother of a 13year old girl)

“...it has taken the burden of secrecy from me...” (Disclosed aunt of a 12year old girl)

Some caregivers experienced emotional relief with disclosing to the HIV diagnosis to the child. They see the disclosure process as having reduced the emotional stress that is associated with not disclosing the HIV diagnosis to the child as illustrated in the statements below:

“It gave me a lot of emotional pressure and it was becoming unbearable for me to keep it secret and always hiding the truth from the child no matter how young she may seem. ” (Disclosed biological mother of a 9year old girl)

“Well after disclosing to her I found myself relived and healed inside of my heart. Now the child better understands her illness” (Disclosed aunt of a 15years old girl)

“ ‘ke ne ka fola jaaka bogobe – (I cooled off like hot porridge)’....It had been a very, very difficult period for me but after disclosing her HIV status to her I became relieved.” (Disclosed aunt of a 15year old girl)

“It has really lifted the heartache I was living with, as I was always wondering how she is going to feel when she finds out about her illness and how she is going to accept the status...” (Disclosed grandmother of a 13year old girl)

4.3.6 Benefits of disclosing child’s HIV positive status

When asked about the child’s behaviour and practices after being told of their HIV positive status, most caregivers noted that they were impressed by their children’s adherence to ARV pills. This is illustrated in the caregiver’s comments below:

“It has reduced the burden on me as am no longer supervising him time again and again he now knows that at a certain time he has to have eaten and drunk the pills.”
(Disclosed aunt of a 12year old boy)

“She does not give us any problems her attitude towards her medication has improved tremendously; she takes the therapy very well we don’t even remind her that she must take the therapy, she understands the whole process.” (Disclosed aunt of a 15year old girl)

Caregivers who have disclosed the HIV diagnosis to the child viewed disclosure as being very beneficial as caregivers believe that children who know about their HIV diagnosis display acceptance of their HIV diagnosis. This is illustrated by the statements below:

“The good thing is that he now can monitor his own behaviour like delaying sex by waiting in order to grow up and fully understand him before he can do some things like having sex.” (Disclosed aunt of a 12year old boy)

“Before disclosure she was a very withdrawn girl and always worried about her never-getting-better health. Also her adherence to the tablets has improved as she now knows why she is taking them, that if she misses taking them she can get sick and die.” (Disclosed grandmother of a 13year old girl)

4.3.7 Reasons for non-disclosure by caregivers

Caregivers gave a wide variety of reasons for not disclosing the child’s HIV diagnosis to the child. Data show that some of the caregivers did not disclose the HIV diagnosis to their HIV infected children because they believe the child will not keep his/her HIV diagnosis a secret as reflected in the following statements:

“When you tell a young one like this one he might end up saying ‘I am drinking ARV of pills etc’ to his friends while playing in the fields.” (Non-disclosed biological mother of an 8year old boy)

“Well we don’t really have any major fears, except that we sometimes fear that if we disclose the child might tell his friends about his HIV positive status and end up being segregated by others”. (Non-disclosed biological father of a 9year old boy)

“Yeah that’s my main worry I don’t trust that she will be able to keep that secret.” (Non-disclosed biological mother of a 6year old girl)

“Also if she is disclosed to at a young age, she might not know how to keep a secret about her illness and go on to talk about her AIDS disease when with other children.” (Non-disclosed mother of a 10year old girl)

The data further shows that caregivers who didn’t tell the children about their HIV diagnosis gave their reason for non-disclosure as the feeling that the child is not old enough to understand the HIV diagnosis disclosure thus they decided against disclosure until the child has reached such an age where they feel he/she will understand. The following statements illustrate this:

“I intend to tell him when he is 15 years old, that is only when he will be able to understand what I am saying, by then his brain will be able to comprehend what I will be talking about.” (Non-disclosed biological mother of an 8year old boy)

“We are waiting for him to be at least the age of his elder sister then we will call him and tell him.” (Non-disclosed biological father of a 9years old boy)

“No we haven’t told her about her HIV positive status, she is still young she is still a child even though she is taking the pills. We have only told her a little...” (Non-disclosed biological mother of a 10year old girl)

“Maybe when she is around 15 years that is when she will be mature enough to understand AIDS information well as most children who are 15 years old understand certain things better.” (Non-disclosed biological mother of a 10year old girl)

Data also shows that caregivers who didn’t disclose to the child stated that they decided against disclosing the HIV diagnosis to the child as they didn’t want to upset the child. The following statements below illustrate this:

“I sometimes think telling him that he is living with HIV can hurt him his emotions and disturb him later in his life as he grows up so now he is still young and it is best I tell him when he is older.” (Non-disclosed biological mother of an 8year old boy)

“My fear is that my disclosure efforts might be misunderstood as the child is still young to understand some things about HIV/AIDS. I sometimes fear that I might hurt the child by telling her that she is HIV positive, you see by the time she gets to understand it she will be hurt.” (Non-disclosed mother of a 10year old girl)

“Again if I tell him now and say that AIDS does not have a cure and that he will die of it he is going to be sad.” (Non-disclosed aunt of an 8year old boy)

Data shows that caregivers who did not disclose fear that their child will be discriminated against in the society once people get to know that the child has HIV and hence preferred not to tell the child about his/her HIV diagnosis. The following statements illustrate this:

“You see being HIV positive is something that is not really accepted in my society, we people living with HIV are always called names and even segregated against but now imagine how a 10 year old child will handle this kind of discrimination if we elders are struggling with it. So I think it is best I wait until she is old enough to keep the secret.” (Non-disclosed biological mother of a 6year old girl)

“Once other people know the whole village will know and we will be called all sought of names. I am just waiting for him to be mature enough to know that this disease should our deepest secret in the family.” (Non-disclosed biological mother of a 10year old boy)

“Every child in that school she goes to know about AIDS and that people with it are going to die so if her friends know they are going to make fun of her that she is not going to live for long as she has AIDS.” (Non-disclosed aunt of an 11year old girl)

Data also shows that caregivers didn't disclose because they feared that the child might blame them for passing HIV to them once they explain to the child how they got infected. This is shown by the statements below:

“It still causes pain to me because I know very well that the reason why this child has the virus is because I didn't enrol in PMTCT which could have helped prevent HIV transmission to the child and also breastfed him.” (Non-disclosed biological mother of a 9year old boy)

“According to the nurses, the virus passed from me to the child during pregnancy. So I really I have a difficult time in explaining this to the child as I fear he might blame me.” (Non-disclosed biological mother of a 10year old boy)

4.3.8 Information told the child by caregivers who did not disclose

Caregivers who did not disclose to the child were asked to share with the researcher the information they told the child about their illness. Data shows that caregivers who did not disclose to their children chose not tell the child the truth about their illness but instead give the HIV/AIDS condition a false name or an inaccurate explanation of the illness. The statements below capture the above assertion:

“The mother however didn’t reveal the truth but instead told him that he is still ill and only the doctor will know if he is healed and will be the only one who tell him to stop treatment.” (Non-disclosed biological father of a 9year old boy)

“She just knows that she has to take her pills so that she doesn’t fall sick so that she can grow up and be able to attend school without falling sick time and again.” (Non-disclosed biological mother of a 6year old girl)

“She was somewhat refusing to drink them and I told her that if she doesn’t take them she will be sick and this forced her to start drinking them with out any fuss.” (Non-disclosed biological mother of a 10year old girl)

4.3.9 Caregiver’s experience with HIV status non-disclosure

When asked to reflect on their experiences with not telling the child about their HIV status, caregivers reported they it is difficult to live and raise an HIV positive child without telling them as the issue has emotional challenges. The statements below demonstrate this:

“This failure to tell the child about their HIV positive diagnosis is really draining me emotionally and mentally.” (Non-disclosed biological father of a 9year old boy)

“I however still regret that I might not be doing the right thing by not telling her that she is living with HIV.” (Non-disclosed biological mother of a 6year old girl)

“I also feel am making life difficult for myself by not disclosing if I had told her that she is was living with HIV and taking the ARVs she will improve on how she takes the pills.” (Non-disclosed biological mother of 10year old girl)

“Almost everywhere people talk about ‘mogare’ and ‘diritibatsi’ in the radios and televisions. This gets me panicking because Zacharia might even up learning about his pills from what he sees in the magazines.” (Non-disclosed biological mother of a 10year old boy)

Chapter 5: Discussions, Conclusions and Recommendations

5.1 Introduction

This chapter provides a summary discussion on caregivers' reasons for disclosure or non-disclosure of the HIV diagnosis to children infected with HIV. The first part of this section addresses the socio-demographic characteristics of caregivers and their children as well as to link their characteristics with their disclosure status. The second part is organized into subheadings aimed at addressing the study's specific research questions such as; reasons for HIV diagnosis disclosure or non disclosure to HIV infected children by their caregivers; experiences and perceptions of caregivers who have disclosed or not disclosed the child's HIV diagnosis to the child.

5.2 Socio-demographic characteristics of the participants

A total of 20 caregivers of children infected with HIV participated in the in-depth interviews. Caregivers were recruited from a paediatric clinic at Thamaga Primary Hospital and all the children were receiving ART at the time of data collection. The age range for the caregivers was 21 - 68 years while the age range for the children in their care was 6 – 15 years. Most of the caregivers, 15 out of 20 were females most were literate and only 2 of the 20 had never been to school, 9 of 20 had primary education, 4 of 20 had junior secondary education, and only 4 of 20 had senior secondary school education and only 1 of 20 had tertiary education.

Eight of the 20 participants were biological mothers to the children, whilst seven of 20 caregivers were other relatives such as aunts, uncles or siblings, four of 20 were grandmothers and only one of 20 caregivers was the biological father of the child. Based on the caregiver's report, 12 of 20 (60%) of the caregivers had disclosed the HIV diagnosis to their children while 8 of 20 (40%) had not disclosed to their children.

Though the results of this qualitative study cannot be generalised because of the small sample size, the prevalence of disclosure in this study is much higher than of other prevalence studies on HIV diagnosis disclosure to children which showed low disclosure rates among caregivers. Boon-Yashidhi, et al., (2005) in Thailand found that only 19.8% of the caregivers reported to have disclosed the HIV diagnosis to their children while a study by Bikaako-Kajura, et al., (2006) in Uganda found that only 29% of the caregivers had disclosed. Recent data from developing countries show that the prevalence of disclosure to HIV infected children remains low and varied (Kallem, et al., 2010; Vaz, et al., 2010). The plausible reason for the high disclosure rates in this study could be attributed to the increasing use of ART in this setting. Previously, Thorne, et al., (2002) had argued that in studies where higher rates of disclosure were observed, disclosure was attributed to increased use of HAART.

5.3 Perceptions about HIV diagnosis disclosure

The data shows that caregivers who had disclosed the HIV diagnosis to children and those who had not disclosed regard telling children about their HIV diagnosis as a good thing to do. These findings are in keeping with previous findings by Azondekon, et al., (2005) and Blasini, et al., (2010) where all of the parents in their study showed a positive attitude towards disclosing the HIV diagnosis to the child. Recent findings from Vaz, et al., (2010) show that although the majority of caregivers had not disclosed to the child, almost all caregivers said that they felt the child should be told his/her HIV status. Data in this study further show that caregivers who had disclosed the HIV diagnosis to the child view disclosure as being important to the child because the child has the right to know of their life threatening illness and they also felt that the HIV diagnosis disclosure will help the child to understand why they are on ARVs. Ironically caregivers who didn't disclose to the HIV-infected child also shared the above sentiments that the child needs to be

told of their HIV diagnosis despite not disclosing to the child. This discrepancy where caregivers support HIV status disclosure but continue to fail to do it requires further research attention, and may also require attention from health care providers working with HIV-infected children.

5.4 Support for disclosure

Both caregivers who had disclosed the HIV diagnosis to the child and those who didn't disclose feel that healthcare workers should assist them in doing the disclosure to the child. They feel that healthcare workers are better informed in answering sensitive and difficult questions that the child might ask them about their HIV diagnosis, their illness; ARV medication and how they got infected with HIV. Similar findings were reported in a number of South African studies on disclosure of HIV diagnosis to children, caregivers also expressed the need for support from health care providers (Kouyoumdjian, et al., 2005; Moodley, et al., 2006; Myer, et al., 2006). Our study findings are also in line with data from other settings, Oberdorfer, et al., (2006) report that in their study, half of the caregivers who intended to disclose the child's diagnosis in future expressed the need to be assisted by healthcare providers during the disclosure.

5.5 Reasons for disclosure

Caregivers in this study cited various reasons for disclosing the HIV diagnosis to their children. The most common reasons reported by caregivers were that the child has a right to know about their medication; that the child will adhere to medication better if they know why they are taking it; fear of accidental disclosure and in some cases the child becoming curious about their illness.

5.5.1 Child has the right to know

The data show that caregivers who disclosed the HIV diagnosis to their child, did so because they felt that it was the child's right to know the correct information about their illness and their ARV treatment regimen. Similar findings were previously reported that one of the reasons caregiver disclosed the HIV diagnosis to the child was that the child has a right to know his/ her HIV diagnosis (Moodley, et al., 2006; Lester, et al., 2002).

5.5.2 Child will adhere to medication

Data further shows that caregivers felt that once the HIV-infected child knows what their medication is for and understands information related to their HIV diagnosis and illness, the child's adherence to ARVs will hopefully improve. Our findings are similar to studies done in other developing countries where adherence to medication was one of reasons caregivers disclosed, they believe that disclosure might help the children to adhere to HAART (Myer, et al., 2006; Oberdorfer, et al., 2006; Vaz, et al., 2008). Furthermore caregivers also felt that once the child knew more about their HIV diagnosis they will be more prepared to accept routine timed medication that the child is on as well as accept routine needle pricking for blood specimen collection done with ARV clinic visits.

5.5.3 Fear of accidental disclosure

Fear of accidental disclosure of the HIV-infected child has been mentioned by some caregivers as the main reason that motivated them to disclose the HIV diagnosis to the child. These findings are consistent with findings from other studies, caregivers disclosed because they were concerned that children would learn the HIV diagnosis from other sources and that such information may not be accurate (Bhattacharya, et al., 2010; Wiener et al., 2007b; Instone, 2000; Nehring, et al., 2000; Weiner, et al.,1996). Caregivers felt that, the more they delayed disclosing the more the child

will have suspicions about their illness and start asking unexpected questions which the caregiver might not be prepared to answer. According to Corona, et al., (2006) children learn about HIV from other sources including the school and television and are able to identify some of the symptoms related to HIV. Similarly, caregivers in this study were concerned that their children were old and can read the labels on their ARVs and also recognize the medication from the television. Caregivers fear that children will be hurt if they learn the diagnosis from other sources because when disclosure is done by caregivers the decision is based on the child's ability to handle the information without being excessively worried or scared (Ostrom, et al., 2006).

5.5.4 Child curious about their illness

Some caregivers identified the child's curiosity as the reason why they ended up telling the HIV-infected child about their diagnosis. Caregivers reported that children were curious about their illness particularly on issues of having to endure the painful process of being pricked with needles for blood collection with every medical review. Specifically the caregivers reported that the children wanted to know when are they going to stop drinking medication, stop being pricked for blood collection and stop having to see the doctor time and again. Findings from other studies also showed that caregivers disclosed because children were persistently asking questions, they wanted to know what disease they suffer from, they wanted to know why they were continuously taking medication while they were not feeling sick (Kouyoumdjian, et al., 2005; Lester, et al., 2002a; Waugh, 2003; Wiener, et al., 1998). According to Vaz, et al., (2010) when children take their dosages of ARVs, they are not experiencing any symptoms compatible with sickness. It is therefore not surprising that children in this study do not understand why they should continue taking medication when they were physically well.

5.6 Child's reaction to disclosure

Similar to previous findings, caregivers in this study reported a range of child emotional responses to the initial HIV disclosure process. Contrary to the belief by most caregivers who had not disclosed the HIV diagnosis to their children because of fear of hurting the child, caregivers who had disclosed to their children in this study reported that though the child got upset after disclosure, they eventually learned to accept their HIV diagnosis and learned to be happy again. This study did not determine how long the children were upset following the disclosure but caregivers reported that with further explaining of the nature of the HIV diagnosis the children began to accept their HIV diagnosis. However previous findings show that more than 70% of HIV infected children had feelings of normalcy six months post-disclosure of HIV diagnosis (Butler, et al., 2009; Blasini, et al., 2004) diagnosis. In this study the children's feelings of hurt were associated with fear of death as HIV and AIDS are associated with death and dying in their communities.

In contrast some caregivers reported that some of the children did not show any reaction during and after being told about their HIV diagnosis. The neutral response to disclosure prompted some of the caregivers to suspect that the child might not have fully understood the implications of the HIV diagnosis. Similarly Murphey, et al., (2006) argue that that most of the children in their study did not understand what HIV/AIDS was when their mothers disclosed to them at an average age of 7. This view point is supported by (Mellins, et al., 2002) that because many children are often disclosed to at a young age, they may not fully understand the diagnosis. While some caregivers were under the impression that maybe the child knew about their HIV diagnosis before the caregiver disclosed to them hence neutral response to the disclosure. These findings are in consistence with previous data where Lester, et al., (2002) found that most of the HIV-infected children in their study reported

knowing about their HIV diagnosis even before disclosure. In contrast Vaz, et al., (2008) report that most youth in their study were surprised to learn of their HIV diagnosis. Many said they were surprised to learn of their HIV diagnosis because they wondered how they could be infected. According to Mellins, et al., (2002), health education messages usually emphasise drugs and sexual behaviour as means of HIV transmission and provide little mention of perinatally contracted HIV . Therefore children do not associate these modes of transmission with them.

5.7 Information told to children during disclosure

The data show that caregivers who took the decision to disclose the HIV diagnosis to their children were comfortable with giving the child the correct information about their illness without being afraid of mentioning words like 'HIV' or the 'AIDS' germ. It appears their decision of disclosing the child's HIV status has helped them not to call the child's illness other names as they have confidence in that once the child knew about their HIV positive diagnosis they will not confuse their illness with other conditions.

5.8 Caregiver's experience with disclosure

Data shows that caregivers had a positive experience with disclosing the HIV diagnosis to their HIV-infected children. Disclosure to their children resulted in great mental relief for the caregivers as they no longer had to wonder if the undisclosed child is going to ask them questions about their illness or ARV medication. The caregivers were relieved that they no longer had to wonder how the undisclosed child was going to react when they get to learn about their HIV diagnosis. This is in line with findings by (Wiener et al.,1998; Blasini, et al., 2004; DeMatteo, et al., 2011; Biadgilign, S., 2011) that some parents reported feelings of relieve of the burden of keeping the secret after disclosure.

Furthermore caregivers in this study also experienced reduced emotional stress after disclosure. Caregivers felt that by not disclosing to the child they were not doing justice to the child by hiding the HIV diagnosis of a deadly disease from the child while pretending that everything is fine.

5.9 Benefits of disclosure

Some of the caregiver who had disclosed to their children reported seeing some benefits in doing so. The caregivers report that after knowing their HIV diagnosis and getting an explanation why their treatment is life-long, children displayed good adherence practices to their ARV medication. Disclosure has been reported to positively influences adherence to ART for some HIV-positive children in several studies conducted in developing countries (Biadgilign, et al., 2009; Bikaako-Kajura, et al., 2006; Vaz et al., 2008). Some of the caregivers reported that children started drinking their pills with minimal supervision, while some caregivers felt that they had less difficulty in persuading the child to take the ARVs or go for medical check-up in cases where the child had a poor adherence record suggesting that the children's adherence to their ARVs improved after disclosure. Similarly (Vaz, et al., 2008) reported that in their study caregivers and youth believed that adherence to treatment improved as a result of being told their HIV diagnosis. In a Ugandan study, disclosure of the HIV diagnosis was necessary to overcome the children's opposition to taking HIV treatment (Bikaako-Kajura, et al., 2006).

Furthermore some caregivers believed that following disclosure the child knew more about their illness and what it meant do miss doses. This they believe assisted children's acceptance of their HIV diagnosis. These findings are consistent with a findings produced by Bhattacharya, et al., (2010) that better self-care among children who were told about their HIV diagnosis was the most frequently cited advantage of disclosure.

5.10 Reasons for non-disclosure by caregivers

5.10.1 Child cannot keep HIV status a secret

The data show that there were various reasons why caregivers delayed disclosure of HIV diagnosis to children in this study. Some of the caregivers who did not disclose the HIV diagnosis to the child had fears that the child might not be able to keep their HIV diagnosis and ARV medication a secret from their friends and other people in the neighbourhood. Consistent with findings from previous studies, caregivers feared that by virtue of being young and naive, children are not able to keep secret. Caregivers feared that children will casually discuss their HIV infection with their friends or other children at school and or in their neighbourhood thereby making the child's and caregiver's HIV status public (Moodley, et al., 2006; Azondekon, et al 2005). Literature shows that caregivers fear that telling others about the child's HIV diagnosis will expose the child and the family to potential discrimination and isolation because of their HIV status (Blasini, et al., 2004; Instone, 2000; Lee & Johann-Liang, 1999; Lester, 2002; Mellins, 2002; Waugh, 2003; Weiner, et al., 1996, 1998). Similarly, caregivers in this study were fearful that children will suffer isolation and name-calling at school. They feared that it will be hard for children to deal with the stigma and discrimination they will be subjected to by society particularly because even adults are still grappling with having their HIV status known by the public in their communities. The same viewpoint is held by Wilfred, et al., (1999) who argue that caregivers fear that when the child's HIV diagnosis is known by other people the child and other family members will be stigmatized, discriminated against or ostracized because that lived in a the society which still discriminates against people living with HIV.

5.10.2 Child is too young to understand HIV disclosure

Data shows that most caregivers believe that younger HIV-infected children are relatively not ready to be told about their HIV/AIDS related illness as compared to

the older ones as they believed they are too young to understand disclosure. As in prior studies of HIV status disclosure in children have shown Lester, et al., (2002), the child's age and maturity remain one of the determining factors in the caregiver's decision to tell the HIV-infected child about their illness. Consistent with this, the study found the average age for children disclosed to be 11.8 years while the age range was 9 – 16 years. Non-disclosed children had a mean age of 8.8 years and an age range of 8 – 11 years suggesting that caregivers are still waiting for the child to reach a 'certain age' before they disclose. These findings are in keeping with those of a previous study by Moodley, et al., (2006) where the child's age was found to be an important predictor of whether or not disclosure had occurred as HIV status disclosure is found to occur mostly in older children. The possible explanation to the delay or waiting for the 'right age' to disclose as it emerged from the data could be because of cultural influence as parents in Tswana culture tend to consider their children only mature at a later age especially at early puberty stage where parents will be comfortable in discussing diseases linked to sexuality like HIV/AIDS.

5.10.3 Fear that the child will be upset

Though almost all caregivers in this study felt HIV status disclosure to the child was very important to the child, caregivers delayed disclosure as they fear it might upset the child. In this study caregivers who did not disclose had concerns that disclosure will have negative emotional consequences for the child. Literature shows that often caregivers delay disclosure of the HIV diagnosis to children to protect them from the negative psychological or emotional consequences of disclosure (Domek, 2010; Funk-Brentano, et al., 1997; Lesch, et al., 2007; Oberdorfer, et al., 2006; Schonfeld, 1997; Wiener, et al., 1996). Another study revealed that some caregivers felt that the child deserves to have as carefree a childhood as possible, not want to scare the child and not wanting the child to be hurt by the reactions of others about their HIV diagnosis (Ostrom, et al., 2006).

5.10.4 Caregiver's fears that the child might blame her

Caregivers of HIV-infected children unlike other people living HIV who don't take care of HIV-infected children, experience a unique struggle with the child's HIV status disclosure mainly because of the secondary disclosure of their own HIV positive status as the child's disclosure often leads to the caregiver answering difficult questions about their own personal history with HIV infection. In line with Oberdorfer, et al. (2006) argument that biological mothers who haven't disclosed fear being blamed for infecting their child with HIV hence choose not to disclose to the child. A study by Waugh, (2003) on this phenomenon found that mothers avoid disclosure because of fear that their child will blame them for the disease and that this will adversely affect the mother-child relationship. Overall, the caregivers reported a sense of guilt about having transmitted their HIV infection to the child.

5.11 Information told to a child not disclose to

Caregivers responded to a question about what had been told to the child about their illness and in contrast with caregivers who have disclosed the HIV diagnosis to the child, caregivers who have not disclosed to their children chose to tell children inaccurate information about their illness when children enquired about their illness or medication. Our findings support recent data showing that half of caregivers in a Ugandan survey reported not having provided their children with any information about their HIV diagnosis while a third reported giving only deceptive information to their children Vaz, (2011). While other studies show that caregivers who reported that the child did not know about the disease had inaccurately explained to the child that he or she had some kind of disease such as allergy, lung, or liver disease, gastrointestinal, cardiac, blood or congenital disorder (Bhattacharya, et al., 2010; Oberdorfer, et al., 2006). Funck-Brentano, et al., (1997) refer to the disclosure strategy whereby caregivers provide children with deceptive information about their illness as partial disclosure. Researchers on disclosure of HIV to children argue that

providing deceptive information is a strategy used when caregivers feel unprepared for full disclosure (Blasini, et al., 2004; 1999; Funck-Brentano, et al., 1997; Wiener, et al., 1998; Wiener, et al., 2007b)

5.12 Strategies to manage disclosure

Previously researchers identified strategies that caregivers use to manage disclosure particularly when the child has not been disclosed to (Ledlie, 1999). Instilling fear was identified as a strategy used by caregivers to coerce children to continue taking medication in the absence of disclosure (Hejoaka, 2008). In an attempt to avoid disclosure, some of the caregivers in this study coerced or threaten children with death or illness to persuade their children to take their medication even when the child is not feeling ill anymore. These findings agree with recent data showing that force and persuasion are often used to get the children to adhere to their medication (Kallem, et al.2010; Bikaako-Kajura, et al. 2006).

One other way caregivers persuade children to continue taking medication was often to use the healthcare providers in their strategies to address the reluctance of the children to take the medicine. In this study caregiver would tell the child to continue with the medication until the doctor tells them to stop. Because of severity of the illness that characterize HIV infection in children, most of the children in this study had been very sick prior to initiation of ART and were possibly admitted in hospital and children are therefore scared of readmission.

5.13 Caregiver's experience with non-disclosure

Data shows that caregivers who did not disclose the HIV diagnosis to their children experienced emotional stress because they didn't tell the child about their illness. In fact some caregivers reported that they live with regret as they fear they might not be doing the right thing by not telling the HIV-infected child about their status. This is supported by one study of HIV-infected children that looked at parental emotional

functioning in relationship to disclosure indicated that parents who chose to disclose actually reported less distress than non-disclosing parents (Weiner et al., 1996). This suggests that despite caregivers not disclosing to the children they experience relatively increased anxiety or depression as opposed to the disclosed caregivers.

5.14 Intention to disclose

Caregivers who did not disclose stated that they see HIV diagnosis disclosure as a good thing to do and intend to do it when the child is emotionally and cognitively prepared to understand the disease. Hence some caregivers reported that they will wait until a child reaches a certain level of maturity and age before they can disclose to them as they believe at that level the child will be able to understand HIV/AIDS information and cope with their status better.

Similar findings were found in a study by Lester, et al., (2002) where HIV diagnosis disclosure to perinatally HIV-infected children is often delayed by caregivers until such a time when the child was well into their school age as they believe at that age children are mature enough to be disclosed to. Furthermore in a study by Lesch, et al (2007) comparing groups of children who had been disclosed to and those who had not, the disclosed groups were significantly older than the non-disclosed groups further affirming this practice that caregivers tend to delay disclosure until a certain the child reaches a certain age.

5.15 Who should disclose

Caregivers saw themselves as primarily responsible for disclosing the HIV diagnosis to the child as they feel disclosure is a painful and sensitive process for both them and the child hence it needs to be done by someone who will take the child's welfare into consideration so as to minimize inflicting emotional hurt on the child. In fact a study by Dematteo, et al (2002) found that HIV-positive caregivers were more likely than those who were HIV negative to feel they were the best person to disclose. Both

caregivers who have disclosed and those who have not disclosed stated that they wished health care workers like a doctor, nurse or social worker could assist them to initiate disclosure and also offer assistance in the event the child asks difficult questions about their illness and medication. In studies by (Biadgilign et al., 2011; Dematteo, et al., 2002; Vaz, et al., 2008) caregivers revealed that they would like the doctor or nurse to hold disclosure preparation activities prior to the disclosure and they wish the preparations would include talking to responses to questions the child might ask during disclosure which the caregiver might not be knowing.

5.16 Conclusions

Based on the findings of this study conclusions can be drawn that this study highlights the emerging challenges of HIV disclosure in children with HIV in Botswana faced by their caregivers. This study further describes these challenges in the context of an African country like Botswana where there is rapid scale-up of HIV/AIDS treatment services and ARV roll-out to HIV-infected children.

A conclusion can be drawn that, HIV diagnosis disclosure is high among caregivers of children on ARV treatment in Botswana and also that most of the disclosure occurred in children who were relatively older and in their puberty years and this is inconsistent with findings from other studies done on pediatric disclosure.

The study can conclude that caregivers who disclose to children with HIV are motivated firstly by a perception that disclosure will improve the child's acceptance of his/her HIV status as well as by a number of reasons to do so and such reasons include; the believe that the child has a right to know about their illness, fear of the child getting to know of their HIV status accidentally from inaccurate sources.

On the other hand, non-disclosing caregivers of HIV-infected children respond to the child's HIV diagnosis disclosure by concealing the diagnosis to the child but only uncovering certain aspects of the disease. Such decision is based on the caregiver's

personal perceptions of self-readiness to tell the child, the child's age or maturity level, fear of causing emotional stress to the child and fear of the child blaming the biological mother for infecting them with HIV. Furthermore, caregivers who do not disclose the HIV positive diagnosis to the HIV-infected child resort to using inaccurate information; lying, substituting names, selective telling when explaining the child's illness and medication.

5.17 Study Limitations

Although this study was limited by its qualitative design and use of convenience sampling, other important limitations include;

- Given our study design we were not able to interview the children so as to get their response of how HIV diagnosis disclosure affected them but instead relied on caregivers who could be biased in their reporting i.e. as they cannot account for every emotion the child was going through during post-disclosure.
- The study did not collect clinical information about the child's health like time disclosure was done and the time child was started on ARVs, history of hospitalization or serious illness related to HIV as we felt caregiver's of the child's health might be more important in understanding disclosure/non-disclosure reasons and experiences
- We also didn't capture the caregivers' own HIV status which might be a strong influence on the caregiver's perceptions and practices are in HIV diagnosis disclosure to the child.
- Another limitation was that we recruited from a health facility that provides medical treatment including access to antiretroviral therapy (ARVs) hence the experiences of caregivers with children who have been diagnosed but do not have access to medical care especially ARVs might be quite different and should be further explored.

5.18 Recommendations

Based on the findings of this study, the researcher has the following recommendations:

- The Government of Botswana as well as its partners in the running of the National ARV Programme and other HIV/AIDS programmes should incorporate the practice of HIV disclosure to HIV-infected children in the HIV/AIDS Policy as this will ensure that HIV diagnosis disclosure becomes a standard practice in management of children with HIV as opposed to where disclosed is done by only those who are interested in doing it.
- The Government and partner organization should look into developing pediatric HIV disclosure guidelines that will guide both caregivers and healthcare workers on the disclosure process as this will lay clear steps of how and when disclosure should be done, what information should be given and by whom with the aim of making disclosure easy and practical to both health care workers and caregivers.
- A longitudinal study using mixed method design should be done to gain further understanding in the processes of disclosure where the qualitative aspect of the study will be used to address the quality of caregiver-child interactions on HIV disclosure, while the quantitative aspect will assess the impact of disclosure. Such a study will help researchers and healthcare workers to gain an in-depth knowledge on factors that promote or hinder HIV status disclosure by caregivers to HIV-infected children.

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Appendix 1: In-depth interview guide-English

Title: Disclosure of HIV infection by caregivers to children with HIV/AIDS in Thamaga Primary Hospital- Botswana: Reasons and Experiences

Thank you for agreeing to participate in this in-depth interview, my name is Paul Oteng Motshome, I am from Scottish Livingstone Hospital and I am a student at the University of Limpopo. I am talking to caregivers/parents of children living with HIV taking ART at Thamaga Primary Hospital ART Clinic. I would like to get your views and opinions about disclosure of HIV positive status of a child. You don't have to have disclosed the HIV positive diagnosis to the child to answer the questions; the discussion is about the reasons to disclose or not to disclose the status of the child. I would like to also get the experience of the caregivers/parents who have disclosed.

Respondent code _____

Date of interview: ____/____/____

Section 1 Demographic profile of caregivers and children

1. Age of the child in years:

2. Child's gender:

Male	<input type="checkbox"/>
Female	<input type="checkbox"/>

3. Is the child schooling?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

4. If the answer to question 3 is yes, what grade is the child in?

Kindergarten	
Primary school level	
Secondary school level	

5. How are you related to the child?

Biological Mother	
Biological Father	
Grandmother/Grandfather	
Other	

6. What is your age in years?

7. Gender

Male	
Female	

8. What is your marital status?

Single	
Married	
Separated	
Divorced	
Living in	

9. What is your religion?

Christian	
Muslim	
Traditional believer	

	Other	
--	-------	--

10. What is your highest level of education?

Never been to school	
Primary level	
Junior secondary level	
Senior secondary level	
Tertiary level	

11. What is your means of earning income?

Full time employment	
Part time employment	
Self employed	
On social welfare support	

12. Apart from you, who else in the family is aware of the child's HIV positive diagnosis?

Mother	
Father	
Grandmother	
Other siblings/Brother/sister	
Other members of the family	

Section 2: In-depth interview guide

The next set of questions is focusing on telling or not telling the child about their HIV status. I would like to once more assure you about the confidentiality of what

were are discussing here, please feel free to tell me when you are not comfortable about any of the questions, but I would appreciate if you could answer as many of the question as possible.

1. Could you tell me if the child knows about his/her status?

Probes

- How did the child learn about his/her status?
- Who told the child about his/her status?
- How old was the child when he/she was told?

2. If the child has been told, could you please explain the main reasons for telling the child about his/her HIV status?

Probes

- Was the disclosure planned or accidental?
- Was the disclosure driven by the child's agenda?

3. Could you please explain the information that was told the child about his/her illness?

4. In your experience was telling the child about his/her disease a good or bad for the family, please explain why you say so?

5. After having had some experience about telling the child about his/her status would you say it is it is important for children to know about their illness?

Please explain

6. Would you say that the time was right to inform the child about his/her status when you told him/her, please explain why you say so

Probes

- Was the age of the child; level of maturity of the child; social support at home right?
7. Could you please explain the reactions of the child when told about his/her HIV status
 8. What made it possible or easy for you to tell the child about his/her HIV positive status?

Probes

- What were some of the strategies, interventions, tools used by the caregiver to facilitate disclosure

Non-disclosed caregivers

1. If the child has not been told about his/her HIV status, please the reasons for not telling him/her?

Probes

- Would you say it is not the right time to tell the child and why so?

- When would you say is the right time to tell the child about his/her status, please explain
2. Who in your opinion should be responsible to tell the child about his/her HIV positive status? Please explain your reasons
 3. In your opinion despite the fact that you haven't told the child about his/her status, do you think it is important or is it good for the child to know their HIV status? Please explain your reasons
 4. In your experience would you say that not telling the child about his/her HIV positive status was good or bad for the child? Please explain your reasons
 5. Could you please explain the information that was told the child about their illness, how have you been able to explain their taking ARVs?

Appendix 2: In-depth interview guide-Setswana

Tlhogo: Mabaka le maitemogelo a batlhokomedu ba bana ba ba tshelang le mogare wa HIV/AIDS fa ba ne ba itsise fa ba tshela le mogare wa HIV/AIDS.

Ke lebogela go bo o dumetse go tsaya karolo mo di patlisisong tse, leina lame ke Paul Oteng Motshome ke direla kwa sepatela sa Scottish Livingstone Hospital gape ke moithuti kwa Unibesiti ya Limpopo kwa Afrika Borwa. Dipatlisiso tse, ke di dira ka go buisanya le batsadi kgotsa batlhokomedu ba bana ba ba tshelang le mogare wa HIV gape ba tsaya diritibatsi tsa ARV mo sepatela sa Thamaga Primary Hospital.

Mo dipatlisisong tse, ke tlaabo ke batla go itse mogopolo kgotsa maitemogelo/dikgwetlho tsa gago mabapi le go bolelela ngwana yoo ka mogare wa HIV yo a tshelang nao. Mme itse gore re botsa batsadi/batlhokomedu ba bana go sa kgathalesege gore a o setse o boleletse ngwana ka seemo sa gagwe sa mogare.

Nomere ya motsaya karolo:

Letsatsi: ____/____/____

Karolo ya ntlha: Matselo a motlhokomedu wa ngwana le ngwana

1. Dingwaga tsa ngawana:

2. Bong jwa ngwana:

Mosimane	
Mosetsana	

3. A ngwana o tsena sekolo?

Ee	
Nnya	

4. Fa karabo kwa potso 3 ele ee,
ngwana o dira lekwalo la bo kae?

Sekolo sa bana	
Sekolo sa Primary	
Sekolo sa Secondary	

5. O sikana jaang le ngwana?

Mmaagwe ngwana ka matsalo	
Rraagwe ngwana ka matsalo	
Mmaagwe mogolo/Rraagwe mogolo	
Tse dingwe	

6. Dingwaga tsa motlhomedi wa ngwana

7. Bong jwa motlhokomedi wa ngwana

Monna	
Mosadi	

8. A o nyetse/nyetswe?

Ga ke a nyala/nyalwa	
Ke nyetse	
Ke tladile	
Re nna mmogo	
Ke swetswe	

9. O obamela tumelo ofe?

Mokeresete	
Momusilum	
Tumelo tsa setso	
Tse dingwe	

10. O tsene sekolo go ema ka lekwalo lefe?

Ga ke is eke tsene sekolo	
Ka sekolo se se potlana	
Ka sekolo se se golwane sa mophato wa ntlha go ema wa bobedi kgotsa wa boraro	
Ka sekolo se se golwane sa mophato wa boraro/wa bone go ema ka wa botlhano	
Tse dingwe	

11. Le itshetsa jang mo lwapeng?

Ke a bereka	
Ke bereka tiro ya letsatsi	
Ke a ipereka	
Re dirisa dithusa tsa batlhoki	

12. Ntle le wena a gona le mongwe yo itseng gore ngwana yo o tshela le mogre?

Mmaagwe	
Rraagwe	
Rraagwemogolo/mmaagwemogolo	
Babangwe ba losika	

Karolo ya bobedi: Dipotso tse di tseneletseng tsa dipatlisiso

Dipotso tse di latelang di itebagantse le go bolelela kgotsa go saa bolelela ngwana ka seemo sa gagwe sa go tshela le mogare wa HIV. Ke sa boeletsa ke go itsesi fa puisanyo ee yame le wena ele magareng ga rona fela mme jalo he eke kopa gore o phuthuloge fa o araba dipotso. Fa go na le ntlha nngwe e o sa go tseeng sentle o seka wa tshaba go tlhalosa jalo mme ke ka itumela thata fa o ka araba dipotso tshotlhe.

1. A ngwana o itse ka seemo sa gagwe sa mogare?

Dintlha

- Go tsile jang gore ngwana a itse ka seemo sa gagwe?
 - Ke mangy o boleletseng ngwana ka seemo sa gagwe?
 - Ngwana o ne a le dingwaga tse kae fa a bolelelwa ka seemo sa gagwe?
2. Fa ngwana a boleletswe ka seemo sa gagwe sa mogare, o bolelea gore mabaka a gore o bolele ngwana ka seemo sa gagwe sa mogare e ne ele eng?

Dintlha

- A go diragetse ka maikaelelo kgotsa ka tshoganetso?
 - A ngwana ke ene a neeng a botsa ka bolwetse jwa gagwe?
3. A o ka tlhalosa gore o boleletse ngwana eng fela ka bolwetse jwa gagwe

4. Go ya ka boitemogelo jwa gago o bona go bolelela ngwana ka seemo sa gagwe sa go tshela le mogare wa HIV go siame kgotsa nnya? Tlhalosa mabaka a karabo ya gago
5. Ka o na le maitemogelo ka go bolelela ngwana ka seemo sa gagwe sa go tshela le mogare HIV, a o bona go le botlhokwa gore ngwana itse gore o tshela le mogare wa HIV
6. A o bona nako e ne e gorogile ya gore o bolele ngwana ka seemo sa gagwe sa go tshela ka mogare wa HIV, ke eng o rialo?
7. Ke kopa gore o tlhalose gore ngwana o ne a tseega jang fa o mmolelela gore o tshela le mogare wa HIV
8. Ke eng se se dirileng gore go nne motlhofo gore o kgone go bolelela ngwana gore o tshela le mogare wa HIV

Dintlha

- O dirisitse tshela efe gore o kgone go dira jalo

Batsadi/Batlhokomedi ba ba sa bolelelang bana gore ba tshela ka mogare wa HIV

1. Fa ele gore ga wa bolelela ngwana ka seemo sa gagwe sa mogare wa HIV, mabaka a gago ke eng?

Dintlha

- A o kare o ne o bona nako ya gore o mo itsise ise e goroge, o raya jang?
- O bona nako ya go itsise ngwana ka seemo sa gagwe sa mogare e siameng ele efe? O ka tlhalosa go ya pele.

2. Go ya ka wena o bona ele maikarabelo a ga mang gore a bolele ngwana gore o tshela le mogare wa HIV? O ka tshalosa go ya pele.
3. Le fa o setse o buile fa o ise o bolele ngwana fa ana le mogare wa HIV, a o bona go mmolelela ele selo se se siameng kgotsa nnya? Tswelela o tshalose karabo ya gago.
4. Go ya ka maitemogelo a gago, a o bona go bolelela ngwana ka seemo sa gagwe sa go tshela le mogare go siametse ngwana? Tswelela o tshalose.
5. Mo sebakeng a o ka tshalosa gore o reile ngwana ware eng ka bolwetse jwa gagwe, o mo tshaloseditse jaang ka melemo ya gagwe ya ARV?

Appendix 3: Informed consent English Version

Informed consent- UNIVERSITY OF LIMPOPO (Medunsa Campus) CONSENT FORM
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Title: Disclosure of HIV infection by caregivers to children with HIV/AIDS in Thamaga Primary Hospital- Botswana: Reasons and Experiences

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

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

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

I hereby give consent to participate in this study.

Name of participant

Signature of participant

Place.

Date _____

Witness _____

Statement by the Researcher

I provided verbal information regarding this study

I agree to answer any future questions concerning the study as best as I am able.
I will adhere to the approved protocol.

.....
Name of Researcher

.....
Signature

.....
Date

Appendix 4: Informed consent Tswana Version

Informed consent- UNIVERSITY OF LIMPOPO (Medunsa Campus) CONSENT FORM
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Mabaka le maitemogelo a batlhokomedi ba bana ba ba tshelang le mogare wa HIV/AIDS fa ba ne ba itsise fa ba tshela le mogare wa HIV/AIDS.

Ke a tlhomamisa gore ke tlhoganya ka botlalo maikemisetso le maikaelelo a dipatlisiso tse ebile ke ne ke filwe sebaka sa go botsa dipotso ebile gape ke ne ka fiwa sebaka sa go ikakanya ka jalo ke tlhalogantse maikemisetso le maikaelelo a dipatlisiso tse ka jalo ga ke a patelediwa go tsaya karolo mo dipatlisisong tse.

Ke atlhaloganya gore go tsaya karolo ga mme modipatlisisong tse ke abo ke ithaopa ka jalo ke ka tswa mo go tsone fa ke sa tseege sentle ntle le go ntsha mabaka ape a go tswa ga mme. Mo godimo ga moo, go tswa ga mme ga go kitla go ama dithuso tsa kalafi tse ngwana a dibonang mo go ba bongaka mo kokelong ee.

Ke a itse gore dipatlisiso tse di rebotswe ke ba Medunsa Campus Research and Ethics Committee (MCREC), University of Limpopo (Medunsa Campus). Gape ke a itse gore maduo a dipatlisiso tse a tla thusa go tokafatsa dithuso tsa ba botsogo gape maduo a ka nna a gatsiwa mo dibukaneng tsa bomaitsaanape ba botsogo ka jalo ke dumalana le se fela fa sephiri sa tumalano ee se ka tshegediwa.

Ka jalo ke dumalana le go tsaya karolo mo dipatlisisong tse.

Leina la motsayakarolo

Seatla sa motsayakarolo

Lefelo

____/____/____

Letsatsi

Mosupi

Lefoko ka mmatlisisi

Ke tlomamisa gore ke file motsayakarolo dithuto tsotlhe ka ga dipatlhisiso tse.

Ke solofetsa gore ke tla araba dipotso tsotlhe mabapi le dipatlisiso tse ka go ya ka maitemogelo ame.

Ke solofetsa fa ke tla sela ditumalano tsa dipatlisiso se morago.

Leina la mmatlisisi

Seatla

____/____/_____
Letsatsi

Appendix 5: Permission Letter

The Chief Medical Officer
Thamaga Primary Hospital
Private Bag 451
Thamaga
Botswana

P O Box 1222
Mogoditshane
Botswana

RE: Permission to conduct a study in Thamaga Primary Hospital

Dear Sir/Madam

My name is Paul Oteng Motshome I am studying for a Master of Public Health Degree at the School of Public Health, University of Limpopo MEDUNSA Campus. I am required to submit a research report for the partial fulfilment of my degree.

I hereby kindly seek permission to undertake a study on disclosure of HIV infection by caregivers to children living with HIV/AIDS in Thamaga Primary Hospital. The study aims to explore reasons for HIV positive diagnosis disclosure and non-disclosure by caregivers to children living with HIV/AIDS and also explore the experiences of disclosing HIV diagnosis children.

My study proposal is still to be reviewed by the Research and Ethics Committee of the National School of Public Health and the MEDUNSA Research and Ethics Committee. Permission will also be sought from the Ministry of Health.

The findings from the study will help develop knowledge on reasons for HIV positive diagnosis disclosure and non disclosure by caregivers of children living HIV and further lay foundation for further research on this issue. The study findings will also be used for intervention purposes in the management of children living with HIV/AIDS particularly the development of HIV diagnosis disclosure guidelines in ART clinics.

Yours sincerely

.....

Paul Oteng Motshome (Mr)

Mobile: +26771845532

Work: +2673555208

Appendix 6: Approval from Ministry of Health Ethics Committee- Botswana

Telephone: (267) 363200
FAX (267) 353100
TELEGRAMS: RABONGAKA
TELEX: 2818 CARE BD



MINISTRY OF HEALTH
PRIVATE BAG 0038
GABORONE

REPUBLIC OF BOTSWANA

REFERENCE NO: PPME 13/18/1 PS IV (63)

25 September 2009

Health Research and Development Division

Notification of IRB Review: New application

Mr Paul Oteng Motshome
P.O. Box 1222
Gaborone

Protocol Title:

**REASONS AND EXPERIENCES OF
CAREGIVERS ON DISCLOSURE OF HIV
INFECTION TO CHILDREN LIVING WITH
HIV/AIDS IN THAMAGA PRIMARY
HOSPITAL - BOTSWANA**

HRU Protocol Number:

HRU 00559

Sponsor:

N/A

HRU Review Date:

September 24, 2009

HRU Expiration Date:

September 23, 2010

HRU Review Type:

HRU reviewed

HRU Review Determination:

Approved

Risk Determination:

Minimal risk

Dear Mr Motshome

Thank you for submitting a new Application for the above referenced Protocol.

This approval includes the following:

1. Application form
2. Proposal
3. Data collection tool
4. Consent form

This permit does not however give you authority to collect data from the selected site without prior approval from the management. Consent from the identified individuals should be obtained at all times.

The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal must be submitted to the Health Research and Development Division in the Ministry of Health for consideration and approval.

Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research, Ministry of Health within 3 months of completion of the study. Approval is for academic fulfillment only. Copies should also be submitted to all other relevant authorities.

If you have any questions please do not hesitate to contact Mr. P. Khulumani at pkhulumani@gov.bw, Tel +267-3914467 or Mary Kasule at mkasule@gov.bw or marykasule@gmail.com Tel: +267-3632466

Continuing Review

In order to continue work on this study (including data analysis) beyond the expiry date, submit a Continuing Review Form for Approval at least three (3) months prior to the protocol's expiration date. The Continuing Review Form can be obtained from the Health Research Division Office (HRDD), Office No. 9A 11 or Ministry of Health website: www.moh.gov.bw or can be requested via e-mail from Mr. Kgomotso Motlhanka, e-mail address: kgmmotlhanka@gov.bw As a courtesy, the HRDD will send you a reminder email about eight (8) weeks before the lapse date, but failure to receive it does not affect your responsibility to submit a timely Continuing Report form

Amendments

During the approval period, if you propose any change to the protocol such as its funding source, recruiting materials, or consent documents, you must seek HRDC approval before implementing it. Please summarize the proposed change and the rationale for it in the amendment form available from the Health Research Division Office (HRDD), Office No. 9A 11 or Ministry of Health website: www.moh.gov.bw or can be requested via e-mail from Mr. Kgomotso Motlhanka, e-mail address: kmotlhanka@gov.bw . In addition submit three copies of an updated version of your original protocol application showing all proposed changes in bold or "track changes".

Reporting

Other events which must be reported promptly in writing to the HRDC include:

- Suspension or termination of the protocol by you or the grantor
- Unexpected problems involving risk to subjects or others
- Adverse events, including unanticipated or anticipated but severe physical harm to subjects.

Do not hesitate to contact us if you have any questions. Thank you for your cooperation and your commitment to the protection of human subjects in research.

Yours sincerely



P. Khulumani
For Permanent Secretary



Appendix 7: Ethical clearance certificate

UNIVERSITY OF LIMPOPO

Medunsa Campus



MEDUNSA RESEARCH & ETHICS COMMITTEE

CLEARANCE CERTIFICATE

P O Medunsa
Medunsa
0204
SOUTH AFRICA

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

MEETING: 06/2009

PROJECT NUMBER: MREC/PH/100/2009: PG

PROJECT :

Title: Disclosure of HIV infection by caregivers to children living with HIV / AIDS in Thamaga Primary Hospital – Botswana: Reasons and Experiences.

Researcher: Mr PO Motshome
Supervisor: Ms S Madiba
Department: Environmental and Occupational Health
School: Public Health
Degree: MPH

DECISION OF THE COMMITTEE:

MREC approved the project.

DATE: 05 August 2009




PROF GA OGUNBANJO
CHAIRPERSON MREC

Note:

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

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