HIV disclosure to perinatally infected children and adolescents: A study of healthcare workers' perspectives in Alfred Nzo Health District

By
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Declaration

I, Welfare Cynthia Diko, declare that all the work in and contributions made in this study on “HIV disclosure to perinatally infected children and adolescents: a study of healthcare workers' perspectives in Alfred Nzo Health District, Eastern Cape Province” were carried out by me independently, and all the sources used have been acknowledged accordingly. There is no segment of this dissertation that has been submitted in support of an application for another degree or qualification to any other institution of learning.

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Welfare Cynthia Diko      Date
Acknowledgements:

I say Ebenezer to my God El Shaddai, Jehovah Nissi, M’kdes, Tsidkenu for walking with me until this far.

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Dedication

I dedicate this study to my loving and kind-hearted husband, the father of my children, Dr Prince Mveli Diko, for holding my hand steadily until the going down of the sun, walking with me from the deepest valley until to the highest mountain.

To my adorable, wonderful and precious angels, Vuyiswa, Mveli-Junior and Ovayo, for their love, contributions, understanding, sacrifices and undivided support of my academic journey, irrespective of the family time being compromised.

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To my siblings for believing in me and helping me to run this race to the end.

To my nieces and nephews for believing in me.
Abstract

Introduction
Disclosure to children and adolescents with perinatal HIV (PHIV) is linked to their care and management. Therefore, disclosure to children with PHIV is a process that should be managed and carried out by a team, and health care workers (HCWs) and caregivers are at the centre of the disclosure process. Therefore, joint efforts from caregivers and HCWs is imperative for the successful disclosure to children with PHIV. However, previous research has focussed on the perspectives of caregivers regarding HIV disclosure to children, with the exclusion of HCWs.

Aim and objectives
The aim of the study was to assess the perspectives of health care workers regarding the disclosure to perinatally infected children and adolescents of their HIV status, and to examine their disclosure practices.

Methodology
This research project employed a qualitative exploratory design, involving holding focus group discussions with 51 HCWs offering HAART services to children and adults. Purposive sampling was used to select HCWs from health facilities in the Alfred Nzo Health District, Eastern Cape Province. The data generated were analysed using NVivo version 12, following the thematic data analysis approach.

Findings
The HCWs had different views on when disclosure should be initiated, but emphasised that the age and maturity of the child should be considered in making a decision. They believed that disclosure promotes adherence to a regimen, and cited refusal to take medication and poor adherence as the main reasons caregivers disclose. Disclosure is delayed when the caregivers believe that the child is too young, the barriers to disclosure being identified as fear of stigma and discrimination, inadequate knowledge about HIV, and lack disclosure skills. The most important consequence of delayed disclosure is poor adherence to treatment. Delayed disclosure increases the potential for children to default, to refuse to
take their medication, and to transmit HIV to potential sexual partners and others. The participants reported negative reactions after disclosure. The children disclosed to refused to continue with their treatment, were distressed, angry and sad. The HCWs preferred that the caregiver carry out the disclosure.

**Conclusion**
The study found that despite the lack of disclosure guidelines for children, most of the HCWs routinely disclose to children and adolescents. They approach disclosure as an ongoing process that includes planning for disclosure, the actual disclosure event, and follow-up support for caregivers and children after disclosure. The main barriers against disclosure are the lack of specific paediatric disclosure guidelines and inadequate disclosure skills.

**Recommendations**
Although the World Health Organisation and the National Department of Health have published disclosure guidelines for children, these are not being utilised by the HCWs in the facilities. It is imperative that facilities in the District should adopt the national department of health guidelines for disclosure to children to assist HCWs on the topic of how to conduct disclosure to children and adolescents.

Furthermore, the HCWs should be trained in disclosure counselling for children and adolescents to facilitate disclosure and support the caregivers.
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<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<td>ANC</td>
<td>Antenatal Clinic</td>
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<td>ART</td>
<td>Antiretroviral Treatment</td>
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<td>CHC</td>
<td>Community Health Centre</td>
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<td>HAART</td>
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<td>HIV</td>
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Chapter 1: Background and Introduction

1.1 Introduction

Paediatric HIV infection continues to be a major challenge globally. It is estimated that about 3.3 million children below the age of 15 years are living with HIV globally and over 2 million of these children are found in sub-Saharan Africa (Kiwanuka et al., 2014; Phiri and Chilemba, 2015; Sariah et al., 2016). South Africa (SA) is one of the countries with the highest number of HIV-infected children and adolescents and the largest HAART programme for children in the world (Fatti et al., 2010). It is estimated that in 2012 about 2.4% of children between the ages of 2 and 14 years and 1.7% of children in South Africa under five years of age had been perinatally infected with HIV. Almost half (45%) of the children with perinatal HIV (PHIV) were on antiretroviral treatment (ART) in 2012 (NDOH, 2016).

The increase in the survival rate to adolescence and beyond of children with PHIV is due to the accessibility of ART in developing countries. The scale-up of HAART therapy, which suppresses the HIV replication and prevents opportunistic infections, has contributed to the survival of children with PHIV to adolescence (Heeren et al., 2012). Therefore, children with PHIV are no longer perceived to have a terminal illness but a chronic disease requiring cognitive and emotional adaptation for children and adolescents (Phiri and Chilemba, 2015).

As the increased survival of children with PHIV is observed, the issue of the disclosure of their HIV status to children and adolescents with PHIV arises. Disclosure plays a vital role in the continuum of paediatric HIV care (Madiba, 2016a; Baker et al., 2018). The literature correctly asserts that disclosure improves and expands the knowledge and understanding of the child about the disease, which helps to improve treatment adherence (Madiba, 2012; Turissini et al., 2013; Kidia et al., 2014; Madiba, 2016; Sariah et al., 2016; Baker et al., 2018). The relationship and communication between peers, parents and HCWs are also nourished when children know their HIV status (Namasopo-Oleja et al., 2015).

Moreover, disclosure to children and adolescents with PHIV helps to develop coping skills, to create a bond with and trust in parents and service providers, promotes safe sexual
practices (thus protecting others from being infected), and improves adherence to ART treatment (Madiba and Mokgatle, 2015; Namasopo-Olenja et al., 2015; O’Malley et al., 2015). Apart from intensifying precautionary measures to prevent the spread of HIV, disclosure to children and adolescents can support the appropriate practices to prevent pregnancy (Turissini et al., 2013). Again, disclosure alleviates depression in the children as they grow, and enables their access to social support (Vaz et al., 2011).

Despite the well-documented benefits of disclosure to children and adolescents with PHIV, the literature shows that many children and adolescents remain unaware of their HIV status (Manye and Madiba, 2014; Mumburi et al., 2014). The disclosure rates for children with PHIV vary between continents, but the rates in developed countries are higher than those in developing countries, ranging between 18% and 77% (Kallem et al., 2011; Kenu et al., 2014). The progress of disclosure to children and adolescents continues to be unsatisfactory in sub-Saharan African countries, and in some countries, disclosure is documented as ranging from 1.7% to 41% (Turissini et al., 2013). In general, the disclosure rate of their HIV status to children with PHIV is low, regardless of the actual numbers of infected children (O’Malley et al., 2015).

Health care workers (HCWs) and caregivers of children with PHIV are faced with the challenge of disclosing to these children (Kidia et al., 2014; Sariah et al., 2016). HCWs believe that children are more sensitive than adults. Hence they fear to talk to them about their HIV, because of the unfavourable outcomes that might emerge thereafter (Rujumba et al., 2010, Watermeyer, 2013). Studies have shown that HCWs and caregivers have inadequate guidance on how to approach the issue of disclosure to children with perinatal HIV. They know little more than that full disclosure is encouraged and that it should happen in developmentally appropriate stages (Kidia et al., 2014).

HCWs indicate that HIV disclosure to children is affected by challenges such as the caregivers’ lack of knowledge and disclosure skills, and fear that the children will disclose their HIV status to other people, which could result in the stigmatisation of the family, and discrimination against it. Other barriers to disclosure include the caregiver’s denial of the
HIV diagnosis, the fear of being judged, and the fear of being blamed by the children (Rujumba et al., 2010; Heeren et al., 2012; Madiba and Mokgatle, 2015; Gyamfi et al., 2017).

HCWs have particular views on who is responsible for disclosing to children with PHIV. Most of them view disclosure as the responsibility of the caregiver, who should disclose when they believe that the children are mentally ready (Heeren et al., 2012; Watermeyer, 2013; Namasopo-Olenja et al., 2015; Sariah et al., 2016). According to Madiba and Mokgatle (2015), HCWs argue that caregivers know when the child is ready for disclosure. In addition, HCWs in Tanzania think that caregivers are in a better position to support their children in adhering to the prescribed treatment and to comfort them after the disclosure (Sariah et al., 2016). In addition, children have more trust in their caregivers, who will therefore receive the cooperation of their children during the process (Heeren et al., 2012; Okechukwu et al., 2018).

HCWs see their roles as that of preparing and supporting the caregivers in disclosing when they are requested to do so. They also see their role as that of counselling and providing continuous emotional support to the caregivers, children, and adolescents during and after disclosure (Watermeyer, 2013; Madiba and Mokgatle, 2015; Namasopo-Oleja et al., 2015; Sariah et al., 2016; Okechukwu et al., 2018). On the other hand, HCWs feel that they could disclose if caregivers completely fail to do so (Namasopo-Olenja et al., 2015). In addition, they feel that they are responsible for providing information on medication to promote adherence in children (Beima-Sofie et al., 2014; Madiba and Mokgatle, 2015, Sariah et al., 2016). Lastly, they feel that they have the role of correcting the information that has been provided by caregivers at home (Kidia et al., 2014).

In contrast, some HCWs in South African and Namibian studies see disclosure to children with PHIV as a joint endeavour between them and the caregivers of the children. They regard themselves as having dual roles such as providing information on medication, assessment, and providing continuous emotional support to both the child and the caregiver (Beima-Sofie et al., 2014; Madiba and Mokgatle, 2015). They also emphasise that disclosure to children is not an easy assignment. Hence, the provision of assistance to parents or caregivers by HCWs is imperative (Beima-Sofie et al, 2014; Madiba and Mokgatle, 2015;
To some extent, HCWs believe that they are more knowledgeable than parents or caregivers and are better skilled to manage negative reactions from children during disclosure (Madiba and Mokgatle, 2015; Okechukwu et al., 2018). Although caregivers want to be responsible for initiating disclosure, they stress the need for support from HCWs during the process of disclosure, as they feel their skills are inadequate (Madiba, 2016a). The variation in the views of HCWs concerning HIV disclosure to children leads to inconsistent practices in facilities in sub-Saharan Africa.

Their lack of knowledge of relevant guidelines and their insufficient training also create uncertainty among HCWs regarding their roles and responsibilities in the process of disclosing to children (Watermeyer, 2013; O’Malley et al., 2015; Sariah et al., 2016). In many parts of sub-Saharan Africa disclosure to children and adolescents remains a difficult task for HCWs and caregivers due to their inadequate training on paediatric HIV care, the unavailability of guidelines, and the absence assessment tools (Watermeyer, 2013; O’Malley et al., 2015; Sariah et al., 2016). It is therefore crucial that health services mount disclosure programmes that would allow HCWs to support caregivers to disclose to HIV-infected children (Kidia et al., 2014).

1.2 Problem statement:

The rate of disclosure of their HIV status to children and adolescents with perinatal HIV in sub-Saharan Africa is still low, in spite of the benefits of disclosure acknowledged by HCWs, parents, and caregivers (Beima-Sofie et al., 2014; Gyamfi et al., 2017). This is affected by the fact that HCWs and caregivers have different views about when to, how to, and who should disclose to children and adolescents with perinatal HIV (Heeren et al., 2012; Watermeyer, 2013; Beima-Sofie et al., 2014; Kidia et al., 2014; Madiba and Mokgatle, 2015; O’Malley et al., 2015; Sariah et al., 2016). HCWs are reluctant to participate in HIV disclosure to children whilst some feel uncomfortable and confused about whose role it is to disclose to children with perinatal HIV (Sariah et al., 2016).
Available studies in Sub-Saharan Africa have focussed on the perspectives of caregivers regarding HIV disclosure to children, with the exclusion of HCWs. Yet HCWs are at the centre of the disclosure process and are faced with challenges emerging from it from day to day. As such, there are limited data available focussing on HCWs’ role in HIV disclosure to children and adolescents with perinatal HIV. It is crucial to conduct research into HCWs’ opinions, given the role they play in providing support to caregivers and children in this matter. The findings of the study should assist in the development of HIV-disclosure interventions that can be utilised to facilitate the disclosure process.

1.3 Study aim

The aim of the study was to assess the perspectives of HCWs regarding the disclosure of their HIV status to perinatally infected children and adolescents in the Alfred Nzo Health District facilities, Eastern Cape Province, South Africa.

1.4 Research questions

The study sought to answer the basic questions:

1. What are the perspectives of HCWs regarding HIV status disclosure to perinatally infected children and adolescents in the Alfred Nzo Health District facilities?
2. What are the practices of the HCWs regarding HIV status disclosure to perinatally infected children and adolescents in the Alfred Nzo Health District facilities?

1.5 Research objectives

The main objectives of the study were therefore:

1. To assess the perspectives of HCWs regarding HIV status disclosure to perinatally infected children and adolescents in the Alfred Nzo Health District facilities, Eastern Cape Province, South Africa.
2. To examine the practices of the HCWs regarding HIV status disclosure to perinatally infected children and adolescents in the Alfred Nzo Health District facilities, Eastern Cape Province, South Africa.
1.6 The significance of the study:
The results of this study mark an increase in the existing knowledge on the perspectives and practices of HCWs on disclosure to children and adolescents in sub-Saharan Africa. The results should also assist the Eastern Cape Department of Health to plan interventions that may be put in place towards strengthening the implementation of the existing South African paediatric HIV disclosure guidelines in health facilities. Further, understanding the manner in which HCWs address children and adolescents about their HIV status will have psychosocial and clinical benefits and allow children to take part in the management of their own well-being.

1.7 Conclusion
This chapter has presented a foundation and the general overview of the disclosure of their HIV status to perinatally infected children and adolescents. It has also presented the problem statement that led to the development of the aim of the study and its objectives, and described the significance of the study. It is clear that the literature recognises the challenges of disclosure that are facing HCWs and the importance of HIV disclosure to perinatally infected children in sub-Saharan Africa. The next chapter will focus on the existing literature dealing with the views, practices and experiences of the HCWs on the disclosure of their HIV status to children and adolescents.
Chapter 2: Literature Review

2.1 Introduction:

This chapter presents literature from developing countries on HIV status disclosure by HCWs to children and adolescents with perinatal HIV. The literature review will focus on the views and practices of the HCWs on HIV status disclosure to children and adolescents. Only peer-reviewed literature that is not more than ten years old, focussing on disclosure in relation to children and adolescents by caregivers and HCWs will be referenced in this chapter. The literature will be used to identify points of argument and gaps that will need to be filled in the field of public health research in this matter.

2.2 Guidelines for paediatric HIV disclosure

The World Health Organization (WHO) has developed paediatric HIV disclosure guidelines for HCWs to support children up to 12 years old and their caregivers. The guidelines recommend that school-aged children must be told their HIV status by their caregivers, using incremental disclosure for younger children, in order to accommodate their cognitive and emotional maturity (WHO, 2011). In the South African context, to avoid the violation of children’s and adolescents’ rights, the disclosure should be integrated into the comprehensive management of their HIV disease. However, the ethical and legal frameworks related to the management of children and adolescents living with HIV are complicated (NDOH, 2016).

The disclosure guidelines for children and adolescents in the context of HIV, TB and non-communicable diseases recommend that partial disclosure should start at the age of 3 years and full disclosure should occur from the age of 10 years, without undermining the relevant legal and ethical principles (NDOH, 2016). According to Wiener et al. (2007) full disclosure has occurred when children have been told the name of the illness and been given disease-specific information. In partial disclosure the child is told that he/she has a disease that is described in a way that is consistent with HIV/AIDS, but the disease is not necessarily named (WHO, 2011).
Appropriate disclosure to children with PHIV is linked to the care and management of paediatric HIV in many countries in the world. Therefore, the process of disclosure to children with PHIV should be managed and carried out by a team, and it should be carefully designed to suit the child’s age and level of emotional development (WHO, 2011; Penn, 2015). HCWs such as doctors, nurses, lay-counsellors, social workers, and psychologists are amongst the categories of people that are viewed to have significant roles to play in HIV disclosure to children and adolescents (Madiba and Mokgatle, 2015; Zanon et al., 2016). Therefore, joint efforts from both caregivers and HCWs is imperative for successful disclosure to children with PHIV (Penn, 2015; Madiba, 2016a; NDOH, 2016).

2.3 Involvement of health care workers in disclosure

HCWs have a major role to play in facilitating the disclosure of their HIV status to perinatally infected children and adolescents. There is evidence that caregivers who discuss the disclosure with their HCWs gain skills on how to disclose to their children, and in most cases these caregivers are likely to disclose (Mumburi et al., 2014; Madiba 2012). Another significant role that HCWs play in this matter is to provide psychosocial support and create an enabling the environment that allows the children to express themselves freely during visits to the clinic. This is crucial, because it allows the children to ask questions to enhance their own understanding during the process (Vaz et al., 2011).

Based on the fact that some parents or caregivers have no expertise in disclosure, the involvement of HCWs is mainly to build capacity and provide continuous counselling to caregivers (WHO, 2011; Madiba, 2016a; NDOH, 2016). HCWs are also responsible for providing support, which they can do by establishing support clubs, for instance, to promote the well-being of the child and minimise the harm that may result from the disclosure process (Vaz et al., 2011; WHO, 2011; NDOH, 2016). While caregivers acknowledge their responsibility to disclose to children, they express the need for the support of HCWs to prepare them for disclosure (Heeren et al., 2012; Madiba, 2012; Madiba, 2016a). Consequently, Baker et al. (2018) reiterate the importance of the HCWs support to guide families on how to disclose, mainly because of factors like the parents' status, how HIV is
transmitted, and other family secrets which are eventually revealed by the disclosure of the child's HIV status.

2.4 Reasons for disclosure

HCWs from several studies argued that parents or caregivers should disclose to them when their children are ready for disclosure.

2.4.1 Right age for disclosure

The literature reveals that the age and cognitive development of children contribute to the caregivers' decision to inform them about their HIV status. The age of the child is considered the main determinant of readiness for disclosure to a child with PHIV, but HCWs from different parts of the developing countries have different views on the right age for disclosure. HCWs in Peru thought that disclosure should be initiated when the child approaches the age of 8 years (Baker et al., 2018), in Ghana disclosure should be done at 12 to 13 years (Kallem et al., 2014), in Tanzania disclosure should take place between 10 and 12 years (Mumburi et al., 2014), in South Africa disclosure should occur when the child is over 10 years (Madiba and Mokgatle, 2015), and in Dar es Salaam disclosure should occur by the age of 9-14 years (Sariah et al., 2016).

Disclosure also occurs when children reach the adolescent stage (Madiba, 2012; Namukwaya et al., 2017). Children aged between the ages of 10 and 12 years are regarded as mature enough to understand. Also, they may be or become sexually active, which could put their health status or that of others at risk (Heeren et al., 2012; Madiba and Mokgatle, 2015). However, in Uganda children less than 13 years old are regarded as too immature to be disclosed to (Zanon et al., 2016; Gyamfi et al., 2017). Actually, researchers argue that age cannot be the sole determinant for disclosure. Instead, both the age and the maturity of the children should be considered (Heeren et al., 2012; Watermeyer, 2013; Madiba and Mokgatle, 2015; Namasopo-Olenja et al., 2015). In a South African study, caregivers expressed the opinion that disclosure should commence when children are capable of understanding what the HIV disease is all about (Madiba, 2016a).
2.4.2 Poor adherence to ART

The literature confirms that the frequency and persistence with which children ask questions about their medication and the reasons for their monthly hospital check-ups while they are not sick influence decisions about disclosure (Vaz et al., 2011; Mumburi et al., 2014; Namukwaya et al., 2017). The caregivers disclose in order to make their children understand the benefits of treatment when they threaten to stop taking the treatment (Mweemba et al., 2015; Madiba, 2016a). The caregivers also initiate disclosure when their children do not adhere to their medical regimen and no longer want to visit the clinic (Sariah et al., 2016; Gyamfi et al., 2017).

2.4.3 The right to know

The children and adolescents are also of the opinion that they should be informed about their own HIV status. They view knowing the truth about their disease as a mechanism to help them understand their bodies better and to stop worrying about getting sick. It also brings closure to them to know how they got ill. In studies conducted with children and adolescents, they said that they felt that knowing their HIV status was a basic human right and beneficial for their health (Heeren et al., 2012; Beima-Sofie et al., 2014; Kenu et al., 2014; Madiba and Mokgatle, 2015; Sariah et al., 2016; Baker et al., 2018; Kalembo et al., 2018; Okechukwu et al., 2018).

2.4.4 The right thing to do

Caregivers disclose to their children in order to strengthen their relationship with them and to avoid the mistrust caused by keeping a secret from them (Vaz et al., 2011; Kiwanuka et al., 2014). The HCWs reported that when caregivers realise that children are becoming suspicious about their treatment, they initiate disclosure (Madiba, 2016b). The caregivers are also forced to disclose when their children start school (Bhattacharyya et al., 2011). Disclosure is often perceived by caregivers as honouring children’s right to know about their status (Kiwanuka et al., 2014; Mumburi et al., 2014). Other reasons for disclosure include making the children sufficiently independent for them to be able to attend the health facilities on their own (Vaz et al., 2011). Some parents find it onerous to have to accompany their children on their frequent visits to the clinic (Mumburi et al., 2014).
2.5 Factors associated with delayed disclosure

As already said, disclosure to children with PHIV remains a problem, as caregivers are reluctant to disclose the HIV diagnosis to their children for various reasons (Kallem et al., 2011).

2.5.1 Fear of being blamed

Both the HCWs and the caregivers indicated that sometimes biological parents have a sense of guilt for being responsible for their children’ HIV infection (Bhattacharya et al., 2011; Vaz et al., 2011; Namasopo-Oleja et al., 2015; O’Malley et al., 2015; Madiba, 2016a). Other factors that contribute towards delayed disclosure include denial, fear of being judged as having been promiscuous, and self-blame (Rujumba et al., 2010; Heeren et al., 2012; Watermeyer, 2013; Madiba and Mokgatle, 2015; Gyamfi et al., 2017). Biological mothers fear being blamed by their children for infecting them because they think their children will be angry for not protecting themselves adequately from being infected by HIV (Kiwanuka et al., 2014; Mweemba et al., 2015).

2.5.2 Young age of children

There is no consensus as to the proper age of disclosure of their HIV status to children, but the age of the child is the main reason why caregivers delay disclosure in sub-Saharan Africa. Most caregivers believe that their children are too young to understand HIV-related information. They think that when children are too young they are incapable of concealing their HIV status and will tell their friends that they have HIV, which would invariable disclose the parents’ status too, regardless of their readiness to disclose their own status. This might expose the child and the family to gossip and stigmatisation (Kidia et al., 2015; Madiba and Mokgatle, 2015; Sariah et al., 2016; Gyamfi et al., 2017). Fear of stigmatisation, discrimination, and the isolation of children and the family within their communities are among the factors that were highlighted as dissuading caregivers from disclosing to their children and adolescents (Heeren et al., 2012; Madiba and Mokgatle, 2015; O’Malley et al., 2015; Gyamfi et al., 2017).
2.5.3 Lack of disclosure knowledge and skill
It has been established that some caregivers need support from HCWs during disclosure to their children and adolescents. In a study conducted in South Africa, caregivers admitted that the lack of disclosure skills contributed to their delayed disclosure to their children and adolescents with PHIV (Madiba, 2012). Similarly, other studies found that caregivers have insufficient knowledge and skills to be able to conduct disclosure and provide answers to children during the process of disclosing. Besides not knowing how and what to tell their children during disclosure, the caregivers also lack skills in how to handle the child’s reaction to the disclosure (Heeren et al., 2012; Madiba and Mokgatle, 2015; Namasopo-Oleja et al., 2015; O’Malley et al., 2015; Sariah et al., 2016).

2.5.4 Fear of negative reactions to disclosure
There is general consensus among researchers in sub-Saharan Africa that caregivers delay disclosure to children with PHIV because of their fear that disclosure will have negative psychological or emotional effects on the children. They fear that the negative emotional effects of disclosure might destroy the child-parent relations (Bhattacharya et al., 2011; Heeren et al., 2012; Watermeyer, 2013; Madiba and Mokgatle, 2015; Namasopo-Oleja et al., 2015; Gyamfi et al., 2017). Furthermore, in a study done by Madiba and Mokwena (2012), caregivers said they were afraid to disclose the HIV diagnosis to infected children because they believed that when children learn that they have the same disease that killed their mothers or fathers, they will live in fear of death. Although children react differently to disclosure, most HCWs and caregivers cited sorrow, hurt or discouragement upon learning their HIV status.

2.6 Implications of delayed disclosure
Concerns related to delayed disclosure include incidents of accidental disclosure which may negatively affect the children emotional and psychological health. When children are not informed about their HIV status they tend to suspect that they may be infected, which may cause serious harm to them. Thus, there is a possibility that such children may isolate themselves and be confused, frightened and suicidal after discovering their status on their own. Delayed or untruthful disclosure opens a knowledge vacuum on important information
that would enable the children to understand how they should behave when HIV-positive, and the implications of inappropriate behaviour (Watermeyer, 2013; Beima-Sofie et al., 2014; Kidia et al., 2014). Delayed disclosure may also exacerbate the progression of the disease and poor health, and may even lead to premature death (NDOH, 2016).

2.7 The disclosure process

Disclosure is considered to be a process that continues until the child becomes ready for disclosure, and not a once-off event (Watermeyer, 2013; Beima-Sofie et al., 2014; Sariah et al., 2016). However, HCWs and caregivers apply different ways of engaging children in the disclosure process (O’Malley et al., 2015; Nzota et al., 2015; Sariah et al., 2016). Several studies have found that HCWs first assess the readiness of the children when they plan to initiate disclosure. The readiness assessment includes determining what the children know about their HIV status, their adherence status, and their level of understanding in order to gauge the maturity level. Furthermore, their social situation is assessed which is additional to age and maturity (Beima-Sofie et al., 2014; Sariah et al., 2016). Gachanja and Burkholder (2016) report that HCWs ask questions such as about their parent’s status, about why they have to take medication, about why they have to visit the clinic frequently, and about the main cause of the death of some family members. Beima-Sofie et al. (2014), working in Kenya, found that that HCWs are inclined to postpone disclosure until the child is either 7 or 8 years old, after giving a thorough explanation to the parent or caregiver. The literature suggests that HCWs prepare children through partial disclosure to help them understand the basics of their own condition and the importance of taking their medication.

The readiness assessment also includes the readiness of the caregivers. HCWs consider the psychological capability, fears, concerns and knowledge of HIV of the caregivers in order to balance the needs of both the caregivers and the children. The caregivers are encouraged to disclose to their children at home, if they are capable of carrying out the process (Beima-Sofie et al., 2014; Kidia et al., 2014; Gachanja and Burkholder, 2016). While HCWs used different approaches to prepare for disclosure, most reported that monthly meetings in the facilities were used as strategies to enable parents or caregivers to carry out disclosure on their own (Beima-Sofie et al., 2014; Gachanja and Burkholder, 2016; Sariah et al., 2016).
HCWs and caregivers employ different methods to disclose their HIV status to children. The most common include using dolls, drawings, story-telling, and third-party disclosure (Nzota et al., 2015; Sariah et al., 2016; Zanon et al., 2016). HCWs in Namibia use an assessment tool, a disclosure form, and a book with some components guiding them through gradual disclosure that is matched to the child readiness (O’Malley et al., 2015). However, it is also reported that the HCWs consider direct disclosure where possible, and event event-driven disclosure where necessary (Nzota et al., 2015).

The HCWs emphasised the importance of using suitable language that matches the maturity and understanding of the children during disclosure (Heeren et al., 2012). Disclosure messages should be tailored to accommodate the level of the child’s understanding, starting with partial disclosure which leads eventually to full disclosure. As disclosure progresses to the advanced stage, words like the immune system, virus and CD4 count are used, and the term "HIV" is used only at an appropriate age (Beima-Sofie et al., 2014).

2.8 Barriers against disclosure to children

There are various barriers against disclosure that are documented in the literature. One of the key challenges that confronts HCWs is their lack of formal training on paediatric HIV disclosure. The lack of guidelines and policies in facilities were identified as challenging HCWs in many settings in developing countries (Watermeyer, 2013; Madiba and Mokgatle, 2015; Nomasopo-Oleja et al., 2015; O’Malley et al., 2015; Penn, 2015; Sariah et al., 2016; Kalembo et al., 2018; Okechukwu et al., 2018). In addition, the HCWs mentioned the unavailability of standard operating procedures, posters and assessment tools as a barrier to disclosure to children (Rujumba et al., 2010; Watermeyer, 2013; Beima-Sofie et al., 2014; O’Malley et al., 2015; Sariah et al., 2016). As a consequence, the HCWs in many settings in sub-Saharan Africa lack the necessary skills and competency to carry out disclosure to children.

There is general consensus that the caregiver is at the centre of the disclosure to children. Madiba and Mokwena (2012) have argued that caregiver readiness facilitates or deters disclosure to children and adolescents with PHIV. A number of studies have identified the
caregiver as a barrier to disclosure. The caregivers’ concerns and unpreparedness to disclose
due to fear of family reactions, community gossip, and misconceptions are regarded as
significant barriers against optimal disclosure (Watermeyer, 2013; Kidia et al., 2014; Madiba
and Mokgatle, 2015; O’Malley et al., 2015; Sariah et al., 2016; Gyamfi et al., 2017).

Furthermore, a lack of referral networks for HIV-positive children, child-friendly facilities to
carry out disclosure, and adequate staffing, regardless of the great number of clients to be
serviced daily, compromises the attention provided to children with special needs (Rujumba
et al., 2010; Beima-Sofie et al., 2014; Kidia et al., 2014).

2.9 Strategies to improve disclosure to children

Given that disclosure to children is a challenging task for both HCWs and caregivers, it is
imperative that the health care system implements disclosure programmes that would
make it possible for HCWs to participate in the disclosure of their HIV status to children with
PHIV (Rujumba et al., 2010; Watermeyer, 2013; Kenu et al., 2014; Kidia et al., 2014).
Experienced HCWs in paediatric HIV care should also provide support to unskilled and
inexperienced professionals (Rujumba et al., 2010; Beima-Sofie et al., 2014; Sariah et al.,
2016). In many settings HCWs need in-service training, and workshops on paediatric HIV
care and disclosure are suggested to support those required to disclose to children (Vaz et
al., 2011; Watermeyer, 2013; Beima-Sofie et al., 2014; Madiba and Mokgatle, 2015;
Sariah et al., 2016; Kalembo et al., 2018; Okechukwu et al., 2018).

Various studies stress the need for the distribution of disclosure guidelines and materials to
support HCWs caring for children in health facilities, in order to improve their confidence
and capacity (Watermeyer, 2013; Beima-Sofie et al., 2014; Madiba and Mokgatle, 2015;
Namasopo-Oleja et al., 2015; Sariah et al., 2016). Continuous counselling and debriefing of
staff who are dealing with children living with HIV were suggested as being likely to be
helpful (Kallem et al., 2012; Madiba and Mokgatle, 2015).

2.10 Conclusion

In brief, the literature clearly articulates that HCWs believe that it is important for children
and adolescents to be informed about their status as a basic right, even though they hold
different opinions about who should disclose and the timing of disclosure. Most HCWs think that caregivers should lead disclosure to their children. They suggest that partial disclosure should take place between 3 and 8 years, and full disclosure at 10 years old, or older. At the same time, parents’ or caregivers’ decisions to disclose were reported to be influenced by factors such as inadequate knowledge about HIV, the fear of discrimination and stigma, the fear of being blamed, and the desire to protect the children from being hurt. More importantly, the HCWs lack the skills and guidelines necessary to be able to carry out disclosure successfully, and the chronic staff shortage and poor infrastructure create an unfavourable environment for disclosure to a child. The HCWs believe that disclosure is a process, so paediatric HIV disclosure training and the making available of policies, guidelines and protocols could assist them to clearly understand where they should play a role, when and how to participate in disclosure without compromising either the rights of the parent or caregiver, or those of the child.

The next chapter will reflect on the methodology that was applied in the pursuit of this study.
Chapter 3: Research Methodology

3.1 Introduction
The focus of this chapter is on the research strategy and the empirical techniques that were practised during the data collection. It describes the methods and materials utilised for data collection. It presents the elements of the research process, from the design of the study to its study setting and the sampling of the research population to identify participants in the focus groups discussions. The chapter also supplies a description of the methods of data collection and analysis that were adopted. Lastly, it describes the steps taken to ensure and maintain trustworthiness and ethical probity.

3.2 Study design
According to Creswell (2009), qualitative research is a means of exploring and understanding the meaning individuals or groups ascribe to a social or human problem. In this study a qualitative, descriptive design was used as a method of exploring with HCWs their perspectives and practices regarding the disclosure of their status to children with PHIV. The study used focus group discussions as a method of choice for the data collection. Patton (2002) indicates that FGDs aim to provoke into conversation individuals who have the same background and experiences pertaining to an extensive subject that influences the way they do things. In this study, the FGDs were used to enable the researcher to explore the opinions of many HCWs at once, and to gather rich data from them about the services they provide to children with PHIV.

3.3 Study setting:
The study was conducted in facilities in the Alfred Nzo Health District (ANHD) in the Eastern Cape Province. Alfred Nzo District Municipality is a category C municipality in the north-eastern corner of the Eastern Cape Province, and is a deeply rural district with an estimated catchment population of 866 646 (Massyn et al., 2017). It is the smallest district in the Eastern Cape Province, covering about 6% of the geographical area (Local Government Handbook, 2017). It is the home of diverse race and ethnic groups. About 88 571 (10.22%) of the total population in this municipality is infected with HIV, representing 11% of the
Eastern Cape population living with HIV (ECSECC, 2017). About 6,354 children under the age of 15 years were enrolled in the HAART programme in 2018 (WEB-DHIS, 2018), which is 7.2% of the total population living with HIV in the district. There is a total of seventy-two clinics, two community health centres (CHC), six district hospitals, and one TB hospital.

3.4 Study population:
The total number of health facilities sampled was 23. These consisted of four hospitals, one CHC and eighteen clinics that are offering HIV services to children, adolescents and adults. The facilities were purposely selected, prior to data collection. The researcher requested, accessed and analysed the district data for children and adolescents that were on the HAART programme before the facilities were selected. Then the facilities were identified based on the number of children registered on their HAART programmes. The study population therefore included staff of all kinds in all categories, including dieticians, social workers, and lay counsellors who offer HIV services to children, adolescents, and adults on HAART in the sampled facilities. The total population comprised of 482 HCWs from the 23 facilities, and 51 HCWs participated in the study.

3.5 Sample and sampling technique
Purposive sampling, which is non-probability technique, was used to select the participants in the FGDs. Brink et al. (2006) define purposive sampling as selecting representatives of the population based on their knowledge of the phenomenon under study. The rationale for using purposive sampling in this study was to ensure that the HCWs selected would provide rich information in answer to the research question. Heterogeneous participants were sampled to gather views from different categories of HCWs, programme involves a multidisciplinary team. Etikan et al. (2016) refer to a heterogeneous sample as a sampling that includes participants representing different categories with an extensive understanding about the study phenomenon. The sample in this study comprised only different categories of CHWs in health facilities offering HIV care services to children, adolescents, and adults on HAART.
According to Patton (2002), in qualitative research there are no rules for determining the sample size, what the researcher wants to know, the purpose of the study, what will be credible and useful. Time and resources, as well as how the results are to be utilised, determine the sample size. Furthermore, researchers are guided by a rule of thumb of having three to five groups with 6 to 10 participants in each. The sample size in qualitative research is also guided by data saturation. According to Patton (2002), data are regarded to have saturated when no new ideas or relevant themes are being generated win subsequent interviews.

Eight FDGs with 5 to 8 participants in each of them were conducted in this study. During the data collection, emerging themes were included in the interview guide, and questions that referred to issues where the data had reached saturation were dropped, after consulting the supervisor. The original interview guide was used for the first 6 FGDs, and after asking some questions had resulted in data saturation, amendments were made to collect data from the last two FGDs.

3.6 Inclusion and exclusion criteria
The study included HCWs offering paediatric HIV care services in the selected health facilities who had more than three months working experience and who provided written consent to participate in the study. HCWs with less than three months working experience in offering care and services to children and adolescents living with PHIV were excluded.

3.7 Recruitment of participants
Various mechanisms were utilised to gain access to health facilities to conduct the study. Recruitment commenced after ethical clearance had been obtained from the Sefako Makgatho University Ethics Committee (SMUREC) and the Eastern Cape Province ethics committee; also after permission had been obtained from all the relevant levels of the administration of the district. Following the receipt of the district managers’ permission, the researcher introduced the study to the managers of the facilities during management meetings of the district. The researcher also personally engaged the facility managers in face-to-face meetings and delivered letters of request to facilities that were less than 100
km from the residential place of the researcher. Telephonic negotiations with managers were also explored to request access to selected facilities beyond the 100 km radius. The facility managers suggested convenient dates and times between Monday and Friday for the researcher to conduct the study. The HCWs were recruited from selected facilities with the assistance of the facility managers. All venues for the research sessions were organised and prepared by the facility managers. The researchers were introduced by the facility managers to the HCWs in the study sites before the data collection began. The HCWs who volunteered to participate were informed that the interviews were going to be in the form of focus group discussions. The same recruitment process was repeated until the completion of the data collection.

3.8 Data collection and tools

An English interview guide with open-ended questions was used to collect data through the FGDs. Though the plan was to conduct the interviews in English only, the researcher allowed the HCWs to respond in the language that they were comfortable with for maximum participation. During the interviews, the researcher observed that some of the HCWs had difficulty in understanding the questions when they were asked in English. These questions were then asked in IsiXhosa to ensure that the HCWs understood them clearly.

Structured questions were used to gather demographic information from the HCWs. The researcher adopted a previously used tool found in a similar study by Madiba and Mokgatle (2015).

The researcher recruited an experienced research assistant with a master’s degree, who had already participated in several other research projects, to assist in data collection. The following procedures were followed throughout data collection. For all the FGDs, the researcher introduced the aim and objectives of the study, informed the HCWs about the role of the research assistant, the procedure to be followed for the FGDs, the use of a digital audio recorder, and set some ground rules.

Prior to the focus group discussion, the researcher assured the HCWs about the confidentiality of the information collected and the matters to be discussed during the FGD,
and provided them with the option to use pseudonyms in order to protect their identities. The researcher also explained the rationale for using a digital audio recorder and requested permission from the HCWs to do so. The HCWs were given an opportunity to seek clarity and decide if they were comfortable to continue participating in the study. Thereafter, those who were willing to participate were requested to sign the consent forms. Only then did the FGD begun. Only one focus group discussion took place per week, and the researcher provided all of the facilities with the 2016 South African paediatric disclosure guidelines via the managers' office after each discussion as a response to some of the study findings.

The researchers conducted the FGDs in conducive environments such as boardrooms and consultation rooms, as arranged by the facility managers. However, not all allocated spaces had minimal disturbances. It was important that they should not be noisy if the researchers were to be able to conduct the research smoothly. During the focus groups discussions, the questions on the guide were not asked sequentially as outlined. Instead, the researcher allowed conversation to run, to earn the active involvement of HCWs and to allow the emergence of new thoughts. Each FGD lasted for between 1 and 2 hours.

The collection of the data started in April 2018 and ended in September 2018. Initially the data collection was planned to start in April to May 2018. However, it had to be postponed due to unforeseen circumstances that the district was experiencing, such as blockage of roads due to community protests. All the FGDs were conducted in the health facilities during free time on work days, based on prior arrangements made with the managers. As already indicated, the study sample was drawn from 23 health facilities, which consisted four hospitals, one CHC and eighteen clinics. Four FGDs were conducted at the four hospitals (one in each), four in the 18 clinics, and 1 in the CHC. Since the number of PHC HCWs providing HIV services to children was limited in any one facility, HCWs from several facilities were combined to form single focus groups.

The demographic data questionnaire was completed by the participants immediately after the FGDs. Refreshments were offered to participants at the end of each FGD. Participants who used transport to travel to the venues of the study were reimbursed their travelling costs by the researcher.
A pilot study was not conducted, since this was an exploratory study. For this purpose, the researcher adapted a tool that had previously been used for the same population on the same phenomenon in the Mpumalanga Province, SA. In a qualitative research project, the method of data collection can be continually modified in response to the emerging findings, and a researcher can spontaneously refine questions that are not addressing the study objectives in the same interview. So the qualitative study can proceed without being piloted (Kinchin et al., 2018).

3.9 Data analysis

Thematic analysis was used to identify, analyse and report patterns within the data. Thematic analysis is a process of identifying patterns or themes within the qualitative data (Maguire and Delahunt, 2017). In preparation for data analysis, the researcher immersed herself in the data by conducting verbatim transcriptions in English and IsiXhosa of all the audio-recorded interviews, and read and reread the field notes taken during the data collection. The verbatim transcription was conducted by the researcher and the research assistant. The digital recorder was listened to repeatedly to ensure that the transcription accurately captured what had been recorded. The transcribed IsiXhosa data were translated into English. The translated data were cleaned up by the researcher before the analysis. The transcribed data and field notes were read, to make detailed notes and to discern meaningful patterns. Re-reading of the transcribed data was also done in order to obtain the general sense of what the participants were saying. This also helped the researcher to gain a better understanding of the opinions and practices of the participants and to develop a code list.

As the first step of coding, the researcher started by manually coding the transcripts with different colours. The researcher generated numerous codes during this stage through the identification of key words from the typed transcripts. The researcher then developed a code book, which defined the themes and the codes. The transcripts and recorded data were then imported into NVivo 12, which is computer-assisted qualitative data analysis software, in order to create nodes, refined themes and sub-themes. This was also done to
describe the data and to show how the HCWs had talked about the phenomenon under study. Thereafter, similar nodes were combined into categorise of concepts, properties and patterns. During coding, the researcher initially came up with 47 codes. Thereafter, the second level of coding led to the development of core themes in each main category. The researcher and the supervisor reviewed the codes, redefined the themes, and merged some of the sub-themes. When final consensus about the emerging themes was reached between the supervisor and the researcher, 10 priority themes were derived, and 31 sub-themes were created using quantitative data to make comparisons of participants. All of the quantitative demographic data were typed, arranged in an Excel spreadsheet, cleaned and coded. The data were imported to Stata analysis software version 13.0 for analysis in terms of the mean, median, and a ratio of variables.

3.10 Trustworthiness

Trustworthiness is regarded as a key form of identifying the quality of the data collection and analysis in a qualitative study (Mandal, 2018). The four criteria of trustworthiness credibility, dependability, transferability, and conformability as established by Kumar (2011) were used to minimize bias and ensure the truthfulness of the results in this study. Credibility in qualitative research refers to whether the researcher accurately represented what the participants think, feel and do. Dependability refers to the stability of the findings over time. Transferability refers to the probability that the research findings have meaning to other similar situations. Conformability refers to the degree to which results research of inquiry can be confirmed or corroborated by other researchers (Kumar, 2011).

Strategies for Trustworthiness:

Different methods of data collection such as observations, the writing of field notes and the audio recording of the discussions were used as a means of triangulation of the entire data collection process. The researcher and research assistant observed and noted the reactions of participants to the questions during the FGDs.
The researcher had peer debriefing sessions with the research assistant and the supervisor after each FGD, to test developing ideas and interpretations. The researchers used a high-quality digital audio recorder to ensure the accurate verbatim transcription of the data. All data collected were transcribed verbatim by both the researcher and the research assistant. The translation of the transcribed data was done by the researcher and verified by the research assistant, because he had credible experience in translating IsiXhosa into English. The researcher kept an audit trail and documented all the research information from the beginning to the end of the research. The paper trail that was made for audit purposes included the process involved, the instruments used, the number of participants and facilities that took part in the study, the time period when the data were collected, and all the other information regarding the study, including the changes that were made from time to time. This was done to provide a thick description of the phenomenon under the investigation.

Quotations and participants’ own words were presented in a way that would enable reviewers to track how data analysis was done, stemming from the verbatim responses of the participants. The data were coded-recorded and categorised in a dependable and credible way, in consultation of the supervisor. NVivo 12 was utilised to analyse the qualitative data and Stata version 13.0 was used to analyse the quantitative demographic data.

3.11 Ethical considerations

Ethical clearance was received from the Sefako Makgatho Health Sciences University Research Ethics Committee (SMUREC) and the Eastern Cape Department of Health Research Ethics Committee. The researcher obtained permission to conduct the study from the district manager of the Alfred Nzo Health District, the sub-district managers and the facility managers (Appendix B).

The researcher provided a full, truthful, credible, accurate and honest explanation of the research process to the prospective participants to gain their voluntary participation before the study commenced. They were given a chance to accept or refuse to participate in the research, and also the freedom to withdraw from participation at any time during the FGD.
sessions. They were assured by the researcher that their decision to refuse or withdraw from the study would be respected and that it would not be used against them in any measure at their workplace or anywhere else. Informed consent was obtained from all study participants, in writing.

The researcher acted in the best interests of those subjects who chose not to participate by not discussing their decisions not to participate in the study with their superiors, to avoid any possible negative effects of their decision, and to prevent their suffering at work. The researcher always maintained a professional demeanour throughout the research process by respecting the participants’ right to dignity, regardless of their responses during the data collection sessions. The research sessions were held in private rooms in the facilities. All participants used pseudonyms in order to protect their identities, and the facilities were coded, to avoid using their names. Where it happened by mistake that participants used their actual names during the interviews, the researcher removed the names during the translation of the data and the reporting. The participants were not required to indicate their names in the demographic questionnaire.

All paper-based information collected was kept in a safe and lockable cabinet away from the workplace to limit access to people not involved in the research process. Recorded information, spreadsheets, typed transcriptions and translations were saved in a computer with a password to prevent irregular access. The discussions of the FGs were not shared with managers or anyone in the workplace or even at home. The researcher ensured scientific integrity by all means from the beginning until the end of the data collection process.

3.12 Conclusion
This chapter has laid out how the study was conducted, including the design applied, the population of the study, the data collection method and the analysis. The participants’ ideas and key words were used to generate the themes. Strategies of trustworthiness and ethical procedures observed during the study have also been presented.
The next chapter will focus on the results of the study.
Chapter 4: Presentation of Results

4.1 Introduction

This chapter focuses on the participants’ discussions in order to establish their opinions and practices pertaining to the disclosure of their HIV status to perinatally infected children and adolescents in the Alfred Nzo Health District facilities, Eastern Cape Province. The chapter is divided into sections, which present the demographic information relating to the participants and the results of the FDGs.

4.2 Demographic data of the HCWs

Table 4.1 presents the demographic information of the HCWs who participated in the study. A total of 51 HCWs participated. There were more females (46; 90.2%) than males (5; 9.8%). Their ages ranged between 22 and 68 years, with a mean age of 43.4 years. Most were between 40 and 49 years old (16; 31.4%) whilst the fewest participants were those between 60 and 69 years old (1; 2%).

With regard to the categories of HCWs, more professional nurses (24; 47.1%) participated than lay counsellors (16; 31.2%), social workers (5; 9.8%), dieticians (3; 5.9%), enrolled nurses (2; 3.9%) and enrolled nursing assistants (1; 2%). Most (20; 39.2%) had a university qualification, followed by a college qualification (16; 31.4%), “completed matric” (10; 19.6%), and incomplete secondary education (5; 9.8%).

Concerning their experience with HIV-positive children, most (36; 70.6%) had been working with such children for five years and more, and 15 (29.4%) had experienced fewer than five years. Most (44; 86.3%) HCWs knew of no disclosure guidelines for children and 31 (60.8 %) had had no paediatric disclosure training. Of those who had received training on paediatric disclosure, 9 (37.2%) had received thorough, full training. Only 36 (70.6%) HCWs confirmed that they were directly involved in children disclosure, whilst 15 (29.4%) had never disclosed to children or adolescents.
Table 4.1. Healthcare workers’ demographic information:

<table>
<thead>
<tr>
<th>Variables/Characteristics</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>46</td>
<td>90.2</td>
</tr>
<tr>
<td>Male</td>
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<td>9.8</td>
</tr>
<tr>
<td>Employment status of HCWs</td>
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<td></td>
</tr>
<tr>
<td>Contract</td>
<td>17</td>
<td>33.3</td>
</tr>
<tr>
<td>Permanent</td>
<td>34</td>
<td>66.7</td>
</tr>
<tr>
<td>Designations of HCWs</td>
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<td></td>
</tr>
<tr>
<td>Lay counsellor</td>
<td>16</td>
<td>31.3</td>
</tr>
<tr>
<td>Enrolled nursing assistant</td>
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<td>2</td>
</tr>
<tr>
<td>Enrolled nurse</td>
<td>2</td>
<td>3.9</td>
</tr>
<tr>
<td>Professional nurse</td>
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<td>47.1</td>
</tr>
<tr>
<td>Social worker</td>
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<td>9.8</td>
</tr>
<tr>
<td>Dietician</td>
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<td>5.9</td>
</tr>
<tr>
<td>Highest educational level</td>
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<td></td>
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<tr>
<td>Secondary</td>
<td>5</td>
<td>9.8</td>
</tr>
<tr>
<td>Completed matric</td>
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<td>19.6</td>
</tr>
<tr>
<td>College</td>
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<td>31.4</td>
</tr>
<tr>
<td>University</td>
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</tr>
<tr>
<td>HCWs’ age range</td>
<td>22-68 years</td>
<td></td>
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<tr>
<td>HCWs’ age group</td>
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<td></td>
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<tr>
<td>20-29</td>
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<td>27.4</td>
</tr>
<tr>
<td>60-69</td>
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<td>2</td>
</tr>
<tr>
<td>Mode (44 years)</td>
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</tr>
<tr>
<td>Mean age (43.4)</td>
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<td></td>
</tr>
<tr>
<td>HCWs’ Paediatric HIV experience</td>
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<td></td>
</tr>
<tr>
<td>&lt;1 year</td>
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<tr>
<td>1-4 years</td>
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<td>21.6</td>
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<td>5-10 Years CLOSE THE GAP</td>
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<td>&gt;10 years</td>
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<td>HCWs’ training in paediatric HIV disclosure</td>
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<td>20</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>31</td>
</tr>
<tr>
<td>Type of paediatric HIV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Orientation</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>training received</td>
<td>In-service</td>
<td>4</td>
</tr>
<tr>
<td>------------------------</td>
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</tr>
<tr>
<td></td>
<td>Full training</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>No training</td>
<td>27</td>
</tr>
<tr>
<td>Paediatric HIV disclosure material available</td>
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<td>7</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>44</td>
</tr>
<tr>
<td>Should children should be told their HIV status</td>
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<td>50</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>Teachers should be informed about children’s HIV status</td>
<td>Yes</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>23</td>
</tr>
<tr>
<td>Have you ever disclosed</td>
<td>Yes</td>
<td>36</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>15</td>
</tr>
</tbody>
</table>

4.3 Opinions and practices of HCWs on disclosure

Ten themes and thirty-two sub-themes emerged from the responses to the questions asked in the FDGs.

Table 4.2. Themes and sub-themes:

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benefits of disclosure to children and adolescents</td>
<td>Promotes treatment adherence</td>
</tr>
<tr>
<td></td>
<td>Promotes safe sexual behaviour</td>
</tr>
<tr>
<td></td>
<td>Children become responsible and independent</td>
</tr>
<tr>
<td>Consequences of delayed disclosure</td>
<td>Children default treatment</td>
</tr>
<tr>
<td></td>
<td>Poor clinical outcomes</td>
</tr>
<tr>
<td></td>
<td>Denies children a chance to make the right decisions</td>
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<tr>
<td></td>
<td>Accidental disclosure</td>
</tr>
<tr>
<td>Reasons for delayed disclosure</td>
<td>The caregiver has not accepted her/his own HIV status</td>
</tr>
<tr>
<td></td>
<td>The caregiver has inadequate knowledge about HIV</td>
</tr>
<tr>
<td></td>
<td>Children cannot keep secrets</td>
</tr>
<tr>
<td></td>
<td>Fear of children’s negative reaction</td>
</tr>
<tr>
<td></td>
<td>Fear of stigmatisation and discrimination</td>
</tr>
</tbody>
</table>
### Fear of blame

**Timing of disclosure to children**
- Poor treatment adherence
- Age of disclosure to children
- Children are asking questions

**The preferred person to disclose**
- HCWs should disclose
- Caregiver should disclose
- HCW and caregiver should disclose

**The process of disclosure**
- Planning for disclosure
- Disclosure event
- Support provided

**Messages provided to children during disclosure**
- Educate children about the importance of treatment
- Educate children about safe sex practices
- Messages about HIV and mode of transmission
- Encourage children to live healthy lives

**Avoiding accidental disclosure**

**Reaction of children after disclosure**
- Children accept their HIV status
- Children react negatively

**Barriers against disclose**
- Lack of paediatric disclosure training
- Lack of paediatric disclosure guidelines and materials
- Inadequate resources

### 4.4 The views on HIV disclosure

All the HCWs viewed the disclosure of their HIV status to children and adolescents with perinatally acquired HIV to be important. The benefits of disclosure, the consequences of non-disclosure and delayed disclosure, the reasons for delayed for disclosure, the timing of disclosure and the preferred person for disclosure are the themes that came out during the engagement with the HCWs.
4.4.1 Benefits of disclosure to children and adolescents

The participants said that when disclosure is done successfully to children and adolescents it creates independence, promotes treatment adherence, promotes safe sexual behaviour, and prevents the transmission of HIV to others.

4.4.1.1 Children become responsible and independent

The participants reported that since the caregivers are not always available to monitor the children’s treatment adherence, when children know their HIV status they take responsibility of their treatment and health.

“I think the main reason to disclose is for adherence; especially when children are not at home like going out with friends, are in school camps, and sleeping out as youngsters might do. The disclosure enables them to continue to take treatment in the absence of parents who give tablets or monitor them” (FDG1: female dietician, 22 years).

“It is important that the child should know her status and the value of taking treatment so that while the parent is on her drinking spree the child does not default of treatment” (FGD 3: female lay counsellor, 27 years).

“I think it is important for children to know why they take treatment to avoid them from defaulting after the supporter has died” (FGD4: female lay counsellor, 37 years).

4.4.1.2 Promotes treatment adherence

The participants were of the view that disclosure promotes adherence because children gain a better understanding of the disease and the reasons for continuing to take treatment.

“I think another reason for disclosure is for the children to adhere to treatment. Yes ... it is about adherence. In addition, disclosure helps children to know their own health status, about the treatment and about general information when living with HIV” (FGD 1: female social worker, 44 years).
“The parent may sometimes forget the treatment but if the child knows about the importance of the treatment she will always remember and may even remind the parent about it” (FGD 3: lay counsellor, 57 years).

“I think it is important to disclose to enable children who are staying with their grandmothers who have no idea about the treatment to understand the reasons for taking treatment and adhere to the treatment” (FGD 4: female PN, 42 years).

4.4.1.3 Promotes safe sexual behaviour
During the discussions, the participants reflected that disclosure to children and adolescents enables them to practice safe sex in order to prevent the spread of the HIV disease. The participants were adamant that practising safe sex would save children and adolescents living with HIV from developing secondary infections.

“This will ensure that the child practices safe sex when he starts dating and he will be aware that his treatment is for a lifetime” (FGD 2: female PN, 59 years).

“It is important that boys or girls know so that they use condoms when engaging in sexual activity because they are HIV positive” (FGD 4: female lay counsellor, 55 years).

"It will help them to take precautionary measures when they are playing because during playtime it may happen that a child touches blood for an injured HIV-positive child or vice-versa. They are taught not to handle anyone’s’ blood during play time” (FGD 6: female lay counsellor, 42 years).

4.4.2 Consequences of delayed disclosure
Regardless of whether or not parents or caregivers may have genuine reasons for non-disclosure, the participants said that the parents’ decision to postpone disclosure in children could lead to negative and regrettable outcomes. They thought that delayed disclosure or a false diagnosis disclosure contributed to children’s defaulting treatment or sharing their
medication, increased the risk of spreading HIV, resulted in accidental disclosure, and produced undesirable emotional reactions.

4.4.1 Children default treatment

The participants thought that delayed disclosure may cause the children to be rebellious or to refuse treatment or to stop attending the clinic when they feel no pain in their bodies. They further reported that some children hid tablets under their beds and pillows because they got tired of the treatment.

“I realised that unsuppressed viral loads among these children are due to non-adherence of treatment. Children get tired of taking treatment so they stop taking treatment if they don't understand the reasons for taking it continuously” (FGD 2: female PN, 54 years).

“I have an orphan teenage boy who started taking treatment at birth. He was taking the tablets under the supervision of the grandfather but when he entered adolescence he stopped the treatment due to lack of knowledge about it. I discovered during a home visit that he was throwing the tablets under the bed because he was sleeping alone” (FGD 4: female lay counsellor, 35 years).

4.4.2 Poor clinical outcomes

The participants explained that delayed disclosure contributes towards the deterioration of the health status of the children, because defaulting treatment induces treatment failure.

“Some were told false information, such as they have heart disease or other diseases. This has led to the decline of children' health status and they mostly become sick due to poor adherence. One child had to be changed to the second line of treatment” (FGD 1: female dietician, 22 years).

“I have a case of two orphaned children aged 6 years and 13 years old with high viral loads due to non-adherence to treatment. The grandmother explained that they are...
missing treatment because they come back home very late at night. These children don’t even know why they are taking treatment as no one ever told them about it” (FGD 7: female PN, 52 years).

4.4.2.3 Denies children a chance to make the right decisions
The participants also thought that delayed disclosure increases the risk of spreading HIV and the sharing of medication by children with their siblings, or even giving it to others as pain killers due to their lack of knowledge, which is risky.

“Another problem is that some children are the only ones taking the treatment within their families which makes them wonder why other children don’t take the treatment. This sometimes creates serious problems such as a child sharing the tablets with other children who are not on treatment. Sometimes when another child has a headache the sibling gives ARVs to manage the headache” (FGD 2: female PN, 59 years).

"The disadvantage of non-disclosure during adolescence is that you may find the child has already started dating and practising unsafe sex" (FGD 4: Female PN, 52 years).

“Every time the young one takes her treatment she also demanded that even the older one should be given the treatment and she was even asking why was she only one given the treatment. Whenever this young one fetched her treatment she also distributed to others and said that they must also drink. I am not sure what was going on in the mind of this little child whenever she did that” (FGD 8; Female PN, 56 years).

4.4.2.4 Accidental disclosure to children
Non-disclosure contributes to accidental disclosure within the facility during children’ visits because there are no thorough mechanisms to prevent accidental disclosure. The participants had sometimes taken it for granted that children who had been on treatment for longer periods already knew their HIV status.
"If the parent does not disclose, the child may discover his/her HIV status accidentally, which may cause denial for a very long time" (FGD 3: female lay counsellor, 31 years).

“Oooh! Just like what happened to me here. The child has been on ARV treatment for a very long time. I was screening for TB so that the child can start IPT treatment. I said to the child that when you are HIV-positive you take this treatment and there.... the child started screaming. And I asked .... (Pause), don’t you know your status, ma? The child was just crying because he was on ARV treatment for so long without knowing that he is on HIV treatment. So accidents do happen” (FGD 1: female PN, 47 years).

4.4.3 Reasons for delayed disclosure
The participants said that there are various reasons affecting the decisions of caregivers to initiate disclosure.

4.4.3.1 The caregiver has not accepted own HIV status
It emerged during the discussions that when parents have not accepted their own status, they find it difficult to engage their children about the subject. Therefore, parents postpone disclosure because they have not yet dealt with their own HIV status.

“Another parent may fear to disclose because the child was born out of rape. The mother was raped but she didn’t go to the clinic for post-exposure prophylaxis after the rape also did not receive PMTCT services due to non-attendance of ANC. Rape victims or survivors are sometimes very secretive about their rape situation. This may become a very difficult situation for the mother to handle” (FGD 3: female lay counsellor, 55 years).

“Not accepting HIV. Although there is much education about HIV, however some people still find it difficult to accept this reality” (FGD 7: female PN, 44 years)
4.4.3.2 The caregiver has inadequate knowledge about HIV

Caregivers’ inadequate knowledge about HIV was also referred to as a stumbling block for them to initiate disclosure, because they are not confident about how to handle disclosure and deal with the questions that may arise from the children.

"Another thing creating a barrier for the mother to disclose includes the HIV status of other siblings within the family. It happens that this child is the only one infected with HIV among many other siblings. Like for instance if those who were born before and after this child have a negative status makes the mother not know how to handle disclosure to the infected child" (FGD 2: female PN, 59 years).

“Parents lack sufficient information about HIV” (FGD 5: female social worker, 39 years).

4.4.3.3 Children cannot keep a secret

The views of the participants were that sometimes parents or caregivers think children are too young to understand the conversation about HIV. On the other hand, they think young children are incapable of keeping family secrets. The parents are uneasy that children may share the information with their friends and schoolmates, which would compromise the confidentiality of the parents’ HIV status. Yet they are not ready to disclose to other people.

“The child might go and talk to other children; and the children will be not able to keep that secret because children don’t understand confidentiality” (FGD 3: male lay counsellor, 34 years).

"Sometimes parents are scared that children will tell other people than keeping it like a secret which will reveal their status; yet the parents were not ready for other people to know their HIV status" (FGD 4: female PN, 42 years).
4.4.3.4 Fear of the child’s negative reaction

The study found that children’s negative reactions, such as anger, feeling suicidal, isolating themselves, hating their parents, and other psychological factors are barriers preventing caregivers from disclosing to their perinatally infected children. The caregivers are trying to protect their children from the pain of knowing their HIV status.

“Sometimes mothers continue to bring excuses or resist to disclose because they know the personalities of their children very well such as child anger problem, or the child does not eat if he is heartbroken. Sometimes the mother is scared that the child may commit suicide” (FGD 4: female PN, 52 years).

“They think disclosure will trigger children to isolate themselves from other people because of the thought that there are things they will never able to do in life also that they will die tomorrow” (FGD 5: female social worker, 39 years).

“Other parents don’t disclose because they fear that they might lose their children. They say ‘Eish! I might lose this child if she discovers that she got infected through me’” (FGD 7: female PN, 57 years).

“The other thing that causes fear to a parent is the perception that the child might blame her of infecting him; therefore, hate her for life blaming her of infecting him” (FGD 8: male PN, 31 years).

4.4.3.5 Fear of stigmatisation and discrimination

During the discussion the participants articulated the opinion that caregivers also delay disclosure because they fear that children will be stigmatised, bullied and isolated at schools and even in their communities.

“There is a stigma around HIV because family members think they will be infected; some feel that they are disgraced and many other things” (FGD 2: female social worker, 35 years).
“The society looks at you with a different eye when HIV-positive. HIV is an unacceptable disease in some families and they even isolate people who are HIV-positive. The lack of acceptance within homes and society drives those who are HIV-positive to live in constant denial of their condition” (FGD 7: female PN, 57 years).

“There is a common and continuous thought from the past that when one has HIV it then means she/he is promiscuous. This notion prevailed to such an extent that it has created a serious stigma about HIV. It makes it so difficult to talk about HIV” (FGD 8: female lay counsellor, 44 years).

4.4.3.6 Fear of blame

The fear of blame by the children for infecting them was also referred to as a major reason for the delay of disclosure by caregivers, particularly biological mothers. Mothers are thought to live with feelings of guilt as well as to blame and judge themselves for their children’ HIV status.

“Possibly, parents are feeling responsible for passing the disease to the kids. So that’s why they don’t want to disclose” (FGD 1: female dietitian, 22 years).

“I think the parent also fear that as the child grows he will blame her, accuse her of infecting him with HIV. These are some of the things that are happening and that we deal with during engagements with families” (FGD 2: female dietician, 44 years).

“I think the parent feels guilty and also thinks that the child will blame her for carelessness and for failing to take precautionary measures to protect her. So, the parent is avoiding to be blamed and accused as the reason that the child is positive” (FGD 6: female PN, 50 years).
4.4.4 The timing of disclosure to children

4.4.4.1 Age of disclosure to children

The data revealed that the participants had different views about the timing of the disclosure to children. Age emerged as an important consideration; however, the participants had different views about the appropriate age.

“The important thing is to consider the age of the children. Check if they are really matured to take that” (FGD 1: female lay counsellor, 44 years).

“Personally, I think at least at the age of 10 years the child has some light and can understand better because this is when puberty starts” (FGD 1: female social worker, 28 years).

“I also think 12 years is the appropriate age because they can give consent about services provided to them in health facilities without the parents’ involvement according to the regulation” (FGD 4: female lay counsellor, 37 years).

“I don't think there is a specific time or age that a child can be ready but every time the healthcare worker meets the child should assess the maturity to determine readiness” (FDG 4: male PN, 34 years).

4.4.4.2 Poor adherence to treatment

It was reflected that besides age and maturity and the child’ refusal of treatment, poor treatment adherence should be considered for disclosure.

“There are many children accessing treatment from our clinic and who have been on treatment for quite some time but still they have unsuppressed viral loads and with treatment failure; this is when I intervene” (FGD 2: female PN, 59 years).
“Poor adherence because he/she does not know why he is taking treatment. Once you realise that the child is not adhering, it is the time” (FGD 4: female lay counsellor, 37 years).

“I think if the child refuses to take treatment or rebelliousness” (FGD 5: female dietician, 24 years).

### 4.4.3 Children asking questions

The participants thought that when children start to be suspicious or to ask questions about their treatment, disclosure should be initiated.

“Disclosure can be initiated when the child starts to have questions to the parent or the caregiver. Once they grow older they start to be suspicious and have questions about the treatment. So, this when you need to engage them about their own status” (FGD 2: female social worker, 39 years).

“I think the right time is when the child starts asking questions about the pills he is taking. The child starts to be curious when you continuously tell him that he should not miss time to take tablets or when you continuously emphasise to him that the tablets should be taken at a specified time” (FGD 6: female PN, 42 years).

### 4.4.5 The preferred person for disclosure

The discussions demonstrated that the participants had different views regarding the preferred person to initiate disclosure. Some contemplated that the caregiver should initiate disclosure, others thought the HCWs were responsible, whilst yet others were of the view that both the caregivers and HCWs should work together during disclosure.

#### 4.4.5.1 Caregiver or family should disclose

Some participants believed that caregivers or families are responsible for disclosing to their children at home, because the children are staying with them, and they trust their families than HCWs.
“I say it is the parent..., and I want us to move away from this notion that the parent may not know because that statement on its own it is discriminatory. Parents know their children. I think disclosure is the right that should be given to the parent. I agree that we should provide support to the parents” (FGD 1: female lay counsellor, 44 years).

“The relatives should initiate disclosure. It becomes difficult for the health worker to inform the child about her status if the family did not disclose to her but told her that she is taking TB treatment. The primary relationship for the child is within the family and trusts them more than nurses at the clinic. Family-initiated disclosure builds trust to the child also helps her to believe what healthcare workers will tell her at the clinic” (FGD 4: female PN, 39 years).

4.4.5.2 HCWs should disclose
Some were of the view that the HCWs should disclose to children who attend clinic alone or if parents or caregivers refuse to disclose. Other suggestions were that HCWs should disclose when the parents or caregivers approach them for assistance.

“Healthcare workers should disclose because we have better information than the parents. Unless if parents can be taught first when they come with their children to collect treatment as we involve them. But what is wrong about them is that sometimes they give false information to children” (FGD 1: female social worker, 28 years).

“In actual fact, the HCW should not disclose but provide support to the mother after she has disclosed to the child. However, the reluctance of parents to disclose to their children leaves us with no option but to disclose to the children ourselves” (FGD 7: female PN, 57 years).

4.4.5.3 HCWs and caregivers should disclose together
Some of the participants argued that disclosure should be a joint effort made by HCWs and caregivers, because HCWs have adequate skill to deal with the emotional reactions of
children that may be triggered by the disclosure. Secondly, the HCWs will be able to guide parents and provide additional information that they could not provide to children during disclosure.

“I think the HCW can initiate disclosure but do it in the presence of the mother. During this process, both the mother and the healthcare worker should talk, because the role of the healthcare worker is to support the parent” (FGD 7: female PN, 49 years).

“I also support that the mother should disclose to the child but the HCW, as the person who has more information about HIV will be giving assistance to the mother especially when she realises that the mother has inadequate information” (FGD 7: female PN, 57 years).

“The parent and the HCW should work together during disclosure because it is the HCW who has more information relating to health matters. The HCW is in a better position to explain what will happen if the treatment is not taken as prescribed” (FGD 8: Female PN, 31 years).

4.5 The practices of HCWs during disclosure
4.5.1 The process of disclosure
The participants described the processes and procedures they followed during the disclosure of their HIV status to children and adolescents. They observed that disclosure was not a once-off occurrence but was a process that included planning and initiation, the disclosure event, and follow-up provided to caregivers and children

4.5.1.1 Planning for disclosure
The participants reported that the process of disclosure involved continuous discussions about the disease in the context of the cognitive, emotional, and sexual maturity of the young patient, to ensure that the children and adolescents were provided information that they could handle.
“I assess the maturity of the child to check if the child is matured enough to understand HIV information. After the maturity assessment, I start to ask questions such as what is HIV, how is HIV contracted to test what does she/he understands about HIV” (FGD 1: female lay counsellor, 44 years).

“I first checked if she understood anything about HIV. I did this to check her readiness so that it could be easy for me to disclose. After the counselling, it was easier for me to disclose. I made it a point that the counselling session both the mother and the child were involved and it was very basic” (FGD 3: female lay counsellor, 35 years).

“I first establish what the child knows, sometimes the child educates me and thus I intervene when I realise the child has some knowledge.” (FGD 2: female PN, 59 years).

4.5.1.2 The disclosure event

The participants reported that disclosure is carried out in stages using a suitable language that can be understood by children and adolescents. Where caregivers are available, the participants involved them during the process of disclosure.

“Information provided to children is incremental. Disclosure counselling to children is not a once-off activity but an ongoing process. We do follow up and on every appointment, I continue until I realise that the child understood” (FGD 1: female lay counsellor, 44 years).

"We don't disclose everything at once but it is being done in stages. Children don't accept what they are told immediately. Disclosure is done step by step every time the child comes to the clinic. We continue to educate the child every time she/he visits the clinic to build an understanding and for acceptance” (FGD 4: male PN, 34 years).

4.5.1.3 Disclosure support and follow-up
The discussions revealed that the participants provide continuous support to both children and caregivers. The HCWS revealed that when the parents or caregivers are reluctant to disclose, they are equipped with the skills to disclose. The caregivers are also capacitiated in how to deal with the emotional reactions of children after disclosure.

“I establish the reasons for the reluctance of disclosure from the mother. It helps me to know how I should help the parent before referring her to the social worker because there may be something that makes the parent not to disclose to the child” (FGD 1: female lay counsellor, 49 years).

“I refer to a psychologist when I realise that the child is not improving after several sessions..., when I see that the situation is beyond my counselling scope” (FGD 2: female social worker, 35 years).

“Another thing, we refer the child to the support group with all ages so that he sees that other children and even adults also live with the disease. We always ask the child if he is ready to join the support group before referring him so that you explain the advantages of the support group if he is not interested” (FGD 4: female PN, 52 years).

“After I have disclosed, I give them a follow-up date which is not far so that I meet them to establish a rapport. It is only after this follow-up session that I then refer them to another HCW when I have exhausted every skill I have but the child continues to be emotional” (FGD 7: male PN, 48 years).

4.5.2 Messages provided to children during disclosure

The discussions revealed that different messages were shared with the children or adolescents during disclosure. The participants said that during engagement with the children they educate them about the importance of treatment, safe sex practices, HIV transmission, and healthy living.
4.5.2.1 Educate children about treatment

The HCWs reported that children are taught about the importance of treatment in order to promote adherence.

“I stressed that he should take the ARV treatment daily and at a specific time. I also educated the sister to take responsibility for her brother, ensure that he takes ARV treatment as prescribed and the reasons why adherence is important” (FGD 1: female PN 47, years).

“We educate them that if they can adhere to their tablets and eat healthily they will stay healthy” (FGD 2: female social worker, 35 years).

“I further explain that she will be on treatment for the rest of her life. She should continue taking them because they will make her live healthy for a very long time. The pills will control and suppress the virus especially if she takes them routinely, e.g., 07:00 p.m. daily, without fail. I don’t give the child any hope that one day she will stop the treatment but I emphasise that the treatment is for the rest of her life” (FGD 7: female PN 52, years).

4.5.2.2 Education on safe sex practices

The participants said that during their disclosure and adherence counselling engagements with adolescents, they promote good behaviour and safe sexual practices. The adolescents are taught to use protection such as condoms when engaging in any sexual activity, but also to abstain if possible, to prevent the spread of diseases to others and also to protect themselves from secondary infections.

“I also educate the child on how to ensure healthy living including condom use if the child is at the age of dating because condom use is relevant” (FGD 2: female PN, 59 years).

“We educate them to engage on protected sex to avoid infecting others. The child is educated to use protection during sexual engagement for his own protection too in
order to live long. I don't know if this is what you were expecting” (FGD 6: female PN, 34 years).

“The children are educated about abstinence and protecting other people because the reality is that these children have partners as they grow” (FGD 6: female lay counsellor, 28 years).

4.5.2.3 Explaining HIV and the modes of transmission

The participants reported that they explain how HIV is transmitted from one person to the other so that the children can have a better understanding of the disease and protect others. They explain that HIV can be acquired through a sexual encounter, mother-to-child transmission, and touching the blood of an infected person.

“I explain to him that he got infected from parents because they were HIV-positive and that the pills he is taking are for life. I explain that he was born infected with the virus hence he is HIV positive.” (FGD 2: female social worker, 39 years).

“I disclose to the child that she was infected during pregnancy because his/her parents had HIV or they died of HIV and in the olden days there was no treatment. I further explain that some years back women had to choose whether they want to test or not during pregnancy. Although some would test positive but had a phobia to use Nevirapine because HIV was not well understood so that is how she got infected” (FGD4: female professional nurse, 52 years).

4.5.2.4 Encouraging children to live healthy lives

The study revealed that the participants encourage and help children to accept their own status for positive living. It is emphasised during the counselling that HIV is a chronic disease just like other diseases, and also that there are many people living with it. The children are also encouraged to disclose their status once they start dating.
“Just to add, during disclosure, children are taught about positive living, lifestyle and that being infected is not the end of life but there are many people who live with the virus” (FGD 2: female PN, 54 years).

“We talk to them about positive living style and disclosure readiness. You counsel and assist the child to reach a stage of becoming comfortable to disclose her own status to other people like partners and friends. We encourage them to disclose to their partners or friends when they are ready” (FGD 2: female social worker, 39 years).

“If the child is still attending school, I tell him that there are many other children in his school who are also HIV-positive but he may not notice them because they are not labelled. I further tell him that perhaps his desk-mate is also HIV-positive but the child is not labelled, which marks no difference between them. I tell the child that he will leave the clinic the same and no one will ever notice his HIV status. I further tell him that he is living with HIV but he doesn't have AIDS” (FGD 3: female lay counsellor, 55 years).

4.5.3 Avoiding unplanned disclosure

The focus groups revealed that not all facilities have strategies to prevent unplanned disclosure to children when they visit the facilities alone. Inconsistent practices among HCWs that expose the child to unplanned disclosure were reported during the FGDs. Integrated Clinical Services Management (ICSM) is only implemented in few facilities. At the same time these facilities implementing ICSM are not compliant because HIV patients’ files have file numbers regardless that files are the same.

“I request the child to leave the room and talk to the mother about the issue of disclosure. In case the child has another sickness I attend him first then request him to wait in the waiting area so that I am left with the mother only. In the absence of the child, I ask the mother if the child knows anything about his HIV status” (FGD 4: female lay counsellor, 55 years).
"Okay, firstly, the flow of our files is controlled and they are not kept anyhow to avoid children from reading the notes because some can read. In this facility we have messengers that carry the files from OPD to different places where the children will go, avoiding children or parents to carry their own files” (FGD 2: female dietician, 44 years).

“It is difficult. The files are problematic in our facilities. The problem is that though patients use same files, but HIV patient file has a file number which differentiates it from the Hypertensive, epileptic and diabetics files. So the file discloses the status of the client. It is easy to disclose accidentally to an undisclosed child just because of the file” (FGD 4: female PN, 39 years).

“We as the clinics do not have any measures in place to avoid accidental disclosure to children. This means that we are lacking in this regard and we must admit that it does happen that sometimes some children leave our facility having discovered their HIV status accidentally” (FGD 8: female PN, 35 years).

4.5.4 Reaction of children after disclosure

The participants said that the children and adolescents experience emotional reactions after disclosure.

4.5.4.1 Children accept their HIV status

Some participants reported that some of the children and adolescents accept their status after disclosure. There were various reasons why children and adolescents accept their status. The participants believed that some had been suspecting that they might be HIV-positive for a long time, regardless of the caregivers concealing the information from them.

“I never had a child who did not accept his/her status” (FGD4: male professional nurse, 34 years).
"It also depends on the way we implement disclosure to children. I had a 14-year-old child who was reported to default treatment after accessing information from the internet. I provided further counselling to the child after she was brought by her aunt. The child requested that she should be exempted from standing on the queue when she comes to the clinic which we agreed as a team in the clinic because our interest was to see this child adhering to treatment. Whenever this child comes she doesn’t wait on the queue and this has made her be free to come on the appropriate dates and she now even comes on her own to collect the treatment. Her viral load which used to be unsuppressed, it is undetectable as we speak" (FGD 7: female PN, 50 years).

“The child I have experience with, she accepted the disclosure but at first she was crying very bitterly because she was very hurt and deeply pained by discovering that she was HIV-positive” (FGD 8: female professional nurse, 35 years).

4.5.4.2 Children react negatively

Some participants reported that some children experience emotional pain after disclosure. They cry bitterly, develop anger, don’t want to continue with the treatment, become psychotic and even commit suicide.

“The child became depressed after disclosure. The boy was crying bitterly, saying that he has been on treatment for long and he is tired of taking them. However, he kept on defaulting and we continued to trace him and I continued to counsel until he became fine until today” (FGD 4: male PN, 34 years).

“The child cannot be expected to absorb and accept her HIV status immediately, some commit suicide using rats poison” (FGD6: female 59 years).

“Some children start to refuse treatment after they have been disclosed to. There are cases where a child would say ‘If these pills are for HIV then I am not taking them anymore but I rather die’” (FGD 8: female lay counsellor, 44 years).
4.5.5 Barriers against disclosure

During the discussions with the participants it emerged that they were experiencing barriers that affected their provision of support to children, adolescents and their caregivers during disclosure. Three sub-themes emerged in this theme: lack of paediatric disclosure training, lack of disclosure guidelines and materials, and lack of adequate resources.

4.5.5.1 Lack of paediatric disclosure training

The participants said that they facilitate the disclosure process without being skilled. They said that their training was done a long time ago before the roll-out of ART to children. They stated that they are not sure whether what they are doing is correct or not because disclosure to children is different from disclosure to adults. The lack of skills was a reason for some of the participants’ not disclosing to children.

“Currently, as a social worker, I don’t have any information about disclosure of HIV to children. I don’t even know the age that should be considered for children disclosure. All ARV children clients are referred to us yet we don’t have adequate knowledge, we have outdated information” (FGD 2: female social worker, 35 years).

"We need in-service training or short courses on disclosure and adherence counselling. We did receive training a long time ago when HIV was still new. However, no further training was provided to us beyond that" (FGD 2: female PN, 54 years).

“Personally I feel I am not equipped with the technique or skill to do that. We have an understanding but I don’t know how to approach the situation. I don’t have the skill to conduct disclosure to children, so I cannot disclose” (FGD 5: female dietician, 24 years).

“We are not adequately trained on how to disclose, but as professionals, we are expected to do handle disclosure and yet some of us are not equipped enough on how to do it. It would really help if there are workshops conducted on how we should go about doing disclosure because I, personally, was never trained on disclosure” (FGD 8: male PN, 31 years).
4.5.5.2 Lack of disclosure guidelines

The participants said that they work without any specific disclosure guidelines or materials for children and adolescents. They explained that they do what they think is right during disclosure. They reported that they often depend on VCT, HCT and other HIV guidelines, not any specific paediatric disclosure guidelines.

“There are no materials or any guidelines in our facilities, we use our own skills. We are not even sure whether what we are doing is right or wrong but it works for us so we need to be capacitated on children disclosure” (FGD 4: female PN, 52 years).

“The paediatric book has information about disclosure in children but for all the cases I came across I applied my own general knowledge. Mostly I was relying on my gut feeling to disclose to the children” (FGD 6: female PN, 42 years).

“It is a problem that we don’t have a standard document that specifies at which age we should disclose to children. You can see in this very interview that we have been talking about different ages at which we should disclose to children and we are saying all this is based on what we personally think and not what we have been trained on” (FGD 8: male PN, 31 years).

4.5.5.3 Inadequate resources

The participants stated that disclosure to children is affected by their high workload due to the inadequate staffing of their facilities. They also said that disclosure to children and adolescents is mostly done in a space shared with other people such as operational managers, which becomes unconducive. Almost all the adolescents and youth-friendly services are not functional, and the adolescents who visit facilities for HIV services queue outside, regardless of the weather conditions.

“There are no ARV clinic social workers, so as clinical social workers, we are carrying all referrals workload from the ARV clinic; yet, we are not trained on HIV disclosure to children” (FGD 2: female social worker, 35 years).
"There is a need to increase the number of healthcare workers because we are experiencing a high staff shortage. The current situation where these adolescents queue and wait outside without shelter, rained as it happens in my clinic is not fair and unacceptable" (FGD 4: female PN, 52 years).

“The shortage of infrastructure is a huge challenge in my facility right now. For example, the lay-counsellors are using the Operational Manager's office as their workstation” (FGD 8: male PN, 31 years).

4.6 Conclusion
This study demonstrates that the participants perceive disclosure to perinatally infected children to be crucial and beneficial for treatment adherence, involvement in their own health management, the prevention of disease spread, and the protection of their own health. On the same note, the participants viewed delayed disclosure as having repercussions such as poor adherence, the spread of disease and accidental disclosures. Though the participants felt that children and adolescents should be informed about their HIV status, they had different opinions on when to disclose and about the preferred person to disclose. Regardless of the fact that HCWs apply different practices during disclosure, the preparation of both the parents and the children is carried out before disclosure. Families and children are provided with support through follow-ups, home visits, and the involvement of multidisciplinary teams and support groups. The lack of skills, the unavailability of guidelines within facilities, staff shortages and inadequate infrastructure were identified as barriers against HCWs wishing to participate in disclosure to children and adolescents. In addition, HIV stigma was identified as one of the serious social problems affecting disclosure.
Chapter 5: Discussion of Results

5.1. Introduction
The purpose of this study was to assess the opinions and practices of health care workers on the disclosure of their HIV status to perinatally infected children and adolescents in the Alfred Nzo Health District facilities, Eastern Cape Province. The central point of this chapter will be relating the main findings of this research to the literature on the topic. These relationships are drawn in terms of the themes, categories and sub-categories of the objectives of the study. The chapter concludes with a set of recommendations and an identification of the limitations of the study.

5.2. Description of the participants
It is of concern that only 9 HCWs had received full training on disclosure counselling for children, which was explained to be mostly three days. In addition, most (44; 86.3%) reported that they had no disclosure guidelines for children and 31 (60.8 %) had had no paediatric disclosure training. These findings are consistent with those of a Ugandan study which reported that 63.3% of the HCWs who participated in that study had not been trained in paediatric counselling (Rujumba et al., 2010). Recent studies conducted in Nigeria and Malawi also report that most of their participants had not been trained in paediatric HIV disclosure and that they did not have guidelines either (Kalembo et al., 2018; Okechukwu et al., 2018).

Despite the lack of training and guidelines on disclosing to children, over three quarters (36; 70.6%) of the HCWs had participated in disclosure to children, whereas 15 (29.4%) had never disclosed. However, even though some of the HCWs reported that they had never disclosed, they had prepared caregivers to carry out disclosure and supported them post disclosure by providing information to the children. They also dealt with the negative response of children after disclosure. In contrast, this study reported a lower rate (29.4%) of participants who had never disclosed than the 37% reported in the Malawian study (Kalembo et al., 2018).
5.3. The views of HCWs on disclosure

The participants were of the view that it is vital that children and adolescents be told their HIV status, which was also the case in other sub-Saharan studies (Beima-Sofie et al., 2014; Madiba and Mokgatle, 2015; Namasopo-Oleja, 2015; Sariah et al., 2016; Kalembo et al., 2018; Okechuku et al., 2018). They believed that disclosure benefits children and adolescents with PHIV. They indicated that disclosure to children with perinatal HIV promotes adherence, and fosters independence and responsibility in children to continue with their treatment as prescribed, even in the absence of their parents. These findings are similar to those of other studies (Beima-Sofie et al., 2014; O’Malley et al., 2015; Kalembo et al., 2018).

Furthermore, disclosure helps children to better assimilate their HIV status, contributing to treatment adherence and positive health outcomes, a finding reflected in the reports of other studies too (Kidia et al., 2014; Madiba and Mokgatle, 2015; Namasopo-Olenja et al., 2015; Gachanja and Burkholder, 2016; Sariah et al., 2016). Disclosure also improves interaction between HCWs and children, because the children actively participate in their own health management. Similar findings were reported in other studies (Beima-Sofie et al., 2014; O’Malley et al., 2015). The participants also argued that disclosure enables children to take care of their health, regardless of their family circumstances. Adolescents with PHIV who participated in a South African study also shared the same views about the importance of disclosure. They reported that disclosure had helped them to adhere to treatment and take care of their health (Madiba and Mokgatle, 2016).

The participants in the current study said that children become aware of the effects of unprotected sex and the improper handling of someone's blood because disclosure equips them with information on how HIV is transmitted. HCWs who participated in other studies also shared the same observations about disclosure (Beima-Sofie et al., 2014; Madiba and Mokgatle 2015; Gachanja and Burkholder, 2016). Studies conducted with caregivers are in agreement with these findings. The caregivers stressed that disclosure empowers children to share in taking decisions about their own health (Heeren et al., 2012; Beima-Sofie et al., 2014; Kiwanuka et al., 2014; O’Malley et al., 2015).
5.4 The timing of disclosure

The study revealed that the participants had different views on when disclosure to children and adolescents should be initiated, but they were in agreement that it was important that the child’s age and maturity should be considered in this regard. This is congruent with other studies (Heeren et al., 2012; Watermeyer, 2013; Madiba and Mokgatle, 2015; Namasopo-Olenja et al., 2015). The participants felt strongly that full disclosure should happen when the child was between 10 and 12 years old, and for various reasons. They believed that children become sexually active at an early age and argued that at these ages they can keep family secrets. Similar findings were reported in studies conducted in South Africa by Madiba and Mokgatle (2015), who recommend full disclosure for children above 10 years old, and Heeren et al. (2012), who recommend that disclosure should be complete at 12 years of age. The findings of the current study are also in line with the South disclosure guidelines for children and adolescents in the context of HIV, TB and non-communicable diseases (2016). In contrast, other recent studies have made age recommendations different from those in this study (Zanon et al., 2016; Kalembo et al., 2018; Okechukwu et al., 2018).

The participants also indicated that children’s refusal to take their ART medication and poor adherence to the regimen were reasons for caregivers to initiate disclosure. They further reported that HCWs often encourage the caregivers to disclose because the child has defaulted and has poor clinical outcomes. In addition, they indicated that disclosure is initiated when the child starts to be suspicious and curious and to ask questions about the treatment. These findings are consistent with those of other studies (Madiba, 2016b; Sariah et al., 2016; Gyamfi, et al., 2017).

5.5 Reasons for delayed disclosure

In accord with the findings recorded in the literature, the participants in this study reported that caregivers' decision to withhold disclosure is influenced by factors such as a fear of being blamed by their children, a fear of stigmatisation and discrimination, a fear of the negative reaction of their children, a lack of confidence, and inadequate knowledge about
HIV (O’Malley et al., 2015; Sariah et al., 2016). The participants revealed that biological mothers often battle with the idea that their children will accuse them of infecting them and judge them for being irresponsible and promiscuous. They also stressed that mothers feel guilty for failing to take the necessary precautions towards the prevention of mother-to-child transmission and blame themselves for their children’ HIV status. These findings have been made in previous studies (Rujumba, 2010; Heeren et al., 2012; Madiba and Mokgatle, 2015; Gyamfi et al., 2017).

In addition, the participants stated that the caregivers’ denial of their own HIV status influenced disclosure. They argued that a lack of acceptance and the embarrassment of parents about their own status contributed to the concealment of their HIV status from their children. Denial was also reported in several other studies (Rujumba et al., 2010; Heeren et al., 2012; Madiba and Mokgatle, 2015; Gyamfi et al., 2017).

The belief by caregivers that their children are still too young to understand HIV and to keep their HIV status secret influences disclosure. The participants reported that caregivers believe that children may share the secret of their HIV status with their friends and schoolmates, which would reveal the parents’ status to the community and expose the family to stigma and discrimination. These findings are similar to those reported in other studies (Mumburi et al., 2014; Gyamfi et al., 2017). As already said, it was thought that caregivers delay disclosure because they believe that since children have the potential to divulge their HIV status to other people, they will be bullied and isolated in their schools and communities. This study revealed that communities and families still associate HIV with immorality and disgrace, resulting in HIV-positive people’s being unaccepted and isolated. Gyamfi et al. (2017) report similar findings. Studies conducted with perinatal HIV-infected adolescents also report that stigma is attached to the disease, and that this affects the emotional stability of adolescents after disclosure (Vaz et al., 2010; Madiba and Mokgatle, 2016).

The participants in this study also indicated that caregivers delay disclosure to protect their children from hurt and pain, self-isolation, anger, suicidal ideation, and parents’ rejection, which is consistent with what is reported in other studies (Vaz et al., 2011; Kiwanuka et al.,
2014; O’Malley et al., 2015; Madiba, 2016a; Sariah et al., 2016). The current study also shares the sentiments of a report by Sariah et al. (2016), that caregivers are challenged as to how to deal with the questions that might emerge during disclosure, due to their insufficient knowledge about the HIV disease. In a study conducted with caregivers, the participants indicated that they lacked disclosure skills (Madiba, 2012).

5.6 Consequences of delayed disclosure:
The participants reported that there were negative consequences to delayed disclosure to children. Delayed disclosure denies children a fair chance to make right and informed decisions about their health, increases the risk of their defaulting, refusing to take medication, transmitting HIV to potential sexual partners and others, and increases the prevalence of unsafe sexual practices. The study revealed that the most important consequence of delayed disclosure is poor adherence to treatment. The participants stressed the fact that poor adherence has a negative impact on the health outcomes of children, including treatment failure. Several other studies are in agreement that concealment of the child’s HIV status is a major contributor to poor medication adherence (Vaz et al., 2011; Turissini et al., 2013; Madiba, 2016a).

The participants clarified that children become tired of taking treatment and refuse to take it or stop taking the medication when substantial information is not provided. Substantial information can be provided only during or after disclosure. When HCWs disclose to children, they not only reveal the diagnosis but explain the disease and its outcome entirely. They reported that they teach children about HAART, to promote adherence. They also said that they promote good behaviour and safe sexual practices. Lastly, the HCWs encourage the children to accept their own status and live positively. These findings are supported by those of other studies (Mumburi et al., 2012; O’Malley et al., 2015; Madiba, 2016b; Zanon et al., 2016). This study revealed that children share medication with their siblings, or even giving it to others as pain killers due to their lack of knowledge, which is risky.

One other consequence of delayed disclosure that was mentioned with the possibility of accidental disclosure. The HCWs reported incidents of children discovering their HIV
diagnosis accidentally in health facilities during routine visits. Children have been found to have read their clinical notes, and to have overheard conversations in the facility. The participants also stressed that children access information about HIV and treatment from other sources such as the internet and the media. These findings are in agreement with the findings of other studies (Kidia et al., 2014; Sariah et al., 2016; Zanon et al., 2016). The findings of the current study concur with those of other studies, that accidental disclosure happens due to the lack of adequate measures and practices to prevent such events in facilities (Sariah et al., 2016; Zanon et al., 2016).

The participants in the current study described the steps that they take to prevent accidental disclosure. They indicated that parents or caregivers are engaged in the absence of children or adolescents to establish the disclosure status of children. They also said that when children attend the clinic alone they ask them questions to verify if they know about their HIV status. A similar finding is reported in Watermeyer (2013). However, this study revealed that not all facilities are implementing such strategies to prevent accidental disclosure. According to Beima-Sofie et al. (2014), children who experience accidental disclosure feel betrayed, become violent and rebellious, are prone to commit suicide, and have irreversibly spoiled relationships with their caregivers.

5.7 Emotional response after disclosure

The study revealed that children and adolescents react differently to disclosure. Some react negatively whilst others react positively and accept their HIV status. The HCWs and caregivers in a study conducted by Gachanja and Burkholder (2016) also reported the same variation. The study found that some of children and adolescents who were suspicious before disclosure responded positively after disclosure because they had in-depth information about the disease from school and other sources. The results also suggested that acceptance was not easy for some of the children and adolescents. The participants indicated that after home disclosure by caregivers, some of the children and adolescents confirmed the truthfulness of what their caregivers told them at the health facilities. This finding is much the same as that of Beima-Sofie et al. (2014). Another study highlighted that caregivers reported that children upon disclosure were not surprised by their diagnosis,
because they had always suspected the true situation (Vaz et al., 2010). The participants in the current study also suggested that children are freed by disclosure and thereafter continue with their treatment fully. They also said that early disclosure helps children and adolescents with PHIV to live healthily (Vaz et al., 2010).

Sometimes after disclosure children develop negative emotional reactions which frustrate their HCWs (Gachanja and Burkholder, 2016; Sariah et al., 2016). The participants in the current study stated that after disclosure some children refused to continue with the treatment, became depressed, developed anger, and cried bitterly. They also told of occasions where the adolescent committed suicide. Gachanja and Burkholder (2016) report similar reactions to disclosure. Some studies conducted with children and adolescents find that children had the same reactions after disclosure (Vaz et al., 2010; Madiba and Mokgatle, 2016). According to Vaz et al. (2010), the participants in that study witnessed comparable negative reactions from children after disclosure.

5.8 The preferred person for disclosure

The participants had different views about who should carry out disclosure to children. As in other studies, most of the participants suggested that the caregivers should lead the disclosure to their children. They argued that the caregivers know their children better than anyone else, and this makes them the best persons to disclose. Furthermore, children trust their caregivers more than they trust HCWs (Madiba and Mokgatle, 2015; Kalembo et al., 2018). The participants indicated that they had no right to disclose, but suggested that their role was providing HIV education and adherence counselling to caregivers, clarifying questions, and providing additional information that caregivers could not provide during disclosure, and also providing emotional support. The findings of this study are similar to other studies reported elsewhere (Madiba and Mokgatle, 2015; Kalembo et al., 2018; Okechukwu et al., 2018).

Some of participants were also of the view that they should be the ones to disclose to children. They gave reasons why they rather than the caregivers should lead disclosure. They would initiate disclosure when the caregivers requested them to do so, when the child
attended the clinic alone, when the child had been on treatment for a longer period, when the child was under the care of irresponsible caregivers, and or when the caregivers refused to disclose. In the same breath, the participants felt they should initiate disclosure because they were more knowledgeable than the caregivers. They believed that provider-initiated discloser would prevent caregivers from providing inaccurate information to children. However, the participants thought that the caregiver should be present during disclosure to give emotional support to the child. Similar findings were reported elsewhere (Watermeyer, 2013; Kiddia et al., 2014; Madiba and Mokgatle, 2015; Namasopo-Oleja et al., 2015; Sariah et al., 2016; Kalembo et al., 2018).

Furthermore, some of the participants argued that disclosure should be a joint effort between HCWs and caregivers. They believed that the HCWs have adequate skills to deal with the emotional reactions of children, and the capacity to guide the parents and provide additional information on identified gaps during the disclosure. They also stated that sometimes children may not be comfortable to engage with caregivers on certain topics, and the presence of the HCWs would mitigate such awkwardness. These findings are in line with those of other studies (Beima-Sofie et al., 2014; Madiba and Mokgatle, 2015; Sariah et al., 2016; Zanon et al., 2016; Kalembo et al., 2018; Okechukwu et al., 2018). Another study conducted with caregivers also reported that the caregivers thought that disclosure to children should be a shared responsibility between them and the HCWs.

5.9 The process of disclosure

The participants said that they followed some processes and procedures when they disclosed to children and adolescents with perinatal HIV. They approached disclosure as an ongoing process that included the planning and initiation of the disclosure, the actual disclosure event, and whatever follow-up the HCWs provide to caregivers and children after disclosure. The planning for disclosure takes into consideration the caregiver’s readiness and the maturity of the child. After the disclosure event or occurrence, the HCWs provided support and followed up with the children and their caregivers to monitor treatment adherence and the children’s emotional recovery. Other studies share the same sentiments (Beima-Sofie et al., 2014; Gachanja and Buckholder, 2016).
The literature acknowledges that constant engagement between the caregivers and the HCWs has the potential to create an enabling environment to make preparation for disclosure to children feasible (Kalembo et al., 2018). In the current study, the participants also reported that they attempt to create a friendly and comfortable environment for disclosure. In preparation for disclosure, they build rapport with the children and their caregivers, and they test the knowledge of the children about HIV prior to disclosure. In line with other studies (Heeren et al., 2012; O’Mally et al., 2015; Sariah et al., 2016; Zanon et al., 2016), the findings showed that the information provided to children and adolescents about HIV was incremental in nature. The HCWs took into consideration the child’s maturity and started with general information before mentioning the word HIV.

The study revealed that continuous support is provided for both children and caregivers during the planning of the disclosure, the disclosure event, and post the disclosure. The caregivers are equipped with information and skills on how to conduct disclosure and what to expect during disclosure, and are capacitated to manage the emotional reactions of children after disclosure. The participants explained that they encourage and help parents to deal with their fears and other factors which cause them to be unwilling to disclose. A similar practice was reported in the study conducted by Sariah et al. (2016).

5.10 Barriers against disclosure

The participants identified the major barriers that affect their involvement in the disclosure of their HIV status to children and adolescents with perinatal HIV. They said that they have to initiate the disclosure process without the adequate disclosure skills. The lack of skills was the reason why some of the participants had never disclosed to children and adolescents. Several research studies support these findings (Rujumba et al., 2010; Kiddia et al., 2014; Madiba and Mokgatle, 2015; Sariah et al., 2016; Kalembo et al., 2018; Okechukwu et al., 2018).

In addition, the participants stated that a lack of disclosure guidelines and other helpful materials on disclosure to children is a major challenge that confronts them in their day-to-day practice. These findings are in line with those of other studies (Madiba and Mokgatle,
The study revealed that despite the lack of guidelines for disclosure to children, most of the participants disclosed to the children and adolescents routinely. They indicated that they use existing disclosure guidelines for adults, like the Voluntary Counselling and Testing (VCT) and HIV Counselling and Testing (HCT) guidelines. They also depended on their own professional experience, which worked for them in most cases of disclosure. A study of the same nature also reported similar results (Kalembo et al., 2018).

In line with other studies (Rujumba et al., 2010; Beima-Sofie et al., 2014; Kidia et al., 2014), the participants said that disclosure to children is affected by the high workload due to inadequate staffing of facilities. These findings correspond with the report by Penn (2013), that the environment and settings of facilities are a barrier to accomplishing disclosure to children with PHIV.

5.11 Conclusions
This qualitative study assessed the opinions and practices of HCWs on the disclosure of their HIV status to perinatally infected children and adolescents in Alfred Nzo Health District facilities, Eastern Cape Province, South Africa.

The study indicates that HCWs affirmed the value of disclosure, relied on various ramifications for delaying disclosure in children, and had had different views on when disclosure to children and adolescents should happen. However, they emphasised that both the child’s age and the child’s maturity should be considered when deciding whether or not to disclose.

The HCWs believe that disclosure promotes adherence to a medical regimen and fosters independence and responsibility in the children, motivating them to continue with their treatment as prescribed, even in the absence of their parents.
Concerning the motivation to disclose, they referred to a refusal to take ART medication and poor adherence as the main reasons caregivers decide to disclose to their children. The main factors that influence delayed disclosure include the fear of being blamed by their children, the fear of stigmatisation and discrimination, the fear of provoking negative emotional reactions in their children, and the caregivers’ inadequate knowledge about HIV and lack of disclosure skills.

Some HCWs had witnessed extreme negative reactions to disclosure, after which some of the children had refused to continue with their treatment, had become depressed, had developed anger, had become sad and tearful, and had had suicidal ideation.

The study revealed that the most important consequences of delayed disclosure are poor adherence to treatment and poor health outcomes. Furthermore, delayed disclosure increases the potential for children to default, refuse to take medication, and transmit HIV to potential sexual partners and others. One other consequence of delayed disclosure that was mentioned was accidental disclosure, with negative psychosocial consequences for children. Sharing of medication by children to their siblings or other children came out as a risk of delayed disclosure.

Although the HCWs did not agree on the preferred person to carry out disclosure to children, most felt that the caregivers should lead disclosure to their children and that disclosure should happen at home.

The study found that despite the lack of disclosure guidelines for children, most of the HCWs routinely disclose to children and adolescents. They approach disclosure as an ongoing process that includes planning for disclosure, the actual disclosure event, and follow-up support for caregivers and children after disclosure. However, facilities do not have concrete strategies in place to manage and prevent accidental disclosure to undisclosed children and adolescents. The main barriers to disclosure to children are the lack of disclosure guidelines, paediatric disclosure expertise, and inadequate human resources.
5.12 Recommendations

Although the WHO and the NDoH have published disclosure guidelines for children, these are not being utilised by HCWs in the facilities. It is therefore imperative that facilities in the District should adopt the NDoH guidelines for disclosure to children to assist the HCWs in knowing how to conduct disclosure to children and adolescents.

Furthermore, the HCWs should be trained in disclosure counselling for children and adolescents to facilitate disclosure and to support caregivers to disclose.

To enable a conducive environment for children and adolescents in facilities, the District should strengthen its collaboration with non-governmental organisations to roll out and maintain the functionality of the adolescent and youth-friendly services to all facilities.

It is also recommended that the provincial office prioritise the issue of infrastructure and the recruitment of staff so that HCWs can be able to properly support caregivers and their children effectively.

Integrated clinical service management should be rolled out entirely in the District, and ARV units should be merged to the OPD in hospitals who still have ARV unit as a separate entity to deal with the issue of stigma and unplanned disclosure. Debriefing sessions should also be provided to HCWs so that the can deal with the experiences they are facing during and after disclosure.

The District also should look at the issue of the numbering of HIV files to avoid stigma, and also at developing strategies to indicate the status of disclosure for each child attended to, to avoid accidental disclosures in facilities.

It is recommended that the District engage people with different expertise to develop and roll-out a plan for community mobilisation to deal with stigma.

Finally, it is recommended that further research be performed on the practices of HCWs in
the sub-Saharan region on disclosure to perinatally infected HIV-positive children and adolescents.

5.13 Limitations of the study

The combing in the FGDs of HCWs of different kinds and grades of seniority might have caused some to fail to disclose rich and useful information that would have been valuable to the study. The researcher probed and made follow-ups to deduce more information from some of participants who were more reserved. The presence of the main researcher as part of the district management team during data collection might have caused discomfort to some of the participants, who might therefore have failed to disclose valuable data. And if further research is to be undertaken, it would be important to train a research assistant with whom the participants are not familiar, so that they feel free to talk during the process of data collection.
References


**Appendices**

**Appendix 1: Interview Guide**

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**Evaluation of the implementation of disclosure counselling to children on antiretroviral treatment:** *HIV disclosure to perinatally infected children and adolescents: a study of health care workers’ perspectives in Alfred Nzo Health District*

I am Cynthia Diko, an MPH student of SMU conducting research among health care workers on HIV status disclosure to perinatally infected children and adolescents. I will be working with Mveli Diko for the data collection. We will be using a recorder apart from notes taken as a back-up of the captured data. The recorded data will enable us to rewind and listen to get clarity on information that might have been missed in the written notes in order to produce quality data. We would like to assure you that everything we discuss in this focus group will be kept confidential. Please feel free to talk, but you are not compelled to respond to questions that make you feel uncomfortable. We would however, appreciate if you could respond to as many of the questions as possible. However, before the interview starts I would like to give you an opportunity to ask questions or seek clarity pertaining the information presented.

1. **What are your views about disclosure of HIV status to children and adolescents?**
   
   **Probes:**
   - Can you explain why it is important to disclose HIV status in children and adolescents?

2. **In your opinions, who should initiate disclosure to children living with HIV?**
   
   **Probes:**
   - What do you think is your role as a HCW on disclosure when dealing with HIV positive children and adolescents?
   - What do you think is the role of the parent or caregiver in HIV disclosure to children?

3. **What do you think are some reasons for parents or caregivers not to disclose HIV status to their children living with HIV?**
   
   **Probes:**
   - What do you think are the main causes of stigma?
   - What is it that could be done to reduce stigma in HIV?

4. **When do you think is the right time to disclose HIV status to children living with HIV?**
   
   **Probes:**
   - What informs your decision to initiate disclosure?
   - How is the disclosure process carried out in your facility?

5. **Have you ever disclosed?**
   
   **Probes:**
   - What are the reasons for your non-disclosure?
   - What do you do if you meet a child that needs to be disclosed?
6. **How is the disclosure process carried out in your facility?**
   **Probes:**
   - What do you tell the children and adolescent when disclosing their HIV status?
   - Can you share how do you handle children who react negatively after disclosure?

7. **How do you ensure that children and adolescents don’t get their status accidentally in the facility?**

8. **How are families supported during the HIV status disclosure to children and adolescents?**
   **Probes:**
   - How do you handle parents or caregivers continue to show reluctance to the idea of HIV disclosure to their children?

9. **Can you share your experiences on disclosure of HIV status to children and adolescents?**
   **Probes:**
   - What are some challenges you face in implementing disclosure counselling to children?

10. **How useful is the training that you received in your day to day HIV disclosure activities to children?**

11. **According to your own views, how can the disclosure counselling to children living with HIV be improved?**

12. **What is the successful disclosure to children and adolescents according to your opinions?**
Appendix 2: Part A: Demographic Information

Evaluation of the implementation of disclosure counselling to children on antiretroviral treatment: HIV disclosure to perinatally infected children & adolescents: a study of health care workers’ perspectives in Alfred Nzo Health District

Declaration by participants: The aim and objectives of the study were explained to me and are sufficiently clear. I understand that participation is voluntary and that I may withdraw from it at any time and without supplying reasons. I also understand that confidentiality will be maintained. By completing this questionnaire, I hereby consent to participate in this study.

<table>
<thead>
<tr>
<th>Demographic Profile</th>
</tr>
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<tbody>
<tr>
<td>Name of the study site:</td>
</tr>
<tr>
<td>1. How old are you?</td>
</tr>
<tr>
<td>2. Sex</td>
</tr>
<tr>
<td>3. What is your highest level of education?</td>
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<tr>
<td>4. What is your occupation in your facility?</td>
</tr>
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<td>5. What type of an employment are you on?</td>
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<tr>
<td>6. How long have you been working with children and adolescents living with HIV?</td>
</tr>
<tr>
<td>7. How long have you been working in the current institution?</td>
</tr>
<tr>
<td>8. Do you have any training in paediatric HIV care?</td>
</tr>
<tr>
<td>9. Please specify the duration of the training period</td>
</tr>
<tr>
<td>10. What kind of training have you obtained?</td>
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<tr>
<td>11. Do you have any paediatric HIV disclosure materials in your facility?</td>
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<td>13.</td>
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<td>14.</td>
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<td>15.</td>
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<td>16.</td>
</tr>
</tbody>
</table>
Appendix 3: Consent Form

Sefako Makgatho Health Sciences University- English Consent Form

Statement concerning participation in a Research Project

Title:

I have heard the aims and objectives of the proposed study and was provided the opportunity to ask questions. The aim and objectives of the study are 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 how I will be treated by my supervisor at work.

I am aware that the results of this study will be used for scientific purposes and that reports 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 guardian   Date

Statement by the Researcher

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: SMUREC Approval

Sefako Makgatho Health Sciences University
Research & Postgraduate Studies Directorate
Sefako Makgatho University Research Ethics Committee (SMUREC)
Molotlegi Street, Ga-Rankuwa 0208
Tel: (012) 521 5617/3598 | fax: (012) 521 3749
Email: loralo.phiri@smu.ac.za
P.O. Box 163 Medunas 0204

APPROVAL NOTICE - NEW APPLICATION

05 October 2017

D/O Oho
Department of Public Health
P.O Box 215
Medunas 0244

INVESTIGATION:

08/2017

SMUREC Ethics Reference Number: SMUREC/2265/2017: PG

The New Application received on 26 September 2017, was evaluated by members of Sefako Makgatho University Research Ethics Committee on 05 October 2017 and was approved on 05 October 2017.

Title:
HIV disclosure to perinatally infected children and adolescents: a study of health care workers’ perspectives and practices in Alfred Nzo Health District, Eastern Cape Province

Researcher:
C/O Oho

Supervisor:
Prof S Madiba

Department:
Public Health

Schools:
Health Care Sciences

Degree:
MPH

Please note the following information about your approved research project:

Approval Period:
05 October 2017 - 05 October 2018

Please remember to use your protocol number (SMUREC/2265/2017: PG) on any documents or correspondence with the REC concerning your research protocol.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modification, or monitor the conduct of your research and the consent process.

After Ethical Review: Please note a template of the progress report is obtainable in the Research Office and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit. Translation of the consent document in the language applicable to the study participants should be submitted.

Federal Wide Assurance (FWA00025263) Expiry date: 03 March 2021 and NHREC No. REC 214008-003

Sincerely,

PROF C BAKER
DEPUTY CHAIRPERSON SMUREC

Date: 05/10/2017
Appendix 5: Eastern Cape Approval

Re: HIV Disclosure to Perinatally Infected Children and Adolescents: A Study of Health Care Workers' Perspectives in Alfred Ndlo Health District, Eastern Cape Province. (EC_201802_015).

Dear Cynthia Dike,

The department would like to inform you that your application on the abovementioned research topic has been approved based on the following conditions:

1. During your study, you will follow the submitted amended protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.

2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.

3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.

4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Eastern Cape Health Research Committee Secretariat. You may also be invited to the department to come and present your research findings with your implementable recommendations.

5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

[Signature]

SECRETARIAT: EASTERN CAPE HEALTH RESEARCH COMMITTEE
Appendix 5: Editorial Confirmation Letter

TO WHOM IT MAY CONCERN

8 May, 2019

I hereby certify that I have edited the language of a dissertation by Cynthia Diko titled "HIV disclosure to perinatally infected children and adolescents: a study of healthcare workers’ perspectives in Alfred Nzo Health District."

I am Professor Alan Brimer, DLitt (UPE), Professor Emeritus of UKZN.

Yours faithfully,

Alan Brimer

[Signature]