An exploration of disclosure and non-disclosure patterns in HIV-infected children in Cape Town, South Africa.

By

Robert F Shea

(SHXROB001)

Minor dissertation
SUBMITTED TO THE UNIVERSITY OF CAPE TOWN
In partial fulfilment of the requirements for the degree of
Master's Programme in Maternal and Child Health (M.Phil [MCH])

FACULTY OF HEALTH SCIENCES
School of Child and Adolescent Health
UNIVERSITY OF CAPE TOWN

February 2018

Supervisor:
Dr Rudzani Muloiwa, Department of Paediatrics, University of Cape Town

DEDICATION:

My son was ill since birth, and at the age of six months he was diagnosed with HIV. The boy's mother and he tested positive and I tested negative. It was the most frightening moment of my life. I was told that my son would not live beyond three years of age, and I decided that I would make his life as rich and joyful as possible. Despite the medical advice I remained positive, provided my son with everything he needed to thrive, and constantly hoped that there would be a miraculous cure for him. He lived each day fully, was completely adherent to the medical regimen prescribed, and disclosed to everyone in my family circle about what my son was dealing with. Because of my son's HIV status I immersed himself in caring for him and started reading everything I could find about the disease. I retired from my business went back to college so that I could study psychology. The invitation to serve on the Community Advisory Board of Children's Hospital (University of California State) presented an opportunity of meeting several members of the South African Research teams doing research into youth and adolescent medication adherence. I travelled to South Africa where I started running camps for children attending the Infectious Diseases Unit at Tygerberg Hospital. Compared to HIV-infected children in California, families in Cape Town had extremely limited resources at their disposal. My son was his own advocate and could confidently disclose his status to others from the age of four years. After realising that parents were not disclosing their children's HIV status to them, I decided to focus my research on disclosure patterns with the purpose of helping to establish a disclosure process with clinical staff so that parents could be supported in this challenging task.

When I enrolled in the master's programme at the University of Cape Town (UCT) my son developed B-cell lymphoma, and he was seriously ill. I had deferred my studies to return to the U.S. and care for him. It was the most difficult years of my life, and I could not complete this research as planned. Sadly, he passed away in March 2016. I am completing this research in honour of my courageous son.

Plagiarism Declaration

“This thesis/dissertation has been submitted to the Turnitin module (or equivalent similarity and originality checking software) and I confirm that my supervisor has seen my report and any concerns revealed by such have been resolved with my supervisor.”

Name: Robert F Shea

Student number: SHXROB001

Signature: Signed by candidate

Date: 15 October 2018

ACKNOWLEDGEMENTS

My sincere acknowledgements go to every single person who contributed to this research. I remain forever grateful and humbled by your support.

- My family who were patient and believed that I could do this.
- The patients and staff at Red Cross War Memorial Children's Hospital whom I cannot name for fear of missing out on anyone who advised, guided, counselled, and gave up endless hours of their time and wisdom to this research.
- The administrative staff at the University of Cape Town postgraduate office, Mrs Adri Winckler, Mrs Salega Tape, Mrs Dianne Pryce, Mrs Debbie Moodie, Mrs Zerina Davis and Ms Geanine Hopley. Your help was immeasurable. Thank you.
- Dr Alex Muller and Dr Di Cooper who supervised the conceptualisation of this research.
- Dr Rudzani Muloiwa who selflessly took on the supervisory role when I was close to giving up, taking time away from his beloved daughter and wife to guide me.
- My late sister-in-law who tirelessly assisted with data entry.
- Siya Baleni, Sinazo Peter, Sibu Sishuba and Manyeleti Sambo for assisting with data collection.
- My fellow students who shared their academic struggles with me, and who listened patiently to my own, advising and guiding throughout the process.

TABLE OF CONTENTS

Title Page Number

LIST OF TABLES

FIGURES

APPENDICES

ABBREVIATIONS AND ACRONYMS

3Tc	Lamivudine
AIDS	Acquired immune deficiency syndrome
ALHIV	Adolescents living with HIV
AZT	Zidovudine
ART	Antiretroviral therapy
ARV	Antiretroviral
CLH	Children living with HIV
d4T	Stavudine
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
MTCT	Mother-to-child-transmission
BMSM	Black men who have sex with men
NVP	Nevirapine
PLHAs	People living with HIV & AIDS
PMTCT	Prevention of mother-to-child-transmission
RXH	Red Cross War Memorial Children’s Hospital
SDG	Sustainable development goal
UCT	University of Cape Town
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV &AIDS
VCT	Voluntary counselling and testing
WHO	World Health Organisation

DEFINITION OF TERMS

Adolescent:	Refers to any person between the ages of 10 and 19 years of age (World Health Organisation [WHO], 2018a).
Adolescence:	Adolescence is a transitional phase of growth and development that extends between childhood and adulthood. Although ages 10 to 19 years is sometimes regarded as the adolescent period, biological age is appropriate for assessing biological age, and does not take into account the nuanced psychosocial transitions that occur in adolescence (WHO, 2018a).
Caregiver:	A caregiver is anyone who cares for child in their own environment on a regular basis. The caregiver is related to the child receiving care, and is not a professional caregiver (Schoenmakers, Buntinx, & Delepeleire, 2010).
Child:	Any person under the age of 18 years of age, unless married or emancipated by a court order (Constitution of the Republic of South Africa, No. 108 of 1996; Children's Act No. 30 of 2005).
Child disclosure:	Child disclosure refers to an HIV-infected child being told their HIV status by a parent or caregiver, or the child's disclosure of their HIV status to others (Lesch et al., 2007).
Parental disclosure:	In this study disclosure refers to the primary caregiver's perception of having told an HIV-infected child about the HIV & AIDS diagnosis (Vreeman et al., 2013).
Social support:	Social support is defined as:" supportive functions performed for the individual by significant others, such as family members, friends, and co-workers (Thoits, cited in Bekelele et al., 2013, p. 337).
Stigma:	Stigma is described as: "a negative attribute that is mapped onto people who, by virtue of being different, are understood to be negatively valued in society" (Stuber, Meyer, & Link, 2008, p. 5)
Youth:	The term young people and youth applies to people between the ages of 10 and 24 years of age (WHO, 2018a). In South Africa youth refers to persons between the ages of 14 and 35 years (National Department of Health [NDoH], 2015, p.19).

ABSTRACT

A cross-sectional, descriptive study combining with open-ended (qualitative) interview questions with quantitative component was conducted to explore disclosure experiences of mothers and caregivers of HIV-infected children. The study was conducted with 102 parents and caregivers at a tertiary hospital in Cape Town delivering care to 303 HIV-infected paediatric patients. The study sample included 102 participants, ranging in age from 16 years to 71 years. The sample included 73 mothers (72%), six fathers (6%), 11 foster-mothers (11%), and 12 caregivers or grandmothers (12%). The median age of participants' children was 4 (IQR 2-8) years and ranged from five months to 16 years. Only 48 (47%) were old enough for disclosure to be possible. Disclosure or disclosure delay was associated with several factors, including the child's age or ability to understand, anxiety and guilt about being blamed for infecting the child, fear of exposing the child to stigma, discrimination and social exclusion related to the child disclosing to others, and the hope that the child would be adherent if they understood their illness and the way in which the medication could improve their health outcomes. Only 16 (33%) of 48 participants actually disclosed the child's HIV status. The results indicate that HIV-disclosure remains a challenging, emotionally-charged experience for mothers and caregivers. The findings of this research, and similar studies, point to the value of integrating disclosure support and planning into routine care for children and adolescents, as well as their parents and caregivers.

CHAPTER ONE: BACKROUND AND INTRODUCTION

This dissertation is located at the juncture of human immunodeficiency virus (HIV) infection and child well-being. This chapter presents the connectedness of HIV and child well-being as a backdrop and rationale for the current study. The purpose of this chapter is not to provide a comprehensive discussion of each of the concepts, but instead aims to provide a contextual background to the study.

1.1.Background and Introduction

The number of AIDS-related deaths in children aged 0-14 years is steadily declining, from 210,000 in 2010 to 120,000 in 2016 (Joint United Nations Programme on HIV & AIDS [UNAIDS], 2017). The rapid scale-up of antiretroviral medication (ART) made available to pregnant women through the prevention-of-mother-to-child-transmission (PMTCT) programme increased from 47% in 2010, to 76% in 2016 (UNAIDS, 2017). In children the number of new infections dropped by 47%; this trend could be attributed to enhanced PMTCT coverage and improved access to highly active antiretroviral therapy (HAART) for children. Improved survival and health outcomes in HIV infected children draws attention to the psychosocial challenges related to growing up with a chronic, potentially life-threatening, stigmatised illness (Mutumba et al., 2015; Tadesse, Foster, & Berhan, 2015). As HIV infected children transition into adolescence, they must negotiate issues of disclosure, stigma, and practicing safer sex (Madiba & Mokgatle, 2016). Improved access to antiretroviral medication and the associated positive health outcomes and survival makes HIV disclosure to children and adolescents an important aspect of HIV management (Vaz, Eng, Maman, Tshikandu, & Behets, 2010; Kenu et al., 2014).

In 2010 it was estimated that 30% of all pregnant women attending antenatal clinics in South Africa (SA) were HIV-infected (Barron et al., 2013). In October 2015 HIV prevalence among antenatal attendees was 30.8% (National Department of Health [NDoH], 2017). The alarmingly high maternal seroprevalence, with its associated morbidity and mortality, renders children vulnerable on two scores. First, maternal HIV infection results in paediatric HIV infection becoming a sizeable public health problem in SA. An estimated 184,680 children are living with HIV, with 303 receiving care at Red Cross War Memorial Children's Hospital (RXH) in Cape Town (Dr J. Nuttal, personal communication, 2016). In a study conducted in two centres in SA, the availability of simpler, cost-effective methods for diagnosing HIV, as well as the availability of affordable and appropriate paediatric antiretroviral (ARV) regimens was found to reduce HIV-related child mortality by 76%, with a reduction disease progression by 75% (Violari et.al., 2008). Ironically, the second significant consequence occurs when HIV-infected children access antiretroviral therapy (ART) and have a reduced risk of dying during childhood, precipitating the need for explaining their diagnosis (Kenu et al., 2014; Midtbø, Shirima, Skovdal, & Daniel, 2012; Mutumba et al., 2015).

Disclosing an HIV status to a child remains one of the most challenging aspects of the disease (Kenu et al., 2014; Pantelic, Shenderovich, Cluver, & Boyes, 2015). For parents and caregivers, knowing when and how to start the disclosure process to children can be daunting and anxiety-provoking (Evangeli & Kagee, 2016). Although HIV disclosure has received significant attention in the past two decades, the actual disclosure process remains challenging and uncertain (Das, Detels, Javanbakht, & Panda, 2016). This is of particular significance in low-income countries (LICs) in sub-Saharan Africa (SSA) where HIV remains a heavily stigmatised disease (Pantelic et al., 2015). Explaining an HIV diagnosis to children and adolescents can be particularly confusing to those who are asymptomatic (Kenu et al., 2014). HIV non-disclosure could in fact impede access to treatment for infected children, which could be detrimental to their health and well-being (Gyamfi, Okyere, Enoch, & Appiah-Brempong, 2017). Reported disclosure concerns relate to fears about children's cognitive and emotional development, capacity to understand, their ability to cope with the illness, being stigmatised, concerns about emotional support, and concerns about the implications for social relationships (Gyamfi et al., 2017; Oberdorfer et al., 2006; World Health Organisation [WHO], 2011). WHO recommends that children of school-going age be told their HIV status, and that younger children be incrementally informed of their health status (WHO, 2011).

Mother-to-child transmission (MYCT) of HIV

The United Nations AIDS (UNAIDS) Report 2014 indicated that at least 19 million of the 35 million people infected with HIV are unaware of their HIV status (UNAIDS, 2014). Despite the increasing availability to HIV screening through PMTCT programme, 54% of pregnant women in low- and middle-income countries (LMICs) do not have an HIV test during the antenatal period. Vertical HIV transmission rates remain high, ranging from 15% to 45% (WHO, 2018b). In 2010 it was estimated that 30.2% of all women attending antenatal clinics in South Africa (SA) were HIV-infected, and at least 70.4% of all maternal deaths in 2011 were HIV-related (Barron et al., 2013). Testing infants for HIV in SA before the age of two months increased from 36.6% in 2008, to 70.4% in 2011 (Barron et al., 2013). During that period the number of children who tested positive declined from 9.6% in 2008, to 2.8% in 2011 (Sherman et al., 2012). In 2015 MTCT increased from 4.9% at six weeks of age, to 8.9% at the end of the breastfeeding period (UNAIDS, 2016). Of the number of children infected with HIV, approximately one third die before their first birthday, and half die by their second birthday. Once the diagnosis is confirmed and children are started on antiretroviral treatment, HIV-related mortality can be reduced by as much as 75% (UNAIDS Gap Report, 2014). Fast-tracking progress toward the elimination of MTCT requires improvements in access to lifelong ART, as well as appropriate attention to the complex psychosocial factors that negatively affect care-seeking, disclosure, and retention in care (Prudden et al., 2017).

South Africa introduced WHO’s “Option B+” in April 2013, to replace “Option A”. The new treatment regimen provided all HIV-positive women a three-drug ART for the duration of the pregnancy and breastfeeding period, irrespective of the mother’s baseline CD4 count (Maskew et al., 2018). Despite these modifications, a prospective cohort study conducted at a primary health care clinic in Johannesburg, South Africa found that although ART-initiation in pregnancy was starting at an earlier gestational age, ART adherence was sub-optimal (Maskew et al., 2018). In 2011 it was estimated that 2.7% of HIV-exposed infants attending baby follow-up services tested HIV-positive at four to eight weeks of age (Burton, Giddy, & Stinson, 2015).

Importance and benefits of HIV Disclosure

An ill child is a concern to family members. Once the child's health has stabilised, caregivers are tasked with the responsibility of HIV disclosure. For many children the discovery of their positive HIV status is secondary to an episode of illness (Tadesse, Foster, & Berhan, 2015); hence the diagnosis is often a shocking and unpleasant surprise. Informing children living with HIV (CLH) of their status is important from the clinical diagnostic and treatment significance, as well as the overall psychological well-being perspective (Das et al., 2016; Prudden at al., 2017). Challenges that parents and caregivers have to consider include when to disclose, how to disclose, who should disclose, how much to disclose, and what is in the child's bests interest (Kenu et al., 2014). HIV disclosure carries benefits for parents as well as children living with HIV. Parents who disclose their HIV status to children reportedly experience stress and anxiety to a lesser degree than those who do not. Disclosure allows the child to ask questions, clarify misconceptions, adjust to the situation, grieve, and access social support (Ostrom Delaney, Serovich, & Lim, 2008; Kenu et al., 2014). In a cross-sectional study conducted with 71 mother-child dyads in Ghana, researchers found that HIV disclosure helped children to understand their illness and treatment, which improved participation in disease management (Kallem, Renner, Ghebremichael, & Paintsil, 2011). Children who were told their HIV status tend to have better self-esteem than those who do not know their status, and tend to experience less psychological distress (Domek, 2010). Moreover, children's awareness of their HIV status is associated with improved medication adherence (Kallem et al., 2011; Tadesse et al., 2015; Vreeman et al., 2010; Vreeman et al., 2013).

Barriers to HIV status disclosure

Disclosure is a significant component of long-term HIV management, and an essential step for children as they transition from paediatric to adolescent and adult care (Vreeman et al., 2013). In a study conducted in

Kenya by Vreeman et al. (2010) only two caregivers in a sample of 120 study participants explained to the child why they were taking ARVs. The main reason for delaying disclosure was caregivers' fear of adverse psychological consequences (Oberdorfer et al., 2006). In a cross-sectional study conducted with 177 children in Southern Ethiopia, caregiver reasons for non-disclosure of the child's HIV status included fear of hurting the child's feelings, fear of self-harm, concerns that the child might not be able to accept the information, and fear that the child might refuse to continue taking the medication (Tadesse et al., 2015). In a cross-sectional study conducted in Ghana with 118 caregivers of HIV-infected children, the main reasons for non-disclosure were fears that the child might be too young to understand, the desire to protect the family from shame, the effect of disclosure on the mother-child relationship, the effect of disclosure on the child's emotional and psychological well-being, and the fear that the child might perceive the mother as having led an irresponsible life (Gyamfi et al., 2017). Maternal non-disclosure could cause children to read into the signs related to bouts of illness, hospital visits, and hospitalisation, which could result in anxiety and fear (Ostrom Delaney et al., 2008). Non-disclosure can be detrimental to child and adolescent well-being as it could be a barrier to care when cooperation and treatment adherence behaviour are being developed (Lesch et al., 2007; Tadesse et al., 2015).

1.2. Motivation and Justification for the Study

Paediatric HIV & AIDS affects children in significant ways, including physiological, psychological, and social ways. Emerging evidence suggests that children are profoundly affected by their HIV status and face an increased risk of developing mental health problems associated with stress emanating from parental loss, lack of social support, social exclusion, feelings of shame, and poor body image (Dow et al., 2016; Lam et al., 2007). They often feel betrayed and many experience confusion, depression, anxiety, fear, anger, guilt and loneliness (Brown & Lourie, 2000; Dow et al., 2016; Ruiz, 2000). Appropriate attention to the psychosocial needs of HIV-infected children tends to lag behind responses to biomedical aspects of the disease (Domek, 2006). In many contexts living with HIV includes facing significant stigma and shame that can adversely affect children's coping and general sense of emotional wellbeing (Earnshaw & Chaudoir, 2009). Children who know of their parents' HIV serostatus often have to cope with stigma as well as their fears about the potential loss of a family member (Dow et al., 2016; Wiener et al., 2000).

The availability of improved paediatric ART regimens has transformed HIV & AIDS in children from a rapidly terminal disease to a longer-term chronic condition (Gillard & Roark, 2013; Kenu et al., 2014). HIV care is a process involving caregivers and the paediatric patient through all their developmental stages and disclosure is one of the crucial steps in the process. Non-disclosure to children can result in feelings of loneliness, emotional and psychological distress and the fear that there is something so seriously wrong that it has to be kept secret (Domek, 2005). Caregivers often defer disclosure or fail to disclose at all. Surrounded by the fear of stigma, abandonment and social isolation, there are often significant social, cultural traditions and circumstances that have to be taken into account when preparing caregivers to disclose to an HIV-infected child (Domek, 2005; Ostrom Delaney et al., 2008).

Children and caregivers change and develop over time, therefore different ages require different responses and different kinds of information about their health status. Depending on the child's age, non-disclosure is likely to create different degrees of adjustment difficulty (Kenu et al., 2014). For example, for the child under four years of age, disclosure may not be as significant for the child aged 5-6 years preparing to enter pre-school or grade one, a period when the child's social circle expands greatly. At age 10-12 years, the pre-pubertal and pubertal stage, the child is looking forward to the major shift in their sense of self in the social circle, where body image and social acceptance amongst peers becomes paramount (Gyamfi et al., 2017; Kenu et al., 2014; Lester et al., 2002; Papalia et al., 2001). Disclosure at this point, depending on how it is handled, can have a devastating impact on the child's development. Managing a chronic condition requires ongoing disclosure and re-disclosure because each time the child engages with a change in their development and the meaning of the illness and its impact on their life, the need for re-disclosing arises

(Gyamfi et al., 2017; Lesch et al., 2007; WHO, 2011). This suggests that with advancing age of the child, caregivers and health providers' way of relating to the children needs to be adjusted (WHO, 2011). WHO recommends that disclosure should be incorporated into the long-term HIV management plan, and that younger children should be informed about their health status incrementally, to accommodate their emotional and cognitive level of maturity (Gyamfi et al., 2017; WHO, 2011).

A critical analysis of the way in which the social context interacts with personal and interpersonal factors to influence disclosure practices to HIV-infected children, at different developmental stages, is essential for the delivery of comprehensive paediatric HIV care. Elements of this study could be used to guide the formulation of culturally sensitive strategies for facilitating disclosure at significant developmental stages in HIV-infected children.

1.3. Research Questions

The study was guided by three questions:

- What factors inform parents/caregivers' decision to disclose their health status to HIV-infected children?
- What are the consequences of disclosure for children and their caregivers?
- How do HIV-infected children respond to disclosure?

1.4. Research Aim

The aim of the study was to explore patterns and challenges associated with disclosure to HIV-infected children as a basis for developing culturally appropriate strategies for facilitating disclosure.

1.5. Research Objectives

1. To determine general disclosure trends in children receiving ARTs at Red Cross War Memorial Children's Hospital (RXH) in Cape Town, South Africa.

2. To explore caregiver’s perceptions and experiences with disclosure to HIV-infected children receiving care at RXH in Cape Town, South Africa.
3. To explore HIV-infected caregiver perceptions about their children’s understanding about their health status and experiences with disclosure.
4. To make recommendations that could assist caregivers to disclose to children who are HIV positive.

1.6. Summary

The first chapter presented a brief background and introduction to the study. Chapter two is a presentation of the literature review on the topic, and chapter three provides details about the research methodology applied in the study. In chapters four and five the findings of the study are presented and discussed. Chapter six summarises the findings and limitations of the study, and presents recommendations based on the findings of the research.

CHAPTER TWO: REVIEW OF THE LITERATURE

2.1. Introduction

This chapter presents a review of the literature pertaining to HIV disclosure to the infected child. The chapter starts with a description of the background to HIV & AIDS, followed by the diverse dimensions of the disclosure process.

2.2. Review Methodology

The review draws on literature up to and including 2017 identified using keyword searches of electronic databases. The main keywords used in the search were “HIV & AIDS” and “paediatric” with “disclosure”. Other search terms applied were “HIV disclosure to children” and “effects of HIV disclosure in children”. Additional searches were conducted using the terms “HIV and social support” and “HIV and stigma”. Databases accessed included Ebscohost, ScienceDirect, PubMed, CINAHL, and PsychInfo.

2.3. Background to HIV

HIV was first identified in 1984 by Luc Montagnier and colleagues at the Institut Pasteur of France. Transmission of the virus to the newborn can occur in utero, intrapartum, or postnatally through breast-feeding (Magder et al, 2005) resulting in 3.4 million children under the age of 15 years living with HIV (UNAIDS 2010 Global Report on the Global AIDS Epidemic). Intrapartum transmission of HIV from mother to child occurs primarily through direct contact of the fetus with the virus in the genital tract (Thorne & Newell, 2004). While the administration of single-dose Nevirapine has proved to significantly reduce vertical transmission of HIV to the newborn, postnatal transmission of the virus through breastfeeding remains a concern (Magoni et al, 2005; Leroy et al, 2003; Jackson et al, 2003). We know from several studies that the estimated risk of HIV transmission through breastfeeding doubles the overall risk of mother-to-child -transmission (MTCT), contributing a significant 16% to MTCT rates (Thorne and Newell, 2004; Richardson et al., 2003). The UNAIDS Global Plan, focused on the elimination of MTCT and keeping mothers alive has contributed substantively to identifying and implementing interventions for preventing MTCT (UNAIDS, 2016). Since the implementation of the UNAIDS Global Plan in 2011, worldwide the number of new infections in children decreased by 60% (UNAIDS, 2015).

2.4. HIV Prevalence

Globally there are approximately 36.7 million people living with HIV, with 2.1 million being children <15 years of age (UNAIDS Fact Sheet, 2017). In 2016 young women aged 15 to 26 years in eastern and southern Africa accounted for 26% of new infections. Of the estimated 5000 new HIV infections per day, 64% are from sub-Saharan Africa (SSA), and 400 new infections occur in children <15 years of age (UNAIDS, 2017). Women carry more than half (58%) of the HIV-infection burden in SSA. Of the 4500 new HIV infections, 43% are women aged 15 years of age and older (UNAIDS, 2017). In 2013 the number of cases of HIV infection was 2.1 million, a 38% decline from the 3.4 million new cases of HIV reported in 2001. In 2002 the number of new infections in children was 580 000. By contrast the number of new infections in children in 2013 was 240 000, a reduction of 58% (UNAIDS Gap Report, 2014).

Despite the increasing availability of HIV screening through the prevention–of-mother-to-child-transmission (PMTCT) programme, 54% of pregnant women in low- and middle-income countries (LMICs) do not have an HIV test during the antenatal period. Notwithstanding the low uptake of the PMTCT intervention during the antenatal period, vertical transmission of HIV in LMICs declined from between 20-40% to 2.8% in well-performing countries. In wealthy countries the vertical transmission rate is below two percent (Grimwood et al., 2012). Although the dramatic decline in new infections in children is attributed to the provision of antiretroviral medication for pregnant women, in 2015 MTCT increased from 4.9% at six weeks to 8.9% at the end of breastfeeding (UNAIDS, 2016). The rate of mother-to-child-transmission (MTCT) in mothers who do not receive ART ranges from 15% to 45% (WHO, 2018b). However, in the 21 countries in which the Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive was rolled out the mother-to-child-transmission rate was 25.8% in 2009 (UNAIDS, 2015). Since the Global Plan was launched in July 2011, the rate decreased to 15.7% (UNAIDS Gap Report, 2014). In 2016, approximately 76% of pregnant women had access to ART to prevent vertical transmission to their babies (UNAIDS Fact Sheet, 2017). Furthermore, in approximately 25% of pregnant women who tested HIV-positive, lifelong ART was not initiated (Prudden et al., 2017). Despite the 50% decline in the number of new cases of HIV infection in children in SA, in high-prevalence areas it is estimated that at least 40% of pregnant women are infected, resulting in vertical HIV transmission to children (Rochat, Mkwanazi & Bland, 2013; UNAIDS Gap Report, 2014). Since 2009, new infections in children in SA were reduced by 84% (UNAIDS, 2016). Improving access to lifelong ART relies on expanding the supply of PMTCT services, as well as ARV treatment programmes (Prudden et al., 2017). Moreover, structural barriers to HIV prevention, screening, treatment and support services, like non-disclosure and stigma, demand appropriate attention if MTCT prevention goals, and Sustainable Development Goal (SDG) 3 (United Nations [UN], 2015) that addresses the health outcomes of women, newborns, children, and adolescents (Prudden et al., 2017).

2.5. HIV and Stigma

Stigma is recognised as a significant barrier to accessing HIV prevention, testing, and treatment services (Mahajan et al., 2008; Prudden et al., 2017) and is a considerable barrier to HIV disclosure (Abebe & Teferra, 2012; Prudden et al., 2017). According to Goffman, stigma “occurs when a person or group possesses a particular attribute that is viewed by others in society as an undesirable difference” (cited in Harper, Lemos, & Hosek, 2014, p. 543). Goffman established that society stigmatises on the basis of what is perceived as difference or deviance (Goffman, cited in Mahajan et al., 2008). Viewed as a psychological stressor, stigma manifests either as anticipation of negative treatment by others, or as a self-directed internalisation of negative views held by others (Stuber, Meyer, & Link, 2008). In their systematic review of HIV & AIDS stigma, Mahajan et al. (2008) examined the way in which people living with HIV & AIDS

(PLHAs) are labelled and stereotyped by society on the basis of false beliefs, attitudes, and fears. Stigma is not constrained to individual perceptions and is interwoven into the social interactions and processes of families, groups, communities, and society (Mahajan et al., 2008). Wilson et al. (2016) in their systematic review of qualitative studies examining stigma in the context of Black men who have sex with men (BMSM) reported institutional and community-level stigma related to sexuality, femininity, and HIV & AIDS acquisition vulnerability. Societal stigma linked to low socioeconomic status, race, ethnicity, and gender discrimination tends to reinforce secrecy and reluctance to disclose (Eilson et al., 2016). Discrimination is consequent to stigmatisation, and results in unfair and unjust treatment (Smith, Rossetto, & Peterson, 2008). Parker and Aggleton (cited in Mahajan et al., 2008) proposed that stigma functions at the intersection of relations of power and control. The outcome of stigma is social distancing, limiting social opportunities, and lack of support (Mahanjan et al., 2008; Smith et al., 2008). Marginalised groups such as non-white heterosexual men and women, gay men, injection drug users, and sex workers emerged as particularly vulnerable to stigma in the context of HIV & AIDS (Wilson et al., 2016). Social exclusion affects marginalised groups economically, politically and socially. Stigmatisation of marginalised people disallows them the privilege of economic and social opportunities available to others. This also applies to access to health services (Cáceres et al., 2008). Consequently, PLHAs may be hesitant to disclose their HIV status to others, to protect themselves, their family, and friends against potential rejection and discrimination (Smith et al., 2008). To avoid rejection, PLHAs tend to resort to secrecy, deception, and social withdrawal to avoid rejection (Smith et al., 2008). HIV-related stigma and discrimination are social processes linked to inequality and exclusion, with potential adverse psychological, social, and biological consequences (Stuber et al., 2008). Stigma and discrimination at the family and community level, as well as within health services, are recognised as significant social barriers to PMTCT access and retention (Prudden et al., 2017).

2.6. HIV and Social Support

The relationship between perceived or received social support and improved quality of life for adults infected with HIV is well-recognised (Bekele et al., 2013; Liu et al., 2006; Uphold et al., 2005). Social support is defined as:” supportive functions performed for the individual by significant others, such as family members, friends, and co-workers (Thoits, cited in Bekelele et al., 2013, p. 337). Social support was shown to have a positive impact on medication adherence, improvements in CD4 count, and a reduction in HIV symptoms (Bekele et al., 2013). Support can be categorised as emotional, informational, and instrumental. Emotional support is reflected in caring and empathy; informational support includes counseling, advice, and encouragement; and practical support includes assisting with housework, childcare, and the provision of food, accommodation, or money (Kimani-Murage, Manderson, Norris, & Kahn, 2010). Two fundamental ways in which support benefits people living with HIV is by having a positive effect on well-being (main effects model) or by reducing the detrimental effects of stressors (stress-buffering model). In a health survey conducted with 602 adults living with HIV in Ontario, Canada to examine how perceived or received social support contributes to physical and mental well-being, the results showed that social support had an overall beneficial effect on health-related quality of life (HRQOL) (Bekele et al., 2013). Similarly, in a study conducted in Ethiopia to explore the association between depressive symptoms and perceived social support on weight gain and CD4 cell counts, Alemu et al. (2012) found that perceived social support had a positive effect on weight gain and CD4 cell progression. Among the range of support functions, emotional support is thought to have the most significant bearing on overall well-being (Zhao et al., 2011).

The well-being of children and the parents or caregivers tends to be intricately intertwined, and medication adherence in children is affected by the level of caregiver stress and quality of life (QOL), caregiver functioning, and the quality of caregiver-child communication (Merzel, VanDevanter, & Irvine; 2008). Social support is recognised as a salient resource and mediating factor for coping with the challenges of caring for an HIV infected child (Merzel et al., 2012). Kimani-Murage et al. (2010) found the fear of stigma to be a significant deterrent to accessing external support, as well as disclosure of the child's HIV status. Parents and caregivers who struggle to maintain their child's HIV medication adherence might shy away from seeking support from family, friends, neighbours and community members as a result of non-disclosure and fear of stigma (Midtbø et al., 2012).

2.7. HIV Disclosure

In this study disclosure was explored from the perspective of the parents or caregivers; hence disclosure is understood as the primary caregiver's perception of having told an HIV-infected child about the HIV & AIDS diagnosis (Vreeman et al., 2013). Child disclosure refers to an HIV-infected child being told their HIV status by a parent or caregiver, or the child's disclosure of their HIV status to others (Lesch et al., 2007). Disclosure can take the form of a single event, or a gradual process (Madiba & Mokwena, 2012; Mahloko & Madiba, 2012). Several researchers have studied disclosure patterns and found that disclosure trends vary broadly, ranging from vague misrepresentations like telling the child that they take medicine to look after themselves or hiding the child's HIV status behind illnesses like allergy, tuberculosis, liver disease or cancer to telling the child that they have the same disease as the caregiver without using the terms HIV or AIDS (Kenu et al., 2014; Oberdorfer et al., 2006; Ledlie, 1999; Lee & Rotheram-Borus, 2002; Lesch et al., 2007). Some caregivers have reported telling the child that they have a germ in their blood and others have disclosed completely using the terms HIV & AIDS (Oberdorfer et al., 2006; Ledlie, 1999, Lee & Rotheram-Borus, 2002). Based on these insights, complete parental disclosure is defined as a situation in which the primary caregiver and child agree that the child was told about their disease, using the terms HIV or AIDS as well as the way in which ART works to improve health outcomes (Bimaako-Kajura et al., 2006).

Eustace and Ilagen (2010) described the HIV disclosure process as containing antecedents and consequences. Antecedents fall in two categories, namely before and after an HIV diagnosis, and could include individual, family, community, and social factors (Eustace & Ilagen, 2010). Post diagnosis factors include disease acceptance, the desire to protect others, and the need for social support. The consequences of HIV disclosure could be experienced as either negative or positive, in relation to the reactions of family, loved ones, friends, community, and co-workers (Eustace & Ilagen, 2010). Negative consequences could include anxiety related to fear of rejection, stigma, discrimination, loss of love and support, and social isolation. Positive consequences include acceptance, social support, improved relationships, improved adherence, and retention in care (Eustace & Ilagen, 2010).

Disclosure can be anxiety-provoking for parents who often feel a deep sense of guilt about passing the infection to their child. In a study conducted to explore HIV care-seeking behaviours for HIV-infected children in rural SA, caregivers feared that confidentiality would be broken by health providers (Kimani-Murage, Manderson, Norris, & Kahn, 2013). Disclosure was reportedly associated with high perceived social costs, with detrimental effects on the child’s development (Kimani-Murage et al., 2013). Additionally, AIDS is highly stigmatised in most societies as it is perceived to be a consequence of socially unacceptable behaviours like sexual promiscuity, drug use and homosexuality (Wiener et al., 2000). Oberdorfer et al (2006) in their disclosure study conducted in Thailand found the fear of negative emotional consequences for children to be the main reason for delayed disclosure. Reported negative emotional consequences include distress, depression, anxiety, discrimination and isolation (Oberdorfer et al., 2006).

Factors supporting disclosure

Emerging evidence demonstrates a positive correlation between complete parental disclosure, ART adherence and health outcomes (Abebe & Teferra, 2012; Bikaako-Kanjura et al., 2006; Gyamfi et al., 2017; Kenu et al., 2014; Lawan, Envaladu, & Abubakar, 2016). Caregivers report that children who know their HIV serostatus and understand how the medication works to protect their health are “self-motivated to adhere” (Bikaako-Kanjura et al., 2006, p.S88). Where primary caregivers have disclosed completely, children tend to trust that the drugs will prevent them from getting ill, are generally less dependent on their caregivers, and develop their own adherence strategies. In a multi-centre cohort study conducted in five paediatric clinics to explore retention in care among HIV-infected children aged 10 years or more in Cote d'Ivoire, Mali and Senegal, the researchers found that retention in care was higher in those adolescents who knew their HIV status compared to those to whom their HIV status had not been disclosed (Arrivé et al., 2012). Similarly, in a study conducted to evaluate whether selective disclosure or non-disclosure was associated with retention in care, non-disclosure was significantly associated with poor retention in care (Alopre et al., 2015).

Children who experienced complete parental disclosure generally enjoy supportive, trusting relationships and adherence is understood to be a shared responsibility (Bikaako-Kanjura et al., 2006). Lawan et al. (2016) used a case study approach with 400 HIV-infected adolescent children attending an ART clinic in northern Nigeria to examine the disclosure and awareness status of adolescents. The results showed that two-thirds of adolescent participants (251) knew their HIV status, compared to 149 who did not know their status. HIV awareness was positively correlated with age, sex, level of education, and the level of education of mothers (Lawan et al., 2016). HIV awareness was found to play a key role in HIV prevention and risk behaviour (Lawan et al., 2016). Positive outcomes associated with HIV disclosure to children and adolescents include better understanding of their health status, cooperation with medical regimens, improved adherence, improved utilisation of clinical support services, fewer behavioural difficulties, establishing trust, and improved communication of fears and anxiety (Lawan et al., 2016).

Factors inhibiting disclosure

Disclosure to an HIV-infected child can be intensely anxiety and fear-provoking and caregivers try to avoid disclosure as long as possible (Abebe & Teferra, 2012). Non-disclosure affects child well-being by negatively affecting adherence and retention in care, as well as access to care and support services (Gyamfi et al., 2017). The decision to disclose HIV status to a child is informed by the interaction of several compelling factors. In addition to personal processes and the subjective experiences of social influences, there are objective environmental, social, economic and political considerations. Beliefs about the difficulty with accepting their HIV serostatus and diminished ability to cope with their own illness may prevent parents from disclosing to their children. Parents may also feel guilty about infecting their child and fear anger or rejection from their children (The American Academy Committee on Paediatric AIDS, 1999; Vreeman et al., 2013). Several studies report that parents often decide to protect their children against what they perceive to be potentially harmful knowledge and negative experiences, believing that the child is better off not knowing (Claflin & Barbarin, 1991; Funck-Bretano et.al., 1997; Lester et.al., 2002; Thorne et.al., 2002; Evangeli & Kagee, 2016). Consequently, they defer disclosure as long as possible to protect the child. In their study with caregivers of HIV-infected children six years and older in Thailand, researchers found that 12.7% of caregivers who had not disclosed to their children were afraid that their children would be discriminated against, while 53.4% feared negative emotional consequences like distress, depression, anxiety and isolation (Oberdorfer et al., 2006).

Guilt, fear of the consequences of disclosure like shame, alienation, and stigma result in parents and caregivers trying to delay disclosure as long as possible (Abebe & Teferra, 2012; Kenu et al., 2014). Parents and caregivers fear that if they disclose the HIV status to children, they could tell others, resulting in discrimination, alienation, and social exclusion (Kenu et al., 2014). The consequences of delayed or non-disclosure include poor compliance, psychological distress and suicide (Lesch et al., 2007; Harper et al., 2014). Caregivers and health providers often feel inadequately prepared to disclose to children and interventions for caregivers and staff that take into account personal processes, subjective experiences along with compelling cultural and social influences in the disclosure process are essential in paediatric HIV care (Lawan et al., 2016). Where caregivers did not disclose to children, adherence depends on the caregiver or another person, and children report that they take their medication to please significant others. Taking medication is reportedly accomplished through direct observation, threats, bribes or forceful means like verbal or physical abuse (Bikaako-Kajura et al., 2006). Research findings suggest that children and adolescents living with perinatally acquired HIV infection have higher rates of psychiatric co-morbidities than their uninfected counterparts (Midtbø, Shirima, Skovdal, & Daniel, 2012). Health providers caring for HIV-infected children at Red Cross Children's Hospital in Cape Town explained that this is one of the most significant challenges they face. They explained that children often realised that they have HIV and then do not know how to cope as they feel that their parents need to be protected (Conversation with professional nurses, June 2009).

Disclosure processes and models

Although the need for disclosure is understood, there are diverse opinions about when, how, how much, and who should disclose (Abebe & Teferra, 2012; Lesch et al., 2007). The American Academy of Pediatrics (AAP) and WHO encourage HIV disclosure to school-aged children and younger children (American Academy of Pediatrics [AAP], 1999; WHO, 2011). In preparation for full disclosure, continuous, developmentally oriented approach, to accommodate cognitive skills and emotional maturity is recommended (Abebe & Teferra, 2012; Gyamfi et al., 2017; Kenu et al., 2014; WHO, 2011). In their review of disclosure practices and processes Lesch et al. (2007) note that open communication between parents, caregivers and children is the exception rather than the rule. They advise that naming the disease may be less effective in helping children to cope than providing them with age-appropriate information and explanations that could help them understand and make meaning of their illness-related experiences (Lesch et al., 2007). Moreover, it is critically important that children be allowed to ask questions, and that their question be answered honestly.

A family-oriented approach allows HIV-infected children to be viewed and cared for as a comprehensive social unit, living in and experiencing a unique, family, community, and cultural environment (Lesch et al., 2007). Comprehensive, integrated, family-centred services could potentially provide HIV-infected children and adolescents and their families with support and guidance throughout the disclosure process (Lawan et al., 2016; Lesch et al., 2007).

HIV disclosure prevalence

HIV disclosure prevalence appears to be associated with contextual factors. Disclosure resources and procedures include having a disclosure protocol, disclosure counselling, and disclosure training for staff (Arrivé et al., 2018). In a retrospective, longitudinal record review of adolescents living with HIV (ALHIV) in Kericho, Kenya the results indicated an improved mean CD4 count associated with younger age of disclosure (Montalto et al., 2017). The mean disclosure age was found to be 12.34 years (ranging from 9.21–17.05). In an online site assessment survey conducted across HIV care and treatment clinics caring for children within the International Epidemiology Databases to Evaluate AIDS (IeDEA) cohort consortium, 80% of adolescents knew their HIV status by 14 years of age (IQR: 75-80%). The survey found that disclosure counselling was provided by counsellors (88% of sites), nurses (78%), physicians (76%), social workers (69%), or other clinicians (66%) (Arrivé et al., 2018). This shows a distinct improvement in disclosure practices compared to earlier research conducted by Vreeman et al. (2013) in which only two of the 120 parents and caregivers had disclosed the HIV status to the child, and only 16 (33%) of 48 participants whose children were old enough to be disclosed to actually disclosed the child's HIV status.

In a cross-sectional mixed methods study conducted in Tanzania with 334 caregivers of HIV positive children, 32.6 % of caregivers disclosed the HIV status to HIV-infected children. Disclosure practices included the use of direct, third-party, and event-driven approaches as well as the use of drawings of a bad person and a policeman to accomplish the HIV disclosure event (Nzota et al., 2015). HIV-disclosure approaches to children tend to be documented to a lesser extent than HIV disclosure to adults (Nzota et al., 2015). In the current study, children were not directly interviewed regarding their responses to HIV disclosure because they are considered to be a vulnerable population.

2.8. Summary

The literature review reflects differing perspectives on disclosure, and that children have little control over who, how, and when they are informed of the HIV status. Studies have highlighted the challenges and reluctance of parents and caregivers to disclose, which indicates an imperative for family-centred care, and the integration of disclosure support measures into routine paediatric HIV care (Lesch et al., 2017; Kenu et al., 2014; Gyamfi et al., 2017; Lawan et al., 2016). In the South African context disclosure is hampered by factors that could potentially have a negative impact on the lives of children, their families, and their social support networks. Non-disclosure is often driven by the desire to protect children and families from discrimination, social exclusion, limiting social opportunities, and lack of support (Harper et al., 2014; Smith et al., 2008; Stuber et al., 2008).

The potential benefits of disclosure include improved understanding of health status, improved medication adherence, retention in care, improved self-esteem, and a reduction in anxiety, depression, and stress (Midtbø et al., 2012). Although HIV disclosure is pivotal in accessing care, emotional support, and improved retention in care, perceived risks could overshadow potential benefits, resulting in social isolation, poor access to care, and poor health outcomes (Vaz et al., 2011; Vreeman et al., 2013). Positive disclosure outcomes include better understanding of their health status, cooperation with medical regimens, improved adherence, improved utilisation of clinical support services, retention in care, fewer behavioural difficulties, establishing trust, and improved communication of fears and anxiety (Lawan et al., 2016).

This study could contribute to improved understanding and insight into the factors that facilitate or hinder disclosure could facilitate the delivery of interventions and support strategies that could assist caregivers in delivering developmentally and culturally appropriate communication strategies that will help children understand their health status, what to expect with regard to treatments and tests, and how to address concerns they face about their health.

CHAPTER THREE: METHODOLOGY

This chapter presents the research procedures, including data collection, analyses, and ethical considerations relevant to the study.

3.1. Methodology

The study explores disclosure experiences of mothers of HIV-infected children attending Red Cross War Memorial Children's Hospital (RHX) in Cape Town, South Africa. A mixed-method research design was undertaken. The choice was made in order to allow a deeper understanding of disclosure practices than could be achieved with a single data collection method (Cresswell, 2014). We conducted a cross-sectional, mainly qualitative, descriptive study involving explanatory open-ended interview questions. The qualitative portion was anchored on a quantitative component that was used to define characteristics of the study cohort. The quantitative component of the study was developed to allow the researcher to explore important cohort characteristics that informed aspects of the disclosure experience. This was important to explore the complex phenomenon of disclosure to an HIV-infected child that survey questions do not allow for. Additional follow-up questions allowed a fuller exploration of participant experiences. The qualitative semi-structured interview explored caregiver's perceptions and experiences with disclosure to HIV-infected children receiving care as well as explore HIV-infected caregiver perceptions about their children's understanding about their health status and experiences with disclosure. Quantitative data collected provided a response to general disclosure trends in children receiving.

3.2. Study site

Red Cross War Memorial Children's Hospital in Cape Town, South Africa provides comprehensive treatment that includes diagnostic services, counselling, management of opportunistic infections and community-based care to an estimated 303 children with a positive serostatus. The hospital is viewed as a centre of excellence in South Africa as well as on the African continent. It has academic links with the Department of Paediatrics and Child Health at the University of Cape Town (UCT). The hospital provides comprehensive paediatric services with the full range of sub-specialties at secondary, tertiary and quaternary levels of care (Western Cape Government [WCG], 2016). It services the Cape Metro Region as a regional centre and also as a tertiary medical centre for the Western Cape Province (WCP) (Van As *et al*., 2004). Highly trained health professionals deliver specialist care to children who are referred from hospitals, clinics and smaller hospitals from the nine provinces of SA. It is a primary referral hospital, receiving patients from clinics, community health centres and secondary hospitals. The hospital started treating children with ART in 2002 with full roll-out in 2004. Children initiated on ART are referred down to community health centres once they are stable and remain in care (Dr J. Nuttal, personal communication, 2013).

3.3. Study sample

A sample of participants was selected from parents and caregivers whose children are enrolled for treatment at the Infectious Diseases Clinic (IDC) at RXH. Currently there are 303 children in the ARV programme. The minimum sample required for the study is n=100. This sample size to estimate the disclosure rate of HIV status is based on a previous study (Mahkloko & Madiba, 2012) of 40%, using a precision of 10% around the 95% confidence interval.

Usually the sample size for qualitative data is determined by the depth of information emerging from interviews and the point at which theoretical saturation occurs, i.e. the point at which no new information is forthcoming from additional interviews. This remains a tricky aspect of qualitative research as no guidelines or tests for estimating the adequacy of the sample size exists (Morse as cited in Guest, Bunce & Johnson 2006). The sampling strategy aimed to ensure that the views and experiences are diverse and representative of the study population. Given the small sample size, it may not be possible to draw generalisable conclusions from this study. However, this study could yield important insights as a basis for a more comprehensive study. All participants who consented to participate in the research, regardless of the age of the child, answered qualitative questions**.**

3.4. Inclusion and exclusion criteria

Parents and caregivers were eligible for participation if they were the primary or secondary carer of children with a known HIV-positive serostatus (that is children who had an HIV + serostatus confirmed by appropriate diagnostic tests). Parents and caregivers whose children were recently diagnosed (that is who were visiting the clinic for the first or second time) were not be invited to participate in the study as they may still require a period of adjustment to the child's HIV status.

3.5. Data collection

Interviews are used in research to develop insight into the experiences, perspectives, processes, behaviour of social phenomena (Hays & Singh, 2012). If well designed, interviews can be useful in facilitating dialogue between the interviewer and participant that allows participants to share what is important and meaningful to them, in their own words (Hays & Singh, 2012). Interviews were conducted with parents and caregivers to determine whether they had disclosed to the child, at what age they disclosed, their perceptions of the child's and family members' response, and what their perceived consequences of disclosure are. Additionally, caregivers' fears prior to disclosure, their disclosure strategy and whether what they feared actually happened were explored. (See Annexure B: Caregiver Interview Schedule).

The aim of the interview was to construct an interaction between the researcher and the interviewee in a manner that would facilitate an open and rich exchange (Hays and Singh, 2012). In this research the researcher was interested in exploring the beliefs, experience and meaning participants ascribe to disclosing an HIV status to the child. Interviews are valued as a technique for generating normative accounts about disclosure, or non-disclosure. A structured interview protocol was administered to participants. Questions were developed so that it catered as comprehensively as possible to participant experiences of HIV disclosure (Hays & Singh, 2012).

3.6. Study duration

The time-frame for the study was reliant on clinic-attendance. The data-collection period will extended April to October 2014.

3.7. Language and communication

Paediatric patients and the parents attending RXH may be either English-, Afrikaans- or Xhosa-speaking. Recruitment materials, screening tools, consent forms and interviews were translated into Xhosa and Afrikaans (and back-translated to ensure their accuracy). Similarly, all interview sessions were conducted in Xhosa or Afrikaans where appropriate. Fieldworkers fluent in each of the local languages ensured that all communication was conducted in the mother-tongue of the patient and caregiver. Most participants chose to be interviewed in English. Where participants were interviewed in Xhosa, the interviewer transcribed and translated the information on the same day so that she would not lose any of the detail. Transcriptions and translations were checked by a 2nd Xhosa-speaking research assistant.

3.8. Researcher and fieldworkers

The potential disadvantage of interviews is that participants may want to give what they consider to be the right answers (Hays & Singh, 2012). The researcher and research assistants went through a process of training to learn how to establish rapport, how to respect participants, and to understand when participants felt uncomfortable and how to ask potentially intrusive questions. The researcher has 15 years' experience working as a counselor on a residential camp programme in California for HIV+ children and has been conducting day outings and a residential camp programme in Cape Town for children attending HIV clinics since July 2005. Three fieldworkers who had worked on the day outing and residential camp programme were trained for data collection. One of the fieldworkers is a Xhosa-speaking male who has been working as a counselor with children for seven years. A second fieldworker is a mother living with HIV who is employed as a coordinator of a project focused on promoting PMTCT uptake and compliance. The third fieldworker is Masters in Public Health graduate (with an undergraduate degree in Psychology) who spearheaded the psychosocial intervention for counselors working with mothers living with HIV in clinics throughout South Africa.

An experienced social worker (currently a PhD candidate) will be consulted throughout the study to reflect on participant experiences.

3.9. Pilot study

The data collection instrument was pilot-tested with nine participants at a different hospital. The purpose of pilot-testing is to prepare the researcher and assistants for their role, and to test whether participants understand the questions in the same way. Pilot testing allowed the researcher to determine the average time it would take to conduct the interviews, and to find out which questions made participants feel uncomfortable. The researcher made sure that the interview questionnaire was pilot-tested on people who represented participants who were likely to be recruited into the study from RXH, and that the interview was conducted in each language three times. Each participant was asked which questions they experienced as being difficult, and whether the questions were relevant to their experience. Participants were asked whether any questions were not culturally appropriate. After the pilot testing was done the researcher, assistants and supervisor reflected on the feedback and experience with pilot-testing the instrument. Alternative wording was developed for the Afrikaans and Xhosa versions.

3.10. Analysis

Quantitative analysis: Data was entered into an Excel spreadsheet and the analysis was conducted using STATA version 12. Descriptive statistics were examined in relation to the qualitative experiences of participants. Percentages have been used to depict proportions of individuals while means with standard deviation(SD) or medians with interquartile ranges (IQR) summarise all continuous variables.

Qualitative analysis: The section of the interview that yielded qualitative information was audiotaped and transcribed immediately to maintain research integrity (Hays & Singh, 2012; Mays, 1995). There were several stages in the data analysis, specifically the four stages proposed by Heath & Cowley (2003). meaning was generated from participants' perspectives through a process of induction, followed by empirical generalisations derived from the literature, and theorising about the meaning perceived by the researcher Hays and Singh, 2012). Analysis started with each interview as it was being conducted, and continued throughout the transcription of each interview (Hays & Singh, 2012). The data reduction process involved reading without judgement first, followed by a process of organising, segmenting, and analysing the text. In the first stage, the researcher and research assistants categorised words and text that were similar, a process known as coding (Hays & Singh, 2012). Coding is helpful and necessary as it guides theory formulation. Codes were merged into categories, and the coding process flowed into thematic analysis in which broad themes were identified and coded. Broad categories were refined and the data was reviewed to identify relationships in the data. This was followed by an expansion of emerging frameworks and making comparisons. During this stage diagrams, memos and graphic representation of relationships in the data were integrated into an analytical framework that proved beneficial for developing an understanding about what was being revealed in the data in relation to what is already known (Charmaz, 2006). In this regard, a data analysis log was maintained so that new ideas were tested and relationships re-examined through a process of checking and rechecking. In the final stage, the researcher theorised about the insights gained from the data by integrating the memos and data from the log analysis so that it made (Dasterdi, Olson, & Ogilvie, 2012). Emerging themes were examined in relation to published literature. Through this process the researcher was able to present the collective analysis of participants' experience with HIV disclosure.

3.11. Trustworthiness and reflexivity

Conversations with parents /caregivers about HIV disclosure can be rather daunting; hence participants may be inclined to be reticent in their responses. It is very important that the researcher establish a relationship of trust with each and every participant. Additionally, it was crucial that participants be ensured that their right to privacy will be protected at all times. One strategy for alleviating anxiety related to being exposed would be to have participants select a pseudonym known only to the researcher and participant. Participants will be informed that their name will not be linked to the interview and that their names will not be mentioned in any reports or publications emerging from this study (Coombs & Smith, 2003). Furthermore, since researchers cannot always claim to be bias-free, the researcher reflected on and acknowledged and attempted to analyse his own preconceptions, biases and beliefs in the context of the research. Reflexivity in research is essential as the researcher creates new knowledge through respectful engagement with study participants (Ulin, Robinson, & Tolley, 2005). Research findings are constructed through the meaning and interpretation of the researcher and study participants, which is informed by the effects of age, race, class, gender, and the broader social context (Hays and Singh, 2012; Ulin et al., 2005). Even though the researcher has raised and disclosed to a child who was HIV-infected, it cannot be assumed that this facilitated sharing less socially acceptable views. Although the similarity might have been an advantage for establishing rapport, it does not necessarily suggest shared interpretations and meanings. The researcher was cognisant that this could potentially influence his perceptions; hence a debriefing session was held with the assistant researchers after each day of interviewing (Hays & Singh, 2012). He was also aware of the social and power dynamics of being a male interviewing predominantly female participants (Hays & Singh, 2012). The benefits of keeping a diary and field notes throughout the research process is twofold: it allowed the researcher to have a clear audit trail, and it allowed the researcher to reflect on his own subjectivity and influence over study participants (Hays & Singh, 2012; Ulin et al., 2005). Davies and Dodd (2002) are emphatic about the significance of informal, anecdotal and experiential contributions to legitimate knowledge. Likewise, this study places value on the reflective self-examination of the researchers’ own ideas as an integral part of the research process (Green & Thorogood 2009).

Credibility

Credibility relates to the extent to which the research explored what it set to examine (Hays and Singh, 2012). It entailed conducting research in a believable manner, with integrity. The researcher set out to present the findings as close to the lived realities of participants as possible. Strategies for developing credibility include prolonged engagement with study participants and an understanding of the social context (Hays & Singh, 2012; Ulin et al., 2005). Peer debriefing was used in this study to improve reflexivity, and to tests the researcher's interpretation of participant experiences.

Transferability

The researcher provided a detailed description of the research process to allow clinicians and researchers in other contexts to make decisions about the extent to which the findings are relevant in other contexts (Hays & Singh, 2012).

Dependability

Dependability is an evaluation of the quality of research procedures (Ulin et al., 2005). Dependability in this study relates to the extent to which the research team agreed with the study findings. audit trail entails maintaining comprehensive notes related to the background of the data and the rationale for all methodological decisions made during the processes.

Confirmability

Confirmability is similar to dependability and relates to the extent to which the findings of this study are genuine reflections of the experiences of research participants. The data analysis process was an iterative, consultative process. Interpretive discrepancies were resolved through consensus (Ulin et al., 2005). No decisions had to be deferred to another, experienced qualitative researcher for resolution.

Authenticity

The researcher took great care in representing participant perspectives authentically.

Coherence

Interview transcripts were reviewed by two independent and experienced qualitative researchers. A third researcher will be consulted to resolve interpretive discrepancies.

A member check will be done with a randomly selected group of participants at the end of the study to assess whether researcher interpretation is accurate or whether correction and/or elaboration is needed.This study reflects consistency and care in the application of research practices which are cognisant of the partiality and limits of our research findings.

To maintain ***rigour*** in this research, the researcher provides a clear account of procedures used in the study so that there is an audit trail for other reviewers to follow. Interpretations will be supported by evidence from the interview transcripts. The researcher will pay particular attention to information emerging from all research methods employed and will compare the findings to other studies (Green & Thorogood 2009)

Hawthorne effect

The Hawthorne effect refers to the behaviors of participants in response to being researched. All research methods have at least some effect on the responses of participants and qualitative researchers prepare for this factor by explaining the relevance of the research and the way in which it will be used, by reassuring participants of confidentiality and that their responses will be used anonymously (Stevenson et al., 2000). The most important techniques involve establishing an ethical trust relationship and helping participants to feel relaxed. Understanding the multi-faceted, complex and paradoxical features of intense personal processes and choices is best understood from the perspective of the participant, requiring the full understanding and commitment of both the researcher and the participant (Coombs & Smith, 2003). This research is governed by respect for the personal perspectives, opinions and experiences of both the participant and the researcher, engaged in a partnership to better understand the forces that shape caregivers' HIV disclosure or non-disclosure choices.

3.12. Ethical considerations

This research was conducted in accordance with the principles of good clinical practice, and participant protects described in the Belmont Report (1979), The Helsinki Declaration (2013), and the international ethical guidelines for health-related research involving humans (Council for International Organizations of

Medical Sciences [CIOMS], 2016). Ethical clearance was obtained from the Research Ethics Committee of the Health Science Faculty at the University of Cape Town. Participants were fully informed of the study and their rights as study participants were respected. To respect participant autonomy, the researcher explained the purpose of the research and provided each participant with a detailed information sheet. Every effort will be made to obtain informed consent hence the consent form will be issued to each participant to sign only after the research purpose and procedures have been explained simply and clearly (Belmont Report, 1979; The Nuremberg Code, 1949). The informed consent procedure involved making an assessment about the eligibility of the participant for this study. If the participant meets the inclusion criteria for this study, she/he will be approached for recruitment as a study participant. Informed consent was obtained by explaining the purpose of the research, as well as the research procedures in the participant's mother-tongue. All conversations with participants were conducted in a private room to ensure privacy. Every effort was made to maintain the strictest confidentiality and the trained interviewer who assisted with data collection was informed about the obligation of confidentiality. Additionally, the researcher and research assistant assessed the understanding of the content and process of the consent form with each participant before the consent form was signed. Participants were informed that their participation was voluntary, and that they could withdraw from the study at any time if they chose, without consequence. Participant anonymity was assured by allocating a number to each participant. The name and number is known only to the researcher and the research supervisors.

All information, including written notes, transcriptions and data analysis records were stored on a password-protected computer to which only the researcher has access. All notes, interviews and tape recordings were stored in a locked cabinet in the researcher's office. Only the investigator of this study and the research assistant had access to this information. Electronically stored data was password protected on a computer to which only the investigator has access. Data will be deleted after 5 years. Data analysis or published data will not contain personal identifiers.

If the case of participants who were unable to read and write, the researcher explained the purpose of the study and that she/he meets the inclusion requirements. If she/he expressed an interest to participate in the study, the content of the IC will be explained. Subsequent to agreeing to participate, an impartial witness (someone of the participant's approval) will ask her/him whether she understands the study and IC. If she/he agrees, the researcher and witness will sign the IC and the subject will provide a right thumb print on the appropriate area on the document. If the participant is reluctant to have a thumb print, she/he can mark with an 'X' and this will be recorded on the consent form.

3.13. Risks and benefits to participants

Discussing issues of disclosure and non-disclosure could potentially increase emotional distress for caregivers and children alike. The researcher collaborated with social workers and a clinical psychologist to mediate the effects of any adverse experiences. By sharing opinions and experiences about HIV disclosure in children, participants were provided the opportunity of gaining increased self-knowledge and self-confidence about talking to children about their health.

3.14. Clinical significance

Insight into the factors that facilitate or hinder disclosure could facilitate the delivery of interventions and support strategies that could assist caregivers in delivering developmentally and culturally appropriate communication strategies that will help children understand their health status, what to expect with regard to treatments and tests, and how to address concerns they face about their health.

CHAPTER FOUR: RESULTS

This chapter presents the results of the study. Quantitative analysis is followed by explanatory qualitative analysis.

4.1. Demographic characteristics

A summary of the main demographic characteristics of study participants is presented in Table 1. The study sample included 102 participants, ranging in age from 16 years to 71 years. The sample included 73 mothers (72%), six fathers (6%), 11 foster-mothers (11%), and 12 caregivers or grandmothers (12%). Participants included 65 (58%) who were unemployed and 26 (23%) participants who were formally employed. Of the 102 participants, 65 (64%) received a social grant, 3 (33%) received no grant, and three were unclear. Regarding living situation, 35 (34%) participants lived in shacks, 37 (36%) owned a house or flat, 9 (9%) rented a house or flat, and 15 (15%) shared a house or flat with others (6 were unclear).

Table 1: Participant demographics

Variable	Frequency	Percent
Relationship to child		
Mother	73	71.6
Father	6	5.9
Foster-mother	11	10.8
Caregiver/Grandmother	12	11.8
Education		
Primary level	23	22.8
Secondary level	57	56.4
Tertiary level	4	3.9
Employment status		
Formal employment	23	22.8
Unemployed	57	56.4
Casual employment	11	10.9
Self-employed	7	6.9
Full-time housewife	1	0.9
Student	1	0.9
Other	1	0.9
Grant support		
Receive grants	65	64.4
Do not receive grant support	33	32.7
Unclear N/A	3	3.0
Living situation		
Shack on private property	9	8.8

Shack Informal settlement	26	25.5
House/Flat owner	37	36.3
House/flat renting	9	8.8
House/flat sharing	15	14.7
Unclear	6	5.9

The median age of the participants’ children was 4 (IQR 2-8) years and ranged from five months to 16 years. Only 48 (47%) were old enough for disclosure to be possible (Figure 1: Age distribution of children below).

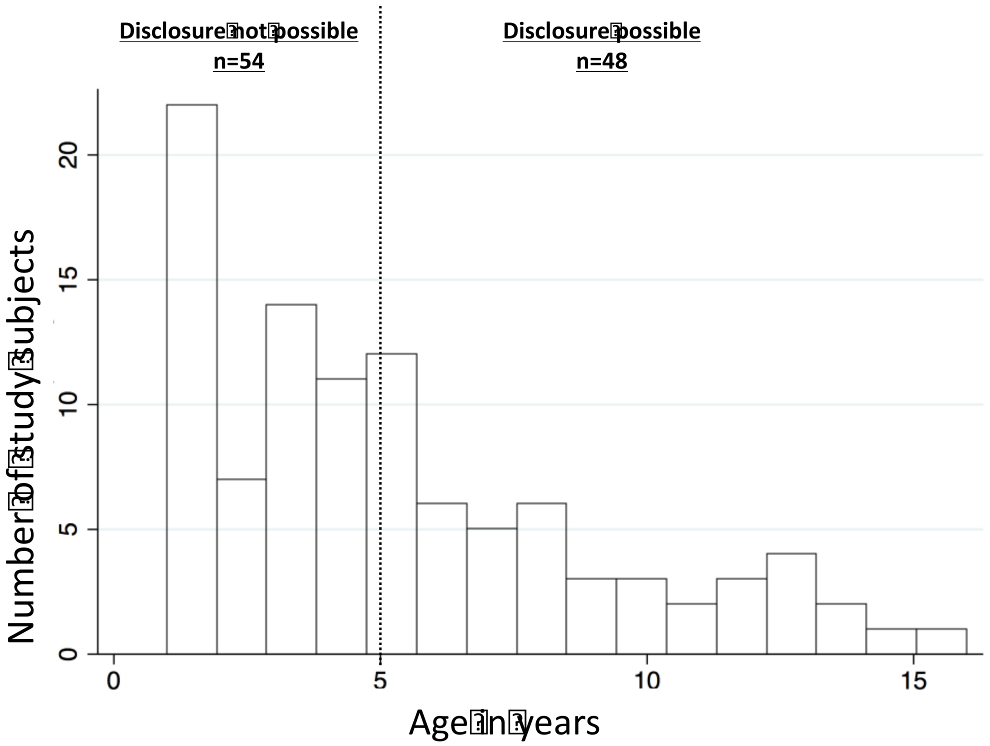

Figure 1. Age distribution of children

4.2. HIV Test

In total, 94 participants (94%) had an HIV test done, four were not tested (4%), and two (2%) stated they did not need a test.

4.3. Disclosure to the child

Disclosure to the child is presented in Table 2 below. Of the 102 participants 86 had not disclosed to the child (48 children were not old enough to be disclosed to) and 16 children had been disclosed to.
The clinic in which the children were being followed up has adopted a tool for step by step disclosure to the child (Eley, Nuttal, & Apolles, 2011).

Table 2: Disclosure to the child

Disclosed to child	**Frequency**	**%**
Yes	16	84.31
No	86	15.69
Total	102	100.00

Table 3 illustrates disclosure in relation to the child's age. In the study sample one child aged 5 to 7 years was disclosed to, seven children 8 to 11 years were told their HIV status, and eight children older than 11 years had their status disclosed. In terms of relationship to the child, nine mothers, two fathers, two foster-mothers, and three caregivers or grandmothers disclosed to the child. Table 4 presents disclosure in relation to the relationship with the child.

Table 3: Disclosure in relation to the child's age group

Child's age	**Disclosed to child n(%)**		**Total**
	No	**Yes**	
5 – 7 years	22(96)	1(4)	23
8-11 years	7(50)	7(50)	14
>11 years	3(27)	8(73)	11
Total	32(67)	16(33)	48

Table 4: Disclosure in terms of relationship to the child

Relationship to child	**Disclosed to child**		**Total**
	No	**Yes**	
Mother	20(69)	9(31)	29
Father	3(60.00)	2(40)	5
Foster mother	5(71.4)	2(29)	7
Caregiver/Grandmother	4(57.1)	3(42.9)	7
Total	32(66.7)	16(33.3)	48

Participants were asked about their perspectives about the child's readiness for disclosure; qualitative responses are presented below.

<u>Caregiver perceptions of the child's readiness for disclosure</u>

Several participants stated that the child readiness for disclosure would depend on their ability to understand, although perspectives differed regarding the age and timing of disclosure-readiness. In general, ages 10 to 12 years were perceived as a good time to disclose as their level of awareness of HIV would be developed and they were likely to understand their illness. One 32 year old mother, whose boyfriend was HIV-negative, explained that her four year old son was too young to understand what HIV is, and that the boy had not questioned why he was taking medication stated:

> "I will tell him when he is 11 years old, when he can completely understand. I give him his tablets and he does not ask me questions because he trusts me".

Age was the most commonly stated reason for non-disclosure, the main worry being that the child might be too young to understand what it meant to be HIV-infected. A 48 year old foster mother felt that five years of age was too young to disclose to a child, and stated:

> "If I tell him that early he might think he is going to die, because he will not understand properly".

A 28-year-old mother of two infants, of whom only one is HIV-infected, disclosed to the child at 6 years of age, saying:

> "I also asked her. When you drink this pill do you know it's for what? She says it's for the heart. Then I sit her and explain that she has HIV. She will respond by saying hay wena. Even when her friend asked her what are the pills for. She tells them it's for the heart"

A 54 year old mother of four children disclosed to her only HIV-infected child at 11 years of age with the help of health staff:

> 'I asked a doctor who arranged with a social worker to speak to her. When she asked me at five years of age I used to say to her that she has to take them for her asthma".

4.4. Disclosure intention

In this study 48 participants had disclosure intentions compared to 54 who did not, and only 16 participants actually disclosed to the children who were at an age in which disclosure should have been done versus those in which it was actually done (presented in Table 5 below).

Table 5: Disclosure intention vs disclosure to children who were at an age in which disclosure should have been done

Intention to disclose	**Disclosed to child**		**Total**
	No	**Yes**	
No	54 (100)	0	54
Yes	32(66.7)	16(33.3)	48
Total	86(84.3)	16(15.7)	102

Participant reasons for disclosure or disclosure delay are presented below. Of the 16 who disclosed, on average disclosure took place when the child was 8.9 (SD 2.3) years. If five years was regarded as the earliest age of possible disclosure, this indicated an average delay of 3.9 (SD 2.3) years.

Reasons for disclosure or disclosure delay

Several caregivers expressed concern about how to disclose to their children, and expressed anxiety related to children asking HIV-acquisition questions and being blamed for infecting the child.

> "He don want to take he tired why only him he taking the other children not taking so why he take this medicine I say I'm also taking you must taking because you are HIV. He say angry who gave me HIV?"

Guilt and shame emerged as a significant concern and cause for disclosure delay, as expressed by 37 year old mother of two children whose second child was HIV-infected:

> "I feel very bad and ashamed that I have given my child this disease that makes people to talk and laugh at us behind our backs. I want my child to be proud of me, to be proud of herself. This child will have to live with my shame for the rest of her life if I tell I gave you HIV. She will think I am a bad person who has many boyfriends and should not be her mum".

Participants who were reluctant to disclose to their children feared exposing their child to discrimination and stigma. A 37-year-old single mother of three children stated:

> "Because he was losing weight nê, and another child he talked to him and said I don't want to play with you. Because you're not right. He came like this he came to cry. My mother, another child say I don't want to play with me".

A biological mother of three children stated:

> "Yes I'm afraid she will not understand and tell other people about her status.

Several participants delayed disclosure which they perceived as protecting the child. This was expressed by a 31-year-old father who stated:

> "I feel ok not to tell her because I'm only protecting her against the people who will discriminate against her".

The fear of stigmatisation extended beyond the instinct to protect the child to fears related to exposing the family to stigmatisation through the child's accidental disclosure. A 48-year-old mother of three children, of whom only the last child is HIV-infected, delayed disclosing until the child was 13 years of age because she was afraid that he would be angry and disclose to his friend who might reject him. She stated:

> “Because I thought he was going to be angry with me. He is the only child that has the virus. I was afraid he was going to tell his friends. Because they will not want to be his friends anymore”.

Some participants expressed anxiety about the possibility that the child might learn about their health status from others.

> **“**I had to tell her at 5 years, because we were at the hospital one day sitting in the foyer at the ear nose and throat clinic, when a mother gave her child his medication. She observed that the child was taking the same medication as her. She then told the lady that she takes the same medication. The lady then asked her whether she has AIDS too”.

Anxiety about disclosure by others before the parent had told the child was mentioned, as expressed by a mother who noticed that the child started showing signs associated with HIV infection:

> “Because there was another child he was sick. And she said to my child, no man you must eat your tablets. Look see the photo here. Look at where I was before but now I’m big”.

In some instances, disclosure was triggered by the child asking questions about their health status, hospital attendance, and medication. A mother who disclosed the HIV status to the child at 10 years of age reported:

> “… initially he wanted to know why he was taking the medication, so I explained to him that he’s taking the medication because of the virus and there’s no cure and because he must use it to take the medication for the rest of his life and then I tried to reassure him”.

A few participants were of the opinion that HIV awareness was increasing, at school and through the media, and children had the right to know their HIV status so that they could be empowered to disclose and develop supportive social networks in school and community environments. A 47-year-old foster parent explained:

> "Because of his understanding about the disease he is now helping the other foster children who come to our home to make sure they take their pills. His sisters, brother and friends also remind him to take his pills".

A 43-year-old father disclosed to the child at 12 years of age, stating:

> "I told him immediately when we found out. It is better to tell your child immediately or at an early age because they will question on why they have to take the medication".

Participants expressed an awareness of shame and self-blame that children could experience when they discover that they are HIV-infected. A 43-year-old mother who disclosed to the child immediately he was diagnosed at 12 years of age who expressed feeling shame about his illness:

> "That it is not the end of the world it is not a death sentence. You did not stand on a mountain to call HIV to you. There is hope because of medication and medical science".

4.5. Prevention-of-mother-to-child transmission of HIV adherence and disclosure to the child

Of the 69 mothers who were enrolled into the PMTCT programme while pregnant, 48 were adherent and 21 were not. A total of 43 PMTCT adherent mothers did not disclose, while 5 disclosed to the child. In total, 21 mothers were PMTCT non-adherent, 16 did not disclose and 5 disclosed to the child. This data must be understood in relation to the number of children who were < 5years of age, hence developmentally may not have been ready for HIV disclosure. Table 6 illustrates the relationship between PMTCT adherence in relation to disclosure to the child.

Table 6: PMTCT adherence in relation to disclosure to the child

Disclosure to child	PMTCT adherence		Total
	No	Yes	
No	16 (27.1)	43 (72.9)	59
Yes	5 (50)	5 (50)	10
Total	21 (30.4)	48 (69.6)	7

4.6. Stigma and disclosure to the child

Mothers' experience of stigma in relation to disclosure to the child is presented in Table 7.

Table 7: Experience of stigma in relation to disclosure to the child

Disclosure to child	Stigma		Total
	No	Yes	
No	59 (86.8)	9 (13.2)	68
Yes	8 (80)	2 (20)	10
Total	67 (86)	11(14.1)	78

4.7. Disclosure strategies

Perspectives about the best way to disclose varied among participants. Several participants shared the perspective that it is the child's right to know about their illness, and that disclosure should be done as soon as the diagnosis is known. A 54-year-old single mother who disclosed to her son at five years of age, believed that she had to be honest with her son from the beginning stated:

> "you see you drink these tablets, your mother has HIV and you have HIV and this tablets is for your life. You must know about HIV. I'm going to tell him if he was 6 or 7 years and my son he will not like if I did not tell him that he has HIV. I always am honest with him yes.
> He will be angry if he is older and if I lie to him".

Another perspective was that disclosure should be a gradual process involving several conversations, preferably initiated by questions from the child. One mother of three children, who initially tested negative for HIV, whose infant was often ill and was diagnosed with HIV after he was hospitalised at three years of age as a result of Tuberculosis (TB), disclosed to her son gradually, and introduced the term HIV when he was 10 years old:

> "I told him bit by bit. Sometimes …. he said to me why my mother take this tablet? I look to him, I told him if you don't take this tablet you gonna die. Because of what? You see you and me too, I am eating my tablet. Because you and I have HIV. If you don't eat your tablets you gonna die".

Some participants confessed to telling children that they have other health problems before having the courage to tell the child the truth, as expressed by a single mother:

> "My son you have asked me many times why you have to take these pills.
> I did not tell you the truth at that time because I thought you were too young and will not understand. Today I will tell you the truth. You are living with HIV that is why you have to take the pills, but you must not be afraid because you know about HIV from the school. If you take the pills and attend the clinic you can live a normal life".

Complete disclosure, in which the child is told about their illness, the term HIV is used, and the role of ARVs in a life-long chronic illness is discussed was mentioned by a 37-year-old single mother disclosed to her daughter at eight years of age:

> "I told her that she has a blood problem and it is called HIV.I told her because she watches programmes on TV and she always says that she does not want to have that sickness. Before she was eight she thought that she was taking the medication for TB and that by taking the medication it will prevent her from getting the virus. Because she was too young to understand".

4.8. Disclosure support

Relationships with and support derived from health providers contributed to a sense of safety and confidence in initiating conversations with children about their HIV status.

A mother who had disclosed to her child recognised the important role of support groups in assisting with disclosure to the child:

> "So if we have a group here with the social worker and the Mums sit together and talk and they help you in the group but also one-on-one when you see the sister would that help you, if the sister helped you to tell the child? Would that work for you?"

A mother who disclosed to her son immediately when he was diagnosed after admission to hospital at 12 years of age stated:

> “When we had counselling we told him, that he is HIV positive, and told him that if he takes he’s medication he will live long and that other people will give him wrong information.

A 47-year-old foster mother of five children, two of whom are HIV-infected, and who disclosed to the boy at nine years, stated:

> “I told him that he has aids and need to be on medication for the rest of his life”.
>
> No he has no fears because he had knowledge about HIV because of the exposure and support he has in the community support group”.

4.9. Disclosure advice to other parents and caregivers of HIV-infected children

Participants were asked what disclosure advice they would provide to other parents or caregivers of HIV-infected children. Understanding the disease, accepting that it is a lifelong chronic condition that requires medication, accessing support, staying in care and helping children to understand and accept their health status were important messages participants shared.

A 39-year-old mother of two, of which only one is HIV-infected, offered the following advice:

> “I will tell them not to be afraid because the medication that helps. There are also group discussions that is like a support structure”.

A 34-year-old caregiver offered the following advice to other mothers:

> “I will tell them they have to support their children, its ok they must just make sure that they take their pills every time and go for regular check up to the clinic. They must also not tell everyone , they must tell people they can trust because they can support you”.

A 34-year-old mother of two children stated:

> “HIV does not kill someone, they kill themselves. Also give your children their medication. Do not skip. Even children without HIV are getting sick. There is no difference for me, for me it’s normal”.

CHAPTER FIVE: DISCUSSION

Increased access to paediatric ART has substantively improved child and adolescent health outcomes, necessitating disclosure practices in paediatric HIV management and care (Evangeli & Kagee, 2016; Jemmott et al., 2015; Tadesse et al., 2015). This study was conducted with 102 parents and caregivers at a tertiary hospital in Cape Town delivering care to 303 HIV-infected paediatric patients. Disclosure or disclosure delay was associated with several factors, including the child's age or ability to understand, anxiety and guilt about being blamed for infecting the child, fear of exposing the child to stigma, discrimination and social exclusion related to the child disclosing to others, and the hope that the child would be adherent if they understood their illness and the way in which the medication could improve their health outcomes. Similar to the findings of research conducted by Vreeman et al. (2013) in which only two of the 120 parents and caregivers had disclosed the HIV status to the child, only 16 (33%) of 48 participants whose children were old enough to be disclosed to actually disclosed the child's HIV status. The results indicate that HIV-disclosure remains a challenging, emotionally-charged experience for mothers and caregivers. Evangeli and Kagee (2016) proposed that contextual factors affect disclosure practices. Socio-economic factors, like employment status and living environment could influence perceived control that parents and caregivers perceive they have over the disclosure process. In this study 64 participants were unemployed, 72 received a social grant, and lived in shacks, suggesting that they had limited material resources. In previous studies caregivers with higher educational levels were found to be more likely to disclose to children (Paintstil et al., 2015; Vreeman et al., 2013). The educational level among participants in this suggests that most participants did not attend school when HIV was introduced into the life-skills curriculum at secondary level, which could have undermined their lack of confidence in sharing information with the child.

The low disclosure rate to children five years of age and older in this study is of concern as HIV disclosure has benefits. In a cross-sectional study of disclosure prevalence and determinants conducted in Ghana, children who knew their HIV status demonstrated improvements in their understanding of HIV and the reason for taking medication, self-efficacy and involvement in taking ART (Kallem et al., 2011). In sub-Saharan Africa non-disclosure remains the principal factor undermining ART adherence in children Paintsil et al., 2015). Although no conclusive evidence supporting the association between HIV disclosure and ART adherence was found in a qualitative study conducted by Vreeman et al. (2013) in Kenya, a study of disclosure conducted among adolescents in Thailand was associated with a CD4 count below 30% (Sirikum et al., 2013). A cross-sectional study conducted with HIV-infected children and adolescents in western Kenya by Vreeman et al. (2014) found no association between disclosure and clinical indicators. Despite these discrepancies, disclosure benefits like improvements in children's physical and psychological well-being, ART adherence, and social functioning support paediatric HIV disclosure (Kallem et al., 2011; Paintstil et al., 2015, WHO, 2011).

The disclosure rate in a systematic review conducted by Vreeman et al. (2013), disclosure ranged between 0% and 69.2%. In the study conducted in Ethiopia, only one third of the 137 caregivers disclosed the child's HIV status (Tadesse et al., 2015). Mweemba et al. (2015) in their study of caregiver disclosure practices to adolescents found the disclosure rate to be 56.7%. Of the 102 participants in the current study, 48 participants had disclosure intentions, and 54 did not, with only 16 actual disclosures to children. It is however important to point out that children ranged in age between five months to 16 years. Only 48 (47%) were old enough for disclosure to be possible which would make the disclosure rate 33%. A total of 57 (54.81%) participants in the current study disclosed their HIV status to their romantic partner, and 47 (45.19%) disclosed the child's HIV status to their partner. A study conducted by Jemmott et al. (2014) that examined predictors of intention to disclose showed that the expectation of approval from significant others was the key driver of the intention to disclose. Parent or caregiver-child communication was also found to be closely related to the intention to disclose (Jemmott et al., 2014). This study did not explore communication as a determinant of disclosure practice.

Disclosure to older children was more likely than younger children in this study. Ages 10 to 12 years and older was the preferred disclosure age, similar to the findings of the disclosure review conducted by Pinzón-Iregui et al. (2013) in which nine studies reported older age as a disclosure predictor. Some parents and caregivers (54) were caring for children who were under 4 years of age, and possibly developmentally not ready to understand what being HIV-infected meant, 23 children were 5 to 7 years of age, 14 were 8-11 years, and 11 were older than 11 years. The concept of "being old enough to understand" was not satisfactorily explained despite attempts at trying to elicit participant understanding of what it meant. The decision to disclose when the child was old enough to understand was a common belief expressed by participants in this study. In their review of HIV disclosure in relation to theories of cognitive development, Lesch et al. (2007) drew on Piaget's cognitive developmental theory which proposes that children have the conceptual ability to understand HIV. Evangeli and Kagee (2016) examined post-intentional disclosure process, affect, as well as social and professional disclosure support and proposed a new model of paediatric disclosure decision-making. They incorporated the child's age, disclosure attitudes, affective and cognitive elements, and normative beliefs about when disclosure should be done. Apart from changing cognitive development, parent and caregiver concerns about adolescent risk behaviour were taken into account. Previous disclosure experience and openness regarding their status influence disclosure to children and adolescents, particularly for those parents who felt shame or guilt (Evangeli and Kagee, 2016).

In this study concerns about disclosure to the child as a catalyst to the child's potential disclosure to others, with subsequent negative social reactions like being the target of gossip, discrimination, and alienation was a strong deterrent to disclosure to the child. Being discriminated against was reported to be a barrier to disclosure in studies conducted in other contexts (Mutumba et al., 2015; Kallem et al., 2011; Pinzón-Iregui et al., 2013; Vreeman et al., 2013). Participants in this study felt a strong need to protect their children and families against painful and unjust treatment, similar to the findings of the HIV disclosure study conducted with 298 caregivers conducted at two teaching hospitals in Ghana (Paintsil et al., 2015).

Participants considered children asking questions about their illness, or refusing to take medication to indicate the need for disclosure. The process of deciding when a child was ready for disclosure appeared to be contingent on individual perceptions about whether the child was ready, or whether the child not knowing their HIV status could potentially undermine medication adherence. Thus caregiver readiness to disclose appears to have an association with perceptions about the child's disclosure readiness, which correlates with the findings of the research conducted by Madiba and Mokwena (2012) and Mahloko and Madiba (2012) in South Africa. Even though parents might have strong disclosure intentions and a positive attitude, they may also experience contradictory anti-disclosure attitude based on the fear of being blamed, negative reactions of children, or fear about the child disclosing to others (Evangeli & Kagee, 2016).

The low disclosure rate in this study could be related to concerns about negative reactions from the child that could potentially impact parent/caregiver-child relationships. Negative anticipated reactions relate to parent affect associated with lack of confidence about communicating the information in the right way, concerns that the child might not understand the information, and the child being either angry or depressed (Evangeli & Kagee, 2016; Paintsil et al., 2015).

Disclosure support was mentioned by participants in this study, suggesting that there is a need for focused disclosure planning in paediatric HIV care. The findings of a group-based behavioural intervention for HIV –infected adolescents and youth in Chicago, New York, Miami and Memphis demonstrated stigma reduction related to disclosure concerns (Harper et al., 2014). The intervention included HIV-related information, and facilitated the development of coping skills for addressing stigma, and building healthy relationships. The researchers reported gendered stigma reduction experiences after the intervention, suggesting that females might need more assistance with regard to developing and maintaining healthy relationships (Harper et al., 2014).

LIMITATIONS

The relatively small sample size (n=102) limited statistical power to detect relations between key variables. As with all qualitative research, participant self-report and the fact that the researcher was perceived to be a health professional means that the responses could have been influenced by social desirability response bias. An attempt was made to mitigate this bias by explaining, during the consenting process, that all information would remain confidential, that participant identity would be protected, and that the insights from the research could be very helpful for other parents and caregivers of children living with HIV. At the time the study was conducted disclosure support had not been integrated into routine paediatric HIV care, and the children were not yet being prepared for transfer to the adolescent HIV care facility. It would be beneficial to conduct further research with HIV infected adolescents to explore their perceptions of disclosure practices of this cohort of parents and caregivers. A further limitation relates to the age of children which presented a barrier to disclosure. Perceptions that children were too young to understand the meaning and implications of being HIV-infected could have been a likely barrier to intention to disclose. Further studies with older adolescents could provide more insight into disclosure trends, specifically factors that hinder intention to disclose. Although participants were asked about the child's response to being told about their HIV diagnosis, substantive information could not have gathered to answer this important question.

Despite these limitations this study yielded insights into parent and caregiver experiences and conceptualisation of disclosure, and the factors that influence their disclosure intentions and practices. The findings of this study correlate with research conducted in other contexts and revealed that parents and caregivers need a great deal of guidance and support in disclosing an HIV status to children and adolescents. Health providers can contribute to improved disclosure management by helping parents and caregivers to think strategically about how and when to disclose to children. A paediatric HIV disclosure intervention was developed and is being implemented at RXH, and further research on the subject of disclosure could be beneficial to health teams caring for HIV infected children and adolescents.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1. CONCLUSION

This study found that parents and caregivers have to mediate complex, often interrelated challenges and concerns about disclosing the HIV status of children. Disclosure intentions are significantly associated with concerns about the right age at which to disclose, whether the child would understand, and fears related to guilt and blame. The study findings correlate with disclosure research conducted elsewhere in South Africa, other low and middle-income countries Africa, and global reviews of disclosure research. It is important that disclosure be understood at the individual level, with due regard for contextual factors that could affect disclosure determinants. Caregiver experiences, attitudes, and anticipated outcomes are important considerations, and are likely to change over time. Anxiety emerged as a significant part of the disclosure experience and is a key barrier in the transition from disclosure intention to actual disclosure. This research highlighted the need for disclosure support and recognises that health providers are well-positioned to respond to child and caregiver disclosure needs in the clinical environment. Although human resource challenges in the public health system are recognised, it is nonetheless important that health professionals expand paediatric HIV care in resource-constrained contexts in Africa to address HIV disclosure.

6.2. RECOMMENDATIONS

This research was conducted before the implementation of a tool for step by step disclosure to the child (Eley et al., 2011). Further studies for evaluating disclosure experiences could yield valuable information about the outcomes associated with the tool, as well as provide guidance for improving processes linked to disclosure practices. New disclosure models are emerging that take child development and caregiver experiences, disclosure attitudes, beliefs, and disclosure barriers into account. The findings of this research, and similar studies, point to the value of integrating disclosure support and planning into routine care for children and adolescents, as well as their parents and caregivers.

The results of the retrospective, longitudinal record review of adolescents living with HIV (ALHIV) in Kericho, Kenya emphasised the strategic role of counsellors, nurses, physicians, and social workers in facilitating disclosure (Montalto et al., 2017). This recommendation is supported by Arrivé et al. (2018) who found that disclosure resources and procedures like having a disclosure protocol, disclosure counselling, and disclosure training for staff contribute to improved disclosure practices (Arrivé et al., 2018). Integrated, family-centred models of care need consideration at policy and programme planning levels. Best practice suggests that disclosure should be incorporated into routine HIV management and care, starting with the development and implementation of an appropriate disclosure guideline for staff, followed by appropriate training for all staff involved in delivering care to children and adolescents who are HIV-infected.

Caregivers and parents could benefit from guidance and training that could assist them in developing confidence in their own HIV-related knowledge, so that they are able to share relevant, appropriate information with children. In this regard it is important that clinical staff routinely assess what the child or adolescent knows about the health status, and the nature of the relationship between the caregiver and the child or adolescent. Age-appropriate disclosure requires specific guidance about understanding children and adolescents’ cognitive, emotional, and social development.

Contextual factors, like adverse social circumstances merit attention, suggesting closer collaboration with, and referral, of families for social service interventions.

REFERENCES

Abebe, W. & Teferra, S. (2012). Disclosure of diagnosis by parents and caregivers to children infected with HIV: Prevalence associated factors and perceived barriers in Addis Ababa, Ethiopia. *AIDS Care*, *24*(9), 1097-1102. doi: https://doi-org.ezproxy.uct.ac.za/10.1080/09540121.2012.656565

Arrivé, E., Dicko, F., Amghar, H., Aka, A. E., Dior, H., Bouah, B., ... & Kouakou, K. (2012). HIV status disclosure and retention in care in HIV-infected adolescents on antiretroviral therapy (ART) in West Africa. *PloS One*, *7*(3), e33690. doi: 10.1371/journal.pone.0033690

Arrivé, E., Ayaya, S., Davies, M. A., Chimbetete, C., Edmonds, A., Lelo, P., ... & Leroy, V. (2018). models of support for disclosure of HIV status to HIV-infected children and adolescents in resource-limited settings. *Journal of the International AIDS Society*, *21*(7), e25157. doi: 10.1002/jia2.25157.

Bekele, T., Rourke, S. B., Tucker, R., Greene, S., Sobota, M., Koornstra, J., ... & Hwang, S. W. (2013). Direct and indirect effects of perceived social support on health-related quality of life in persons living with HIV/AIDS. *AIDS Care*, *25*(3), 337-346. doi: https://doi-org.ezproxy.uct.ac.za/10.1080/09540121.2012.701716

Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research (1979). The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. Retrieved from http://ohsr.od.nih.gov/guidelines/belmont.html

Committee on Pediatric AIDS. (1999). Disclosure of illness status to children and adolescents with HIV infection. *Pediatrics*, *103*(1), 164-166.

Barron, P., Pillay, Y., Doherty, T., Sherman, G., Jackson, D., Bhardwaj, S., ... & Goga, A. (2013). Eliminating mother-to-child HIV transmission in South Africa. *Bulletin of the World Health Organisation*, *91*, 70-74. Retrieved from http://www.who.int/bulletin/volumes/91/1/12-106807/en/

Brown, B. J., Oladokun, R. E., Osinusi, K., Ochigbo, S., Adewole, I. F., & Kanki, P. (2011). Disclosure of HIV status to infected children in a Nigerian HIV Care Programme. *AIDS Care, 23*(9), 1053-1058. doi: https://doi-org.ezproxy.uct.ac.za/10.1080/09540121.2011.554523

Burton, R., Giddy, J., & Stinson, K. (2015). Prevention of mother-to-child transmission in South Africa: An ever-changing landscape. *Obstetric Medicine*, *8*(1), 5–12. doi: http://doi.org/10.1177/1753495X15570994

Cáceres, C. F., Aggleton, P., & Galea, J. T. (2008). Sexual diversity, social inclusion and HIV/AIDS. *AIDS (London, England)*, *22*(Suppl 2), S45–S55. doi: http://doi.org/10.1097/01.aids.0000327436.36161.80

Calabrese, S. K., Martin, S., Wolters, P. L., Toledo-Tamula, M. A., Brennan, T. L., & Wood, L. V. (2012). Diagnosis disclosure, medication hiding, and medical functioning among perinatally infected, HIV-positive children and adolescents. *AIDS care*, *24*(9), 1092-1096. doi: https://doi-org.ezproxy.uct.ac.za/10.1080/09540121.2012.699670

Cantrell, K., Patel, N., Mandrell, B., & Grissom, S. (2013). Pediatric HIV disclosure: A process-oriented framework. *AIDS Education and Prevention*, *25*(4), 302-314.

Constitution of the Republic of South Africa, Act No. 108 of 1996. Retrieved from http://www.refworld.org/docid/3ae6b5de4.html

Das, A., Detels, R., Javanbakht, M., & Panda, S. (2016). Issues around childhood disclosure of HIV status - findings from a qualitative study in West Bengal, India. *Child: Care, Health & Development*, *42*(4), 553-564. doi:10.1111/cch.12338

Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects (October 2008). Retrieved from http://www.wma.net/en/30publications/10policies/b3/index.html

Department of Health Republic of South Africa (2013). The 2012 national antenatal sentinel HIV and herpes simplex type-2 prevalence survey in South Africa. National Department of Health Government Printer: Pretoria.

Domek, G. J. (2010). Debunking common barriers to pediatric HIV disclosure. *Journal of Tropical Pediatrics, 56*(6), 440-442. doi: https://doi.org/10.1093/tropej/fmq013

Dow, D. E., Turner, E. L., Shayo, A. M., Mmbaga, B., Cunningham, C. K., & O'Donnell, K. (2016). Evaluating mental health difficulties and associated outcomes among HIV-positive adolescents in Tanzania. *AIDS Care*, *28*(7), 825-833. doi:10.1080/09540121.2016.1139043

Earnshaw, V. A., & Chaudoir, S. R. (2009). From conceptualizing to measuring HIV stigma: A review of HIV stigma mechanism measures. *AIDS and Behavior*, *13*(6), 1160. doi: 10.1007/s10461-009-9593-3

Eley, B., Nuttal, J., & Apolles, P. (2011). Antiretroviral therapy treatment guideline Red Cross War Memorial Children’s Hospital. Retrieved from http://www.paediatrics.uct.ac.za/sites/default/files/image_tool/images/38/ART_Guidelines_20at_RCWMCH_10_May_2011.pdf

Elopre, L., Hook, E. W., Westfall, A. O., Zinski, A., Mugavero, M. J., Turan, J., & Van Wagoner, N. (2015). The Role of Early HIV Status Disclosure in Retention in HIV Care. *AIDS Patient Care & STDs*, *29*(12), 646-650. doi:10.1089/apc.2015.0205

Evangeli, M., & Kagee, A. (2016). A model of caregiver paediatric HIV disclosure decision-making. *Psychology, Health & Medicine*, *21*(3), 338-353. doi:10.1080/13548506.2015.1058959

Eustace, R. W., & Ilagan, P. R. (2010). HIV disclosure among HIV positive individuals: A concept analysis. *Journal of Advanced Nursing*, *66*(9), 2094-2103.

Ferris, M., Burau, K., Schweitzer, A. M., Mihale, S., Murray, N., Preda, A., ... & Kline, M. (2007). The influence of disclosure of HIV diagnosis on time to disease progression in a cohort of Romanian children and teens. *AIDS care*, *19*(9), 1088-1094. doi: https://doi-org.ezproxy.uct.ac.za/10.1080/09540120701367124

Gyamfi, E., Okyere, P., Enoch, A., & Appiah-Brempong, E. (2017). Prevalence of, and barriers to the disclosure of HIV status to infected children and adolescents in a district of Ghana. *BMC international health and human rights, 17*(1), 8. doi: https://doi.org/10.1186/s12914-017-0114-6

Harper, G. W., Lemos, D., Hosek, S. G., & Adolescent Medicine Trials Network for HIV/AIDS Interventions. (2014). Stigma reduction in adolescents and young adults newly diagnosed with HIV: Findings from the Project Accept Intervention. *AIDS Patient Care and STDs*, *28*(10), 543-554. doi: 10.1089/apc.2013.0331

Heeren, G. A. (2011). Changing methods of disclosure. Literature review of disclosure to children with terminal illnesses, including HIV. *Innovation: The European Journal of Social Science Research*, *24*(1-2), 199-208. doi: https://doi-org.ezproxy.uct.ac.za/10.1080/13511610.2011.553506

International Conference on Harmonization (ICH) Harmonized Tripartite Guideline on Good Clinical Practice (ICH GCP Guidelines). Retrieved from http://www.ich.org/fileadmin/Public_Web_Site/ICH_Products

Jemmott Iii, J.,B., Heeren, G. A., Sidloyi, L., Marange, C. S., Tyler, J. C., & Ngwane, Z. (2014). Caregivers' intentions to disclose HIV diagnosis to children living with HIV in South Africa: A theory-based approach. *AIDS and Behavior, 18*(6), 1027-36. doi: http://dx.doi.org/10.1007/s10461-013-0672-0

Joint United Nations Programme on HIV/AIDS. (2017). Fact Sheet: World AIDS day 2017. Retrieved from http://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf

Joint United Nations Programme on HIV/AIDS. (2017). UNAIDS data 2017. Retrieved from http://www.unaids.org/sites/default/files/media_asset/2017_data-book_en.pdf

Joint United Nations Programme on HIV/AIDS. (2016). On the fast track to an AIDS-free generation. The incredible journey of the global plan toward the elimination of new HIV infections among children by 2015 and keeping their mothers alive. Retrieved from http://www.unaids.org/sites/default/files/media_asset/GlobalPlan2016_en.pdf

Kallem, S., Renner, L., Ghebremichael, M., & Paintsil, E. (2011). Prevalence and pattern of disclosure of HIV status in HIV-infected children in Ghana. *AIDS and Behavior*, *15*(6), 1121-1127. doi: 10.1007/s10461-010-9741-9

Kimani-Murage, E. W., Manderson, L., Norris, S. A., & Kahn, K. (2010). ‘You opened our eyes’: Care-giving after learning a child’s positive HIV status in rural South Africa. *Health & Social Care in the Community, 18*(3), 264-271. doi: 10.1111/j.1365-2524.2009.00891.x

Kimani-Murage, E. W., Manderson, L., Norris, S. A., & Kahn, K. (2013). “It's my secret”: Barriers to paediatric HIV treatment in a poor rural South African setting. *AIDS Care, 25*(6), 744-747. doi: https://doi-org.ezproxy.uct.ac.za/10.1080/09540121.2012.748865

Kiwanuka, J., Mulogo, E., & Haberer, J. E. (2014). Caregiver perceptions and motivation for disclosing or concealing the diagnosis of HIV infection to children receiving HIV care in Mbarara, Uganda: A qualitative study. *PloS One*, *9*(3), e93276. doi: https://doi.org/10.1371/journal.pone.0093276

Kenu, E., Obo-Akwa, A., Nuamah, G. B., Brefo, A., Sam, M., & Lartey, M. (2014). Knowledge and disclosure of HIV status among adolescents and young adults attending an adolescent HIV clinic in Accra, Ghana. *BMC research notes, 7*(1), 844. doi: https://doi.org/10.1186/1756-0500-7-844

Lawan, U. M., Envuladu, E. A., & Abubakar, S. (2016). Does awareness of status and risks of human immunodeficiency virus impact risky transmission behavior among infected adolescents? A case study of clients attending an antiretroviral therapy (ART) clinic in Kano, Kano State, Nigeria. *Indian Journal of Community Medicine: Official Publication of Indian Association of Preventive & Social Medicine, 41*(2), 126.

doi: 10.4103/0970-0218.177533

Lesch, A. I. D. S., Swartz, L., Kagee, A., Moodley, K., Kafaar, Z., Myer, L., & Cotton, M. (2007). Paediatric HIV/AIDS disclosure: Towards a developmental and process-oriented approach. *AIDS Care*, *19*(6), 811-816. doi: https://doi-org.ezproxy.uct.ac.za/10.1080/09540120601129301

Lester, P., Chesney, M., Cooke, M., Weiss, R., Whalley, P., Perez, B., ... & Wara, D. (2002). When the time comes to talk about HIV: Factors associated with diagnostic disclosure and emotional distress in HIV-infected children. *JAIDS-HAGERSTOWN MD-*, *31*(3), 309-317.

Krauss, B. J., Letteney, S., De Baets, A. J., Baggaley, R., & Okero, F. A. (2013). Caregiver's HIV disclosure to children 12 years and under: A review and analysis of the evidence. *AIDS Care*, *25*(4), 415-429. doi:10.1080/09540121.2012.712664

Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Ortiz, D., Szekeres, G., & Coates, T. J. (2008). Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. *AIDS (London, England)*, *22*(Suppl 2), S67. doi: 10.1097/01.aids.0000327438.13291.62

Mahloko, J. M., & Madiba, S. (2012). Disclosing HIV diagnosis to children in Odi district, South Africa: Reasons for disclosure and non-disclosure. *African Journal of Primary Health Care and Family Medicine*, *4*(1), 1-7. doi: http://dx.doi.org/10.4102/phcfm.v4i1.345

Madiba, S., & Mokwena, K. (2012). Caregivers' barriers to disclosing the HIV diagnosis to infected children on antiretroviral therapy in a resource-limited district in South Africa: A grounded theory study. *AIDS Research and Treatment*, *2012*. doi: 10.1155/2012/402403

Maskew, M., Jamieson, L., Mohomi, G., Long, L., Mongwenyana, C., Nyoni, C., ... & Rosen, S. (2018). Implementation of Option B and a fixed-dose combination antiretroviral regimen for prevention of mother-to-child transmission of HIV in South Africa: A model of uptake and adherence to care. *PloS one*, *13*(8), e0201955-e0201955. doi: https://doi.org/10.1371/journal.pone.0201955

Midtbø, V., Shirima, V., Skovdal, M., & Daniel, M. (2012). How disclosure and antiretroviral therapy help HIV-infected adolescents in sub-Saharan Africa cope with stigma. *African Journal of AIDS Research*, *11*(3), 261-271. doi: https://doi.org/10.2989/16085906.2012.734987

Midtbø, V., Shirima, V., Skovdal, M., & Daniel, M. (2012). How disclosure and antiretroviral therapy help HIV-infected adolescents in sub-Saharan Africa cope with stigma. *African Journal Of AIDS Research (AJAR)*, *11*(3), 261-271. doi:10.2989/16085906.2012.734987

Montalto, G. J., Sawe, F. K., Miruka, A., Maswai, J., Kiptoo, I., Aoko, A., ... & Song, K. X. (2017). Diagnosis disclosure to adolescents living with HIV in rural Kenya improves antiretroviral therapy adherence and immunologic outcomes: A retrospective cohort study. *PloS One*, *12*(10), e0183180. doi: https://doi.org/10.1371/journal.pone.0183180

Mutumba, M., Bauermeister, J. A., Musiime, V., Byaruhanga, J., Francis, K., Snow, R. C., & Tsai, A. C. (2015). Psychosocial challenges and strategies for coping with HIV among adolescents in Uganda: A qualitative study. *AIDS Patient Care and STDs*, *29*(2), 86-94. doi: 10.1089/apc.2014.0222

National Department of Health of South Africa. (2015). National adolescent sexual and reproductive health and rights framework strategy. Retrieved from http://www.dsd.gov.za/index2.php?option=com_docman&task=doc_view&gid=578&Itemid=3

Nicastro, E., Continisio, G. I., Storace, C., Bruzzese, E., Mango, C., Liguoro, I., ... & Officioso, A. (2013). Family group psychotherapy to support the disclosure of HIV status to children and adolescents. *AIDS patient care and STDs*, *27*(6), 363-369. doi: 10.1089/apc.2012.0465

Nicholson, O., Mellins, C., Dolezal, C., Brackis-Cott, E., & Abrams, E. J. (2006). HIV treatment-related knowledge and self-efficacy among caregivers of HIV-infected children. *Patient Education and Counseling*, *61*(3), 405-410. doi: 10.1016/j.pec.2005.05.006

Nzota, M. S., Matovu, J. K., Draper, H. R., Kisa, R., & Kiwanuka, S. N. (2015). Determinants and processes of HIV status disclosure to HIV-infected children aged 4 to 17 years receiving HIV care services at Baylor College of Medicine Children’s Foundation Tanzania, Centre of Excellence (COE) in Mbeya: A cross-sectional study. *BMC Pediatrics*, *15*(1), 81. doi: 10.1186/s12887-015-0399-3

Oberdorfer, P., Puthanakit, T., Louthrenoo, O., Charnsil, C., Sirisanthana, V., & Sirisanthana, T. (2006). Disclosure of HIV/AIDS diagnosis to HIV- infected children in Thailand. *Journal of Paediatrics and Child Health*, *42*(5), 283-288. doi:10.1111/j.1440-1754.2006.00855.x

Ostrom Delaney, R., Serovich, J. M., & Lim, J. Y. (2008). Reasons for and against maternal HIV disclosure to children and perceived child reaction. *AIDS Care*, *20*(7), 876-880. doi: https://doi-org.ezproxy.uct.ac.za/10.1080/09540120701767158

Ostrom, R. A., Serovich, J. M., Lim, J. Y., & Mason, T. L. (2006). The role of stigma in reasons for HIV disclosure and non-disclosure to children. *AIDS Care*, *18*(1), 60-65. doi: https://doi-org.ezproxy.uct.ac.za/10.1080/09540120500161769

Paintsil, E., Renner, L., Antwi, S., Dame, J., Enimil, A., Ofori-Atta, A., & ... Reynolds, N. R. (2015). HIV knowledge, stigma, and illness beliefs among pediatric caregivers in Ghana who have not disclosed their child's HIV status. *AIDS Care*, *27*18-27. doi:10.1080/09540121.2015.1007116

Pantelic, M., Boyes, M., Cluver, L., & Meinck, F. (2017). HIV, violence, blame and shame: pathways of risk to internalized HIV stigma among South African adolescents living with HIV. *Journal Of The International AIDS Society*, *20*1-9. doi:10.7448/IAS.20.1.21771

Pantelic, M., Shenderovich, Y., Cluver, L., & Boyes, M. (2015). Predictors of internalised HIV-related stigma: A systematic review of studies in sub-Saharan Africa. *Health Psychology Review*, *9*(4), 469-490. doi:10.1080/17437199.2014.996243

Pinzón-Iregui, M. C., Beck-Sagué, C. M., & Malow, R. M. (2013). Disclosure of their HIV status to infected children: a review of the literature. *Journal of Tropical Paediatrics, 59*(2), 84-89. Doi: https://doi.org/10.1093/tropej/fms052

Prudden, H. J., Hamilton, M., Foss, A. M., Adams, N. D., Stockton, M., Black, V., & Nyblade, L. (2017). Can mother-to-child transmission of HIV be eliminated without addressing the issue of stigma? Modeling the case for a setting in South Africa. *Plos ONE*, *12*(12), 1-19. doi:10.1371/journal.pone.0189079

Saunders, C. (2012). Disclosing HIV status to HIV positive children before adolescence. *British Journal of Nursing*, *21*(11), 663-669.

Sherman, G., Lilian, R., Barron, P., Candy, S., Robinson. P., & Bhardwaj, S. (2012). Laboratory information system (LIS) data is useful for monitoring the prevention of mother-to-child transmission program (PMTCT) in South Africa. In: XIX International AIDS Conference; 2012 22-27 July; Washington, United States.

Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2010). Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas, 66*(2), 191-200. doi: 10.1016/j.maturitis.2010.02.009

Siu, G. E., Bakeera-Kitaka, S., Kennedy, C. E., Dhabangi, A., & Kambugu, A. (2012). HIV serostatus disclosure and lived experiences of adolescents at the Transition Clinic of the Infectious Diseases Clinic in Kampala, Uganda: A qualitative study. *AIDS Care*, *24*(5), 606-611. doi: https://doi-org.ezproxy.uct.ac.za/10.1080/09540121.2011.630346

Sirikum, C., Sophonphan, J., Chuanjaroen, T., Lakonphon, S., & Srimuan, A. (2013, June). HIV disclosure and its effects on treatment outcomes in HIV-infected Thai children and adolescents. In *5th International Workshop on HIV Pediatrics* (pp. 28-29).Kuala lampur, Malaysia.

Smith, R., Rossetto, K., & Peterson, B. L. (2008). A meta-analysis of disclosure of one's HIV-positive status, stigma and social support. *AIDS Care*, *20*(10), 1266-1275. doi: https://doi-org.ezproxy.uct.ac.za/10.1080/09540120801926977

Stuber, J., Meyer, I., & Link, B. (2008). Stigma, prejudice, discrimination and health. *Social Science & Medicine (1982), 67*(3), 351. doi: 10.1016/j.socscimed.2008.03.023

South Africa*: Act No. 38 of 2005, Children's Act* [South Africa], 19 June 2006. Retrieved from http://www.refworld.org/docid/46b82aa62.html

Tadesse, B. T., Foster, B. A., & Berhan, Y. (2015). Cross sectional characterization of factors associated with pediatric HIV status disclosure in southern Ethiopia. *PloS One*, *10*(7), e0132691. doi: https://doi.org/10.1371/journal.pone.0132691

Ulin P.R., Robinson, E.T. & Tolley E.E. (2005). *Qualitative methods in public health. A field guide for applied research.* San Francisco, CA: Jossey-Bass. ISBN 978-0-7879-7634-7

United Nations. (2015). Sustainable development goals: 17 goals to transform our world. Retrieved from http://www.un.org/sustainabledevelopment/

Vaz, L. M., Eng, E., Maman, S., Tshikandu, T., & Behets, F. (2010). Telling children they have HIV: Lessons learned from findings of a qualitative study in sub-Saharan Africa. *AIDS Patient Care and STDs*, *24*(4), 247-256. doi: 10.1089/apc.2009.0217

Vaz, L., Corneli, A., Dulyx, J., Rennie, S., Omba, S., Kitetele, F., ... & Behets, F. (2008). The process of HIV status disclosure to HIV-positive youth in Kinshasa, Democratic Republic of the Congo. *AIDS Care*, *20*(7), 842-852. doi: https://doi-org.ezproxy.uct.ac.za/10.1080/09540120701742276

Vreeman, R. C., Scanlon, M. L., Mwangi, A., Turissini, M., Ayaya, S. O., Tenge, C., & Nyandiko, W. M. (2014). A cross-sectional study of disclosure of HIV status to children and adolescents in western Kenya. *PloS One*, *9*(1), e86616. doi: https://doi.org/10.1371/journal.pone.0086616

Vreeman, R. C., Gramelspacher, A. M., Gisore, P. O., Scanlon, M. L., & Nyandiko, W. M. (2013). Disclosure of HIV status to children in resource- limited settings: A systematic review. *Journal of the International AIDS Society*, *16*(1).

doi: 10.7448/IAS.16.1.18466

Vreeman, R. C., Nyandiko, W. M., Ayaya, S. O., Walumbe, E. G., Marrero, D. G., & Inui, T. S. (2010). The perceived impact of disclosure of pediatric HIV status on pediatric antiretroviral therapy adherence, child well-being, and social relationships in a resource-limited setting. *AIDS Patient Care and STDs*, *24*(10), 639-649. doi: 10.1089/apc.2010.0079

Watermeyer, J. (2015). 'Are we allowed to disclose?': A healthcare team's experiences of talking with children and adolescents about their HIV status. *Health Expectations*, *18*(4), 590-600. doi:10.1111/hex.12141

Wilson, P. A., Valera, P., Martos, A. J., Wittlin, N. M., Muñoz-Laboy, M. A., & Parker, R. G. (2016). Contributions of qualitative research in informing HIV/AIDS interventions targeting Black MSM in the United States. *Journal of Sex Research*, *53*(6), 642–654. doi: http://doi.org/10.1080/00224499.2015.1016139

World Health Organisation. (2011). Guideline on HIV disclosure counselling for children up to 12 years of age. Retrieved from http://www.who.int/hiv/pub/hiv_disclosure/en/

World Health Organisation. (2018a). Maternal, newborn, child and adolescent health: Adolescent development. Retrieved from http://www.who.int/maternal_child_adolescent/topics/adolescence/development/en/

World Health Organisation. (2018b). Mother-to-child-transmission of HIV. Retrieved from http://www.who.int/hiv/topics/mtct/about/en/

Annexure A

Consent Form

Study purpose:
You are invited to participate in a research project being conducted by researchers from the University of Cape Town. The purpose of the study is to better understand what and how caregivers communicate with children about their health and hospital visits. Caregivers attending S4 clinic at Red Cross War Memorial Children's Hospital will be invited to participate in this study. We hope that the results of this study will help to improve health service delivery for children and their families.

Study Procedures:
If you decide to participate in this research study, you will be interviewed by the researcher or the research assistant. The interview will last no more than 30-45 minutes.

The interviews will be recorded on a tape recorder so that the researcher can write down the conversation and is able to listen to it carefully. This will help the researcher understand clearly what the caregiver and child have said. The tape recording and typed pages of the interview will be kept in a locked cupboard in the researchers office. Only the researcher and the research assistant will have access to this information.

The health staff at the hospital will not have access to this information and your participation on this study will not affect the care your child receives.

Voluntary participation:
Participation on this study is voluntary. You are free to refuse to answer any question. If you decide to participate in this study you are free to change your mind at any time and this will not affect the care you or the child receives.

Confidentiality:
Information will be kept confidential. The interview sheet, tape recordings and transcripts will not have your name on it and no information identifying you will be given to anyone. Any reports or publications about this study will not identify you, the child or any other participant.

Possible risks:
While you are participating in this research study, you may experience some emotional discomfort. If this happens and you feel that you need to speak to a counselor or social worker, you will be given the opportunity to do so.

Possible benefits:
You may benefit personally by talking about your experiences you could become more confident about talking to your child about his/her health.

This study has been approved by the Research Ethics Committee at the University of Cape Town. If at any time, you have questions or concerns about this study, please contact
The Principal investigator:
Robert Shea: E-mail: fertileground05@sbcglobal.net

Consent statement

I have read the above information, or it has been read to me. I have had the opportunity to ask questions which have been answered to my satisfaction. I hereby consent to participate voluntarily in this study.
Name:…………………………………………………
Signature:………………………… Date:…………………………….

Witness name:…………………… Signature:…………………………

If unable to write: The content has been explained to me by the investigator or dedicated research assistant in my own language.

Signature/thumb print:…………………… Date:…………………………….

Witness name:……………………… Signature:…………………………

Annexure B

Information Sheet Participants

My name is Robert Shea and I am studying at the University of Cape Town. I am doing research with the parents attending the HIV clinic to understand how parents go about disclosing the HIV status to children. If you agree to be a part of this research, you will meet with me or one of the other researchers who will do an interview with you in a private room. If you would like to be interviewed in your home language, one of the fieldworkers who speaks your language, and who was trained to do this research, will interview you.

It is very important to me in this research not to miss anything you say. So I will use a small recorder to record the conversation we have. I am the only person who will listen to the recording and I will keep notes of what we talk about. I will not write your name on any of my notes and I will not use any names you talk about. I will also not tell anyone what we have talked about. Only I and the doctor who is supervising my research will know what we discussed, and that doctor does not work in this clinic.

Please also remember that if you decide not to be a part of this research anymore, you can do that and you will still be treated the same by everyone. No-one will be upset or angry with you if you decide not to take part in this research. If you feel upset about anything we talked about, please let me or the nurses and doctors know so that we can let you see the social worker. You will be able to tell him or her what upset you.

Do you have any questions now? If you ever have any questions, if there is something you do not understand or need me to explain to you again, please do not be afraid to ask me. I will make time to explain anything about this research to you as many times or whenever you need it.

If you have any queries, please feel that you can contact:
Supervisor : Dr D Cooper
University of Cape Town
Women’s Health Research Unit
Tel: 021 406 6528

Investigator – Robert Shea
University of Cape Town
School of Child & Adolescent Health
Tel: 021 658 5030

Prof M Blockman
Head Faculty Research Ethics Committee
University of Cape Town
Tel: 021 406 6496

Annexure C

Caregiver Interview Schedule

Q01. ***Enter the interview date.*** (dd / mm / yyyy) |__|__| / |__|__| / |__|__|__|__|

Q02. ***Enter participant ID number:*** |__|__|__|__|__|

Q03. ***Enter Interviewer ID number*:** |__|__|__|

BACKGROUND PERSONAL AND MEDICAL INFORMATION

B01.	a. **How old are you?** Or b. **What is your date of birth?** (dd/mm /yyyy)	|__|__| |__|__| / |__|__| / |__|__|__|__|	
B02.	**Where were you born?**	Cape Town	**1**
		Other Western Cape	**2**
		Eastern Cape	**3**
		Other	**4**
B03.	**How long have you lived in Cape Town?**	Years	|__|__|
		Refuse to Answer	**88**

Level of Education	

Relationship to Child	

LIVING SITUATION

LS01.	**Where are you currently living?** ***[Code one response. Probe for most specific living site.]***	A shack on private property	1
		A shack in formal settlement	2
		A house/flat that you own	3
		A house/flat that you rent	4
		A house/flat that you share	5
		Homeless: street	6
		Homeless: shelter	7
		Other	8
		Refuse to Answer	88

		Yes	**No**	**Refuse to answer**
LS02.	**Who do you currently live with?** ***(check all that apply)***			
	a. Partner	1	2	88
	b. Parents	1	2	88
	c. My other child(ren)	1	2	88
	d. Brothers/Sisters	1	2	88
	e. Friends/Other relatives	1	2	88
	f. Alone	1	2	88

LS03.	**What is your current employment status?**	Formal employment (specify occupation): ____________	1
		Unemployed	2
		Casual employment	3
		Home business [specify: e.g. spaza shop, make clothing etc]	4
		Full time housewife	5
		Going to school/college/university	6
		Other	7
		Refuse to answer	88

	Now I am going to ask about grant support:	**Yes**	**No**
LS04.	**Do you receive any grants for yourself or your baby/child?**	1	2
	If No, skip to LS06		

LS05.	**Specify type of grant?** (multiple responses allowed)	a. Child support grant	1	2
		b. Disability grant	1	2
		c. Grant in aid / social relief	1	2
		d. Old age pension	1	2
		e. Child care dependency grant	1	2
		f. Foster care grant	1	2
		g. Child maintenance support [from father]	1	2
		h. Other (specify): ____________________ ____________________________________	1	2

LS06.	**How regular is your income from all sources for the next 6 months, grants included?**		
	No pattern:	No pattern to how much we get and when. Often we might not get anything.	1
	Irregular:	We usually get some money each month, but the time and amount varies.	2
	Mostly fixed:	The date we get money or the amount can change.	3
	Fixed:	The amount of money does not change in time or amount.	4
		No	2
		Sometimes	3
		Refuse to answer	88

LS14.	**Do you currently have a regular romantic partner? By romantic partner, I mean a husband, boyfriend, girlfriend, etc.** If subject answers "girlfriend" to the following, then remember, when asking future questions regarding romantic partners, to refer to that person as "she".	Husband	1
		Boyfriend	2
		Girlfriend	3
		No	4
		Other *(specify):* ________ ____________________	5
		Refuse to Answer	88

LS15.	**Do you live with your partner?**	Yes	1
		No	2

		Other *(specify, e.g. Weekends only)*: ______________________________	3
		Refuse to answer	88

LS16.	**Does your partner provide you with any of the following:**	**Yes**	**No**
	a. Money	1	2
	b. Food	1	2
	c. Clothing	1	2
	d. Shelter	1	2
	e. Other *(specify):*________________	1	2

HIV Testing

Now I am going to change the subject a bit and ask you questions about HIV.

HT01.	**Were you ever tested for HIV?**	Yes	1
		No	2
	If answer is "No" skip to Pfu_01		

HT02.	**If yes, what was the result?**	Positive	1
		Negative	2
		Didn't get the results of the test	3
		Other	4
		Refuse to answer	88

HT03a.	**Do you have your most recent t-cell or CD4 count?**	Yes	1
		Yes, but not available	2
		No, but have taken CD4 test	3
		No, haven't taken CD4 yet	4
		Refuse to Answer	88

HT03b.	**If yes, then what is your t-cell or CD4 count?**	T-cell or CD4 count:	|__|__|__|

HT04.	**Have you received any ARVs for your HIV?**	Yes	1
		No	2

HT05.	**Has your partner been tested for HIV?**	Yes	1
		No	2
		Don’t know	99
HT06.	**Do you know your partner’s HIV status?**	Yes	1
		No	2
		Suspect but don’t know for certain	3
HT07.	**If yes, what is your partner’s HIV status?**	Positive	1
		Negative	2
HT08.	**Have you told your partner your HIV status?**	Yes	1
		No	2
HT09	**Have you told your partner your child’s HIV status?**	Yes	1
		No	2
HT09.	**If yes, what was his response?**	He agreed to get tested	1
		He refused to get tested	2
		He refused to discuss it	3
		Other	4
		No response	5

PMTCT QUESTIONS

Pfu_01.	***I am going to list a number of different aspects of the PMTCT programme, and I want you to tell me which ones you adopted.***	**Yes**	**No**	**Don't know**	**Refuse to answer**
	a. ARV's during pregnancy	1	2	99	88
	b. ARV's at childbirth	1	2	99	88
	c. ARV's for the new baby	1	2	99	88
	d. Testing the baby	1	2	99	88
	e. Exclusive breastfeeding of baby	1	2	99	88
	f. Exclusive formula feeding of baby	1	2	99	88
	g. Mixed feeding of baby	1	2	99	88

Pfu_02.	**Which antiretroviral drugs did you receive during labour?**	**Yes**	**No**	**Don't know**	**Refuse to answer**
	a. Nevirapine	1	2	99	88
	b. AZT	1	2	99	88
	c. Nevirapine and AZT	1	2	99	88

Pfu_03.	**Which antiretroviral drugs did your baby receive?**	**Yes**	**No**	**Don't know**	**Refuse to answer**
	a. Nevirapine	1	2	99	88
	b. AZT	1	2	99	88
	c. Nevirapine and AZT	1	2	99	88

BABY FOLLOW-UP

BYfu_01.	**Did you take your baby to the well-baby clinic for any of the following (at 6 weeks):**	**Yes**	**No**	**If NO, what was the reason?**
	a. Weighing	1	2	______________________ ________________
	b. Milk formula	1	2	______________________ ________________
	c. Immunization	1	2	______________________ ________________
	d. Because baby was sick	1	2	______________________ ________________

BYfu_02.	**Did you take your baby to the well-baby clinic for any of the following (at 14 weeks):**	**Yes**	**No**	**If NO, what was the reason?**
	a. Weighing	1	2	______________________ ________________
	b. Milk formula	1	2	______________________ ________________
	c. Immunization	1	2	______________________ ________________
	d. Because baby was sick	1	2	______________________ ________________
	e. To have an HIV test	1	2	______________________ ________________

BYfu_03.	**Since the birth of your baby, has the baby been so sick that s/he had to stay in hospital?**	Yes	1
		No	2
		Don’t know	99
		Refuse to answer	88
BYfu_03a.	**If yes, how many days?**	|__|__|__|	

SOCIAL SUPPORT

Next are some questions about the support that is available to you.

<table>
<tr><td rowspan="3">SS01.</td><td colspan="3">About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?</td></tr>
<tr><td>SS01a</td><td>Number of close friends</td><td>|__|__|__|</td></tr>
<tr><td>SS01b</td><td>Number of close relatives</td><td>|__|__|__|</td></tr>
</table>

SS02. **People sometimes look to others for companionship, assistance, or other types of support.**

X=letter of the kind of support in table below

SS02(X)_1. **How often is each of the following kinds of support available to you if you need it, and how satisfied with this support are you?**

Use cups to again represent scale of 1 to 5:
1=None of the time
2=A little of the time
3=Some of the time
4=Most of the time
5=All of the time

SS02(X)_2. **Circle the happy or frown face to signify how satisfied you are with the support.**

1. Satisfied
2. Unsatisfied

		SS02(X)_1					**SS02(X)_2**	
A	Someone to help you if you were confined to bed.	1	2	3	4	5	☺	☹
B	Someone you can count on to listen to you when you need to talk.	1	2	3	4	5	☺	☹
C	Someone to give you good advice about a crisis.	1	2	3	4	5	☺	☹
D	Someone to take you to the doctor if you needed it.	1	2	3	4	5	☺	☹
E	Someone who shows you love and affection.	1	2	3	4	5	☺	☹
F	Someone to have a good time with.	1	2	3	4	5	☺	☹
G	Someone to give you information to help you understand a situation.	1	2	3	4	5	☺	☹

H	Someone to confide in or talk to about yourself or your problems.	1	2	3	4	5	☺	☹
I	Someone who hugs you.	1	2	3	4	5	☺	☹
J	Someone to get together with for relaxation.	1	2	3	4	5	☺	☹
K	Someone to prepare your meals if you were unable to do it yourself.	1	2	3	4	5	☺	☹
L	Someone whose advice you really want.	1	2	3	4	5	☺	☹
M	Someone to do things with to help you get your mind off things.	1	2	3	4	5	☺	☹
N	Someone to help with daily chores if you were sick.	1	2	3	4	5	☺	☹
O	Someone to share your most private worries and fears with.	1	2	3	4	5	☺	☹
P	Someone to turn to for suggestions about how to deal with a personal problem.	1	2	3	4	5	☺	☹
Q	Someone to do something enjoyable with.	1	2	3	4	5	☺	☹
R	Someone who understands your problems.	1	2	3	4	5	☺	☹
S	Someone to love and make you feel wanted.	1	2	3	4	5	☺	☹
T	Someone to help take care of your children when you can’t.	1	2	3	4	5	☺	☹

STIGMA

		Yes	No	Refuse to answer
S01	**Because of your HIV, have you ever experienced any of the following?**			
	a. Told you couldn’t go to someone’s house because of HIV.	1	2	88
	b. Couldn’t play with someone else’s children because of HIV.	1	2	88
	c. Can’t eat with or on their plates or can’t use their glasses or knives and forks because of HIV.	1	2	88
	d. Can’t touch or hug someone because of HIV.	1	2	88
	e. Can’t cook food because of HIV.	1	2	88
	f. Can’t use someone’s toilet because of HIV.	1	2	88
	g. Was laughed at or teased because of HIV.	1	2	88
	h. Was fired from a job because of HIV.	1	2	88
	i. Told you can’t live somewhere because of HIV.	1	2	88
	j. Had your HIV status told without your permission.	1	2	88
	k. Any other experience with stigma?	1	2	88

DISCLOSURE

		Yes	No	Don’t know	Refuse to answer
D01	**Did you discuss getting HIV tested with your partner before you agreed to have the test? .**	1	2	99	88
D02	**Does your partner now know that you went to get tested for HIV?**	1	2	99	88
D03a	**Have you told your partner or does he know your HIV test result?**	1	2	99	88
D03b	**If yes, how supportive was he/she?** *Use feeling faces to gauge the level of support they received from their partner.*	☺ Very supportive			1
		😐 Somewhat supportive			2
		☹ Unsupportive			3

D04a-d	**Who else have you told your HIV status to?** ***If you told any of the following people, indicate how supportive they were.***

D04a	**Family**	☺ Very supportive	1
		😐 Somewhat supportive	2
		☹ Unsupportive	3
		Did not tell them	4
		Refuse to answer	88
D04b	**Friends**	☺ Very supportive	1
		😐 Somewhat supportive	2
		☹ Unsupportive	3
		Did not tell them	4
		Refuse to answer	88
D04c	**Health care workers**	☺ Very supportive	1
		😐 Somewhat supportive	2
		☹ Unsupportive	3
		Did not tell them	4
		Refuse to answer	88
D04d	**Other**	☺ Very supportive	1
		😐 Somewhat supportive	2
		☹ Unsupportive	3
		Did not tell them	4
		Refuse to answer	88

PARENTING

CHILDREN

CH01	**Was this pregnancy your first child?**	Yes	1
		No	2
		Refuse to answer	88
CH02	**If no, how old were you the first time you had a baby?**	|__|__|	|__|__|
		Never had a baby before this one	2
		Refuse to answer	88
CH03a	**How many children have you given birth to?**	|__|__|	|__|__|
		Refuse to answer	88
CH03b	**How many children are still alive?**	|__|__|	|__|__|
		Refuse to answer	88

Open-ended Questions:

1. When did you first tell your child about their health status?
2. What did you say exactly? Please pretend that the translator is your child and repeat exactly what you said to your child at the time
3. What was the reason that you decided to tell your child about their health status at that time?
4. How many times has your child ever asked you or others or given any indications about their concern about their health and coming to the hospital? How did you respond in those situations? How did you feel when that happened?
5. What were your worries/fears about telling the child the real reason that they come to the hospital? What did you actually say to the child?
6. How did it feel when you did/did not tell the child exactly about their health condition?
7. What was the child's reaction to what you said or did not say?
8. Is there anything I have not asked you about talking to your child about their health that you would like to talk about? Are there any questions you would like me to answer?
9. What was it like for you to be asked these questions?
10. What advice would you give to other parents who have children who are living with HIV?

Annexure D

Translated Consent Form

Injongo zokufunda

Uyamenywa ukuba uthathe inxaxheba kwiprojekthi yophando ezakuba ikhokhelwa ngababphandi abaphuma ku Dyunivesithi yase Kapa. Injongo zesifundo kukufuna ukuqonda ngcono ukuba zintoni kwaye besenza njani abaniki boncedo ukuqhakamshelana nabantwana malunga nempilo yabo kunye notyelelo lwabo ezibhedlele. Abaniki luncedo baqhuba iS4 Clinic e Red Cross War Memorial. Isibhedlele sabantwana sizakumenywa ukuba sizokuthabatha inxaxheba kwesi sifundo. Siyathemba ukuba iziphumo zesifundo ziyakunceda kakhulu ukuphucula impilo nohanjiso lweenkonzo kubantwana ndawonye nezihlobo nezelamana.

Imigaqo yokufunda

Ukuba ugqibe ekubeni uthathe inxaxheba kwizifundo ngophando, uyakuba nodliwanondlebe ngumphandi okanye ngumphandi okanye umphandi oncedisayo udliwano-ndlebe alusayi kuthatha ngaphezulu kwemizuzu e 30 – 45.

Udliwano-ndlebe luyakushicilelwa kwi tape recorder khonukuze umphandi abe namanqakwana awabhala phantsi azokukwazi ukuwamamelisisa kakuhle. Yeyonanto izakunceda umphandi ukuba ayiqonde ngokucacileyo ukuba zintoni ezithethwe ngabantwana nabaniki luncedo. Yonke into ethe yashicilelwa yaze yabhalwa emaphepheni ngelaa xesha bekusenziwa udliwano-ndlebe, iyagcinwa ukuze itshixelwe ekhanjini kwi office yabaphandi. Ngumphandi okanye umncedisi womphandi onelungelo lokuyakuvula phaya.

Abasebenzi besebe lezempilo ezibhedlele abasayi kuba nalungelo lwale ngcombolo, nenxaxheba othe wayithatha kwesi sifundo ayisayi kubachaphazela uncedo umntwana alufumanayo.

Ukuthabatha inxaxheba ungajonganga nzuzo

- Ukuthabatha inxaxheba kwesi sifundo ku volontari
- Unelungelo lokungayiphenduli imibuzo oyibuzwayo ukuba ugqibe ekuseni, uthabathe inxaxheba kwesi sifundo, unelungelo lokusitshintsha nangaliphi ixesha xa ufuna. Loonto ayisayi kuluchaphazela uncedo olufunyanwe ngabantwana.

Okuyimfihlo

Iingcombolo mazibe yimfihlo. Iimpepha zo dliwano-ndlebe noshicilelo malungabikho igama lakho kuzo. Mazingabikho neengcombolo ezoya nyaniswa naye nabani, naziphi na iziphumo nezibhengezo ngokwesi sifundo mayingoyanyaniswa nawe,nomntwana okanye nabani na ongumthathi nxaxheba.

Ingxaki ezinokwenzeka

Ngeli xesha uthathi nxaxheba kwezi zifundo zophando, usenokufumana ungonwabi emphefumlweni. Ukuba loonto yenzekile unelungelo lukuthetha nono ntlalontle okanye i khansela, uyakunika ithuba lalonto.

Iinzuzo ezilindelekileyo

Uyakuzuza wena buqu xa unokuthetha ngamava wakho onokuthi wabelane, uthethe ngokuyimfihlo nabantwana ngempilo yabo.

- Esi sifundo siphuculwe yi Research Ethnics Committee kwi Dyunivesithi yase Kapa.
- Ukuba nangaliphi na ixesha unemibuzo okanye izinto onazo ngesi sifundo, nceda qhakamishelana nentloko yezophando [The principal investigator] :

Robert Shea
Email: ourfertileground@gmail.com

Imvume yomthathi-nxaxheba

Ndizifundile inkcukacha zolwazi olungaphezulu kwaye ndizifundelwe. Ndilifumene ithuba lokubuza imibuzo kwaye ndonelisekile zimpendulo. Ndiyavuma ukuthatha inxaxheba kolu vavanyo ngokuzinikela

Igama:……………………………………………..
Intsayino-gama:…………………… Umhla:…………………………….
Ubuthathaka:……………………… Intsayino-gama:……………………

Ukuba kunzima ukubhala: Inkcukatha zicacisiwe ngumhlalutyi, ngolwimi lwam.

Intsayino-gama:…………………… Umhla:…………………………….
Ubuthathaka:……………………… Intsayino-gama:……………………